

PLANNING HOME CARE SERVICES FOR THE ELDERLY:
VARIATIONS IN PERCEIVED NEEDS AND THEIR COSTS

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by

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Alan Peter Sager

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Submitted to the Department of Urban Studies and Planning on
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ABSTRACT

Critics of public long-term care policy in the United States have complained of its heavy emphasis on institutional care for the elderly. Many who would like to see the elderly permitted choice among a variety of alternative sites of care, including their own homes, are fearful of the cost of more generous public funding of these alternatives.

The comparative costs of home and institutional care have been difficult to measure experimentally because of problems in controlling for the initial characteristics of the two samples, in measuring outcomes, and consequently, in learning what services are indeed effective. Given our present knowledge of how well various types, quantities, and providers of long-term care services enhance well-being, costs and effects of long-term care in various settings have not usually been measured well.

This study was designed to improve our knowledge. It begins with a sample of patients in fact about to enter nursing homes, obtains many hypothetical estimates of the cost of an in-home alternative of equal or greater effectiveness, and then compares these costs with those of institutional care actually provided.

But, if the greater availability of public funds for home care will depend in large part on the costs of care at home and in institutions, then the cost of home care itself, in the present research design, depends on the hypothetical care plans written. Given our weak ability to measure effectiveness of long-term care services, how is it to be decided which view of hypothetical home care need is valid -- in that it prescribes appropriate services?

In this scheme, home care costs clearly depend on the types, quantities, and providers chosen by the care plans' designers. But the question of who should control the allocation of in-home services is an important issue in itself. Arguments may be advanced on behalf of competing claims of various professionals, patients, and their families.

The hypothetical nature of the present study permits all claimants to prepare home care plans independently. One measure of the validity of the different views is how well they relate to patients' characteristics: is more care prescribed for patients who might reasonably be thought to need more care? A second measure which points toward validity, for profession-

al plans only, is that of reliability: how well do professionals agree with one another about individual patients? Agreement may be in error, but its absence would certainly weaken the case for professional control over home care planning and, therefore, for relying on costs of professionals' plans as the standard of comparison with the costs of institutional care.

Principal findings were these:

1. Patients, families, and professionals agreed well on average about patients' hypothetical care needs. Agreement in individual cases was not as good. In general, patients and families requested less paid help than professionals thought necessary. Families' evaluations of their own capacity and willingness to help were highest.

2. Care in both long-term care settings is expensive. But, by diverting to home care those patients for whom it would be hypothetically cheaper, substantial savings could be won. By using these savings to subsidize home care of patients for whom it is marginally more expensive, about half of the sample could be cared for at home with no increase in total spending.

3. Patients, families, and professionals all planned care in reasonable relation to patient characteristics: all sought more care for patients who seemed to need more.

4. While professionals agreed well, on average, about the needs of the entire sample, individual care planners did not seem to agree well about individual patients' home care needs.

5. Professional role had little relation to recommended home care; professional training, only a mild relation. Some care planners tended to prescribe more hours of service in their own disciplines. More contact with patients was associated with more prescribed home care, but more experienced professionals prescribed slightly less care.

6. Individual care planners agreed well about which patients needed more and less help. Rankings of patients by care needs were similar. But, professionals did tend to disagree about how much care any individual patient required.

7. Professional agreement was strongest for technical components of home care; weakest for household and personal care services. The latter are the very areas in which patients and families could be expected to be most competent to plan care.

8. The moderate requests by patients for services, combined with relatively weak professional agreement in non-technical areas, suggests opportunities for cooperative care planning among patients, families, and professionals.

Bernard J. Frieden, Professor of Urban Studies and Planning, Thesis Supervisor.

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P A R T O N E

THE CONTEXT OF THE STUDY

CHAPTER I

OVERVIEW

A. Introduction

Two central problems have spurred debate over public policy on long-term care for older Americans. These are the rising cost of care and the marked emphasis on institutions as the settings for publicly-funded care. Broadened eligibility for in-home services and deepened benefit packages have been proposed to simultaneously slow the rate of spending increase and permit greater choice of site of long-term care.

This dissertation is designed to help answer two questions raised by these problems: (1) Should increased public funds for home care of the elderly be made available? (2) If so, who should be permitted to allocate these funds on behalf of individual patients? In both policy and research, these questions are inextricably tied because the costs of home care can be expected to depend in large part on who plans services.

The dissertation manifestly addresses the second question through its choice of method. It has proven difficult to measure directly through controlled experiments the costs of care of equal effectiveness for comparable populations in home and institutional settings. In this study, the sample, composed of a group of older patients

about to enter nursing homes, serves as its own control. Patients enter nursing homes and the hypothetical cost of their care at home is estimated.

In this study, as in real world, the cost of home care depends in large measure on who decides the content of care plans. The daily cost of home care depends on the types, quantities, and providers of services delivered. It is therefore important that those who allocate in-home design service packages which are effective, equitable, and efficient.

Whose views of the home care needs of the elderly should be permitted to prevail? Are professionals, patients, or family members best able to design effective, equitable, and efficient care plans? Because effectiveness, equity, and efficiency are difficult to gauge directly, this question is hard to answer.

Why should we question who should have the right to decide which services are necessary to support older people at home? Why should we not simply continue to permit professionals who should be qualified by virtue of training and experience to allocate services -- as they have done in the past and as they do today? There are several reasons for raising this question.

The first is simply that because, as has just been noted, effectiveness and efficiency and equity of home care are hard to measure, it is difficult today to decide if professionally designed home care plans indeed work.

The second is that there appears to be a lack of professional

agreement about the goals of home care. Long-term care, and home care in particular, falls at the intersection of several cross-cutting categories. Professionals in both medical care and social service have seemingly valid grounds for claiming influence over care plans of patients in need of long-term care. The training of these professionals varies considerably: physicians, who are internists, physiatrists, surgeons, and others; nurses; social workers; and physical and occupational therapists. Further, the roles and training of these professionals intermix: for example, both nurses and social workers are found in the ranks of both hospital discharge planners and home care planners. Finally, there is frequently a disjunction between knowledge and power in home care planning.

One example of the types of problem raised by competing professional outlooks in home care concerns the appropriate roles of medical care, social care, and physical restoration of function. Home care plans written to emphasize each of these different goals might be expected to cost markedly different sums and to achieve markedly different results.

The third reason for raising this question is that a considerable literature has arisen which raises doubts about the congruence of professionals' judgments about means to be employed to attain goals which are agreed upon. This literature spans several areas of medicine and extends into other professional fields, such as criminal justice. Weak professional agreement points to ineffective or inefficient -- and possibly inequitable -- decision-making and consequent resource

allocation.

Good care planning is especially important in the present long-term care context. There appears to be a widespread belief among legislators, administrators, and the public at-large that the long-term care system -- especially its institutional aspects but others as well -- works poorly. In the absence of proven effectiveness of long-term care services; in view of the difficulty of measuring outcomes; and given perceptions of misappropriation, patient abuse, and inefficiency, it is not surprising that pleas for new funding have been largely unheard. Such a perceived environment lends itself to complaints that new program initiatives would amount only to "throwing money at problems." In this context, improvements in the reliability and consistency of care planning might help build the foundation on which greater funding for non-institutional long-term care could be placed.

The fourth reason for raising the question of who should design long-term care plans is that arguments have been put forth 1) that permitting greater choice to older patients is good in itself; 2) that, because the success of a plan of in-home care frequently depends on the active cooperation of the family, the family should be asked in advance to agree that the planned care meets their needs; and 3) that long-term care, by virtue of the non-technical nature of most of its constituent services, is a realm well-suited to the exercise of consumer sovereignty. (Family members, as well as patients, should be viewed as consumers of long-term care.) Long-term care is not the

only field in which calls for greater consumer control and diminished professional control have been heard. Women's health services, ambulatory care in general, biomedical research, and public education are other areas in which this debate has been taking place.

This dissertation lays the foundation for comparing the costs of home and institutional care first by investigating the views of patients, family members, and various professionals regarding needed in-home services; and second by attempting to assess the legitimacy of control over allocation of in-home services by members of the three groups.

One issue to resolve is whether the members of the three groups indeed disagree about the types, quantities and providers of in-home care required by elderly individuals or populations. If, for example, it should be found that patients, family members, and professionals disagree but little, on average, the incremental program cost or saving from non-professional control would be negligible. (For individuals, however, outcomes might well vary with control.)

A second issue to resolve is who should be permitted to influence or control home care planning if patients, their families, and professionals should be found to disagree. What can be learned about the effectiveness, efficiency, or equity of care plans designed by members of the three groups?

Equity is easiest to measure directly because both vertical and horizontal measures of equity are relative. Therefore, one test of

legitimacy of home care decision-making is whether people who seem on reasonable grounds to need more care are indeed prescribed more care (vertical equity) and whether people who seem to need the same amounts of care are prescribed the same care (horizontal equity). Using regression and correlation analyses, the dissertation relates patient variables to the amounts of care recommended by professionals and requested by patients and their families.

Because of the overall lack of good data on outcomes of long-term care in various settings, and the ongoing difficulty of designing valid and easily administered tests of outcome, both effectiveness and efficiency are presently very difficult to measure directly. Indirect support for legitimacy of professional control over home care plans would follow from consistency of views about the service needs of the elderly. Reliability certainly does not ensure validity, but it is hard to conceive of generally efficient and effective and equitable home care plans as the product of a population of professionals who tend to disagree markedly about the needs of individual patients. Further, to take a more discriminating look at the factors associated with greater consistency among professionals, this dissertation will identify the patients, services, and providers of care about whom (or which) agreement is best.

B. Overview

The present study is divided into three parts. The first (Chapters I-III) sets out the context of the study, the second (Chapters IV-VI) describes study goals, methods, and execution; and the third (Chapters VII-X) reports findings and what they suggest.

Chapter II begins by noting the extent and nature of increased public spending on long-term care for the elderly. It then explains the reasons for higher demand for formal long-term care services, and why this care has been delivered principally in institutions. It reviews some of the important arguments made by advocates of higher public spending on home care and of greater choice about site of care. In the course of this discussion, the reasons why outcome of long-term care is difficult to measure are indicated. Finally, the barriers to greater public home care funding are discussed and the importance of better knowledge about comparative costs of home and institutional care is noted.

Chapter III then reviews different methods of gauging these comparative costs. Because initial characteristics of samples receiving care in different sites are hard to control, and because the outcome of care are hard to measure, a scheme of "hypothetical diversion" is proposed. This parallels one legislative approach to funding broader home care benefits: making them available to those about to enter nursing homes who could be cared for at home at no greater cost. On this model of hypothetical diversion, the estimated cost of home care is compared with the real cost of institutional care. Thus, and in the absence of good outcomes measures, it is most important to learn which view of needed home care

services--and their costs--is valid. By reviewing the reliability of professional views in several fields, along with the characteristics of long term care, reasons for a cautious outlook on professional consistency in long-term care are identified.

In this setting, Chapter IV begins part two by setting out the merits and drawbacks of permitting patients, their families, or professionals to influence or control the allocation of in-home resources. The four principal goals of the study are then described: 1) to learn the extent of agreement among the three groups about the types, providers, and quantities of home care thought necessary; 2) to assess whose views of need seem valid; 3) to compare the cost of hypothetical home care and real nursing home care; and 4) to mine the by-products of earlier analyses to learn a) how the home care planning process might be better organized; b) which patients are thought to need which services and providers; and c) what are the patterns of agreement about the various components of home care plans. Chapter IV ends by reviewing methods of data collection.

Chapter V briefly indicates the steps actually taken in the course of data collection. Responses to the problem of initially slow intake of patients into the study sample are reported.

Chapter VI concludes part two by summarizing the likely impacts of forces affecting the representativeness of the sample, describing the sample's characteristics in comparison with such state and national data as are available, and setting out the distinctions between patients at participating hospitals who were screened into the study and those who

were screened out. The salience of the variables characterizing patients to understanding need for long-term care is indicated.

Part three reports major findings of the study and discusses their meanings. Chapter VII compares the costs of home and institutional care; patient variables and patient, family and professional views of home care cost are considered. The costs of services and providers of care recommended are indicated.

Chapter VIII reports the results of attempts to learn whether professional, patient, or family views of home care need differ and if so, whose appear more sensible. Patient variables are compared with the amounts of care recommended by each group. The equity of home care plans prepared by different groups is explored. Then, among professionals only, patient variables associated with the various perceptions of need for various types of care are analyzed. The subject of professional disagreement is introduced by identifying the patient variables associated with more and less consistency.

Chapter IX then analyzes in several ways the extent of agreement among professionals about patients' home care needs. The effects of professional role, training, and available information are investigated. Using analysis of variance, factor analysis, Cronbach's alpha, and Kendall's W, the extent and nature of agreement about the different aspects of patients' home care needs are dissected.

Finally, Chapter X summarizes findings and indicates what they suggest for long-term care policy, methods of planning to meet patients' needs, and further research.

Chapter II

TWO CONCERNS IN PUBLIC LONG-TERM CARE POLICY

A. Introduction

This chapter begins by separately identifying and tracing the histories of the two major concerns in public long-term care policy for the elderly today. These are the cost of care, especially to governments, combined with the high rate of increase in that cost; and the profound emphasis in public long-term care spending on institutional services.

Together, these two discussions form the context of the description of present debates over federal long-term care policy¹ which follows. In the face of high costs of long-term care for the elderly and the emphasis on institutional services, many have argued for increased public funding for home care and for greater choice by the elderly and their families over the setting of care. Some advocates of greater home care funding have argued that this could be accomplished with no increase in total public long-term spending.

¹ It should be emphasized now that the phrase "long-term care" indeed refers to both in-home and institutional services. According to Judith LaVor, long-term care consists of "Activities designed to provide diagnostic, therapeutic, rehabilitative, and maintenance services for individuals who have chronic physical or mental impairments, in a variety of community and institutional settings, with the goal of promoting the optimum level of physical, social, and psychological functioning." See Judith LaVor, "Long-term Care: A Challenge to Service Systems," rev. ed., Washington: Office of the Assistant secretary for Planning and Evaluation, DHEW, April 1977 (photo-offset), Appendix A.

Responses by the U.S. Congress and the HEW bureaucracies to these arguments are noted. Unanswered questions relevant to accurate estimates of the costs of new home care benefits lead to the discussion of the comparative costs of home and institutional care which is presented in chapter three.

Several problems in addition to cost and the purported emphasis on institutional care plague federal long-term care policy-makers. These include the technical quality of services; the decency and humanity with which they are delivered; and the nature of financial and reimbursement controls necessary to minimize fraud and provide incentives for efficiency, quality, and decency. Solution to each of these problems would greatly improve delivery of long-term care in this country -- both institutional and home care. Nonetheless, they will be discussed only incidentally, as they bear on the purposes of this study: to learn more about the extent of agreement about the home care needs of the elderly, and about the comparative costs of home and institutional care of roughly comparable effectiveness for similar populations of older people.

B. The Problem of Increased Public Spending on Long-term Care.

Since the late 1960's, there has been a growing concern in the United States with the problems of rising spending -- particularly public spending -- on health care in general.¹ During the 1970's, long-term care has become a major area of worry within the health care field itself.² This section will begin by documenting the extent and nature of the growth in long-term care spending in this country. It will then explore the various reasons for this growth. The next section will explain why publicly-funded long-term care has been principally institutional. Although spending increases and the institutional emphasis are considered separately, this is not meant to imply that the two are unrelated. Indeed, because of the weakness of evidence of the comparative cost of in-home and institutional care, judgment on any possible relation should be withheld.

1-----

Three examples are: Council on Wage and Price Stability, The Complex Puzzle of Rising Health Care Costs, Washington: Executive Office of the President, December 1976; David Mechanic, "Approaches to Controlling the Costs of Medical Care; Short-range and Long-range Alternatives," New England Journal of Medicine, Vol. 298, No. 5 (Feb. 2, 1978), pp. 249-254; Comptroller General of the United States, "History of the Rising Costs of the Medicare and Medicaid Programs and Attempts to Control These Costs: 1966-1975," Washington: General Accounting Office, Feb. 11, 1976.

2

Health Policy Group, Commonwealth of Massachusetts, "Health Care Expenditures in Massachusetts: 1978 Update," "A White Paper, Boston: Office of State Health Planning, Massachusetts Department of Public Health, June 9, 1978 (multilith); Department of Health, Education and Welfare, "Control Medicaid Cost Increases for Expensive Institutional Long-term Care," "Memorandum for July 14, 1978 Briefing, Major Initiative: Long-term Care/ Community Services, Appendix 6; "Marcia B. Cohen, "Long-term Care and Cost Control: A Critical Analysis," Health and Social Work, Vol. 4, No. 1 (February 1979), pp. 61-88

The extent and nature of increased long-term care spending. From 1970 to 1977, total public nursing home and home care spending on the elderly increased by about 313%, from \$1.4 to \$5.9 billion.¹ This seemingly rapid rate of increase may be only partly real and partly perceived. The preponderance of this spending -- about 90% -- is devoted to nursing home care, and nursing home care has achieved a high degree of visibility in this country. From time to time, powerful journalistic accounts of horrible living conditions are reported. These are frequently combined with charges of misappropriations of huge sums. There are other reasons for the visibility of long-term care spending. A relatively high proportion of long-term care funds are channelled through the Medicaid program, which is the subject not only of federal debate, but of state and frequently local legislative discussion as well. Constant calls for increased choice in setting for long-term care keep vivid the perceptions of high spending on nursing homes -- spending which appears to vacuum long-term care funds which might otherwise have been spent with greater discretion. Finally, in recent months, talk of a gray or graying federal budget -- one which allocates too great a share to the elderly -- has raised fears that perceptions of excessive long-term care spending may preclude more generous funding in the future.

It may be useful to examine these perceptions critically. First,

¹For sources, see notes to Table II-E.

it should be noted that they are, to varying degrees, well-grounded. Tables II-A, II-B, and II-C set out data which can be interpreted to support the view that recent increases in long-term care spending have been unreasonable.

Table II-A, for example, sets out both total and public nursing home spending for various years between 1940 and 1977. From 1960 to 1977 alone, total nursing home spending rose by over 2400% and public spending increased by over 5550%. But these data are both limited and unreliable. Nursing home spending data are limited because they exclude for all years expenditures for long-term mental hospital care, chronic hospital care, and home care for the elderly. Thus, the best available longitudinal data in the field of long-term care spending exclude important elements of that care. This is particularly noteworthy because, as noted later in this section, the share of these other elements has been changing over time. The nursing home spending data reported in Table II-A, while the best available, are internally unreliable for the earlier years, in that they exclude the costs of care for an unknown but probably significant number of older Americans residing in boarding homes and similar facilities in the 1940's and 1950's. Most of these precursors of modern "rest homes" and other institutions seem to have been excluded in earlier bed counts, while their more regulated and formally organized successors seem increasingly to have been included.

Thus, while the increase in public nursing home spending indicated in Table II-A is accurate, it does not reflect possible offsetting

Table II-A
Nursing Home Spending in the United States (million \$)¹

	<u>FY 1940</u>	<u>FY 1950</u>	<u>FY 1960</u>	<u>FY 1966</u>	<u>FY 1977</u>
Total spending	\$28	\$178	\$480	\$1,407	\$12,618
public spending	0	11	127	602	7,184
public % of total	0%	6.2%	26.5%	42.8%	56.9%

sources

1940-1966: Office of Research and Statistics, Social Security Administration, Compendium of National Health Expenditures Data, Washington: USGPO, 1973, Table 5.

1977: Robert M. Gibson and Charles R. Fisher, "National Health Expenditures, Fiscal Year 1977," Soc. Sec. Bulletin Vol. 41, No. 7 (July 1978), Table 5.

¹In recent years, approximately 90% of nursing home residents have been aged 65 and above, the group usually considered "elderly." Virtually all the remainder are aged 55-64. See U.S. Bureau of Census, Statistical Abstract of the U.S., 1977, Washington: USGPO, 1977, Table 166.

reductions in public spending on behalf of older people relocated from other institutions to nursing homes. It should be noted that the growth of formal federal reimbursement programs has led to vastly improved record-keeping over time. The fragmented records of spending by thousands of jurisdictions of many forms of long-term care have given way to consolidated reports for the Medicare, Medicaid, and Title XX programs. For this reason, some of the most useful longitudinal data concern beds -- on which data are more reliable than on spending. Such a longitudinal comparison is presented shortly. The rate of increase in total spending is similarly inflated, by the exclusion in earlier years of many nursing homes' predecessors.¹

Critics of nursing home spending frequently contrast spending increases in various sectors. Table II-B presents one such picture. While interesting in itself, and a useful weapon in the hands of those who would criticize long-term care spending, this contrast is incomplete. It, also, fails to allow for the increase in the nursing home population brought about by such forces as the "de-institutionalization" of large numbers of former mental hospital residents. Still, this table does indicate the very rapid rate of increase on behalf of residents of places called "nursing homes."

¹ Comprehensive reviews of the costs of long-term care discourse frequently on data problems. See, for example, Congressional Budget Office, Long-term Care: Actuarial Cost Estimates, Washington: USGPO, August 1977; Long-term Care Task Force, Commonwealth of Massachusetts, Report, Boston: Office of State Health Planning, August 1977 (mimeo).

TABLE II-B

Proportionate Total Spending Increases: Various Sectors

	FY 1960 (\$million)	FY 1977 (\$million)	% increase 1960-1977
Nursing Homes	\$ 480 ¹	\$ 12,618 ²	2,529%
Hospital Care	8,499 ¹	65,627 ²	672
Total Health Care	25,856 ¹	162,627 ²	529
Education ³	24,700	131,100	431
National Defense ⁴	50,700	118,500	134
OASI ⁵	10,300	71,300	592
Total Federal Spending ⁶	90,300	358,900	297
Total State & Local Spending	61,000 ⁷	321,400 ⁶	427

TABLE II-B

SOURCES

1. Office of Research and Statistics, Social Security Administration, Compendium of National Health Expenditures Data, Washington: USGPO, 1973, Table 5.
2. Robert M. Gibson and Charles R. Fisher, "National Health Expenditures, Fiscal Year 1977, Soc. Sec. Bull., Vol. 4 , No. 7 (July 1978), Table 5.
3. U.S. Bureau of the Census, Statistical Abstract of the U.S., 1977 Washington, D.C. 1977. Table 201, "School Expenditures - Public and Non-public, by Type of Control and Level of Instruction: 1940- to 1977."
4. ibid, Table No. 564, "Federal Budget Outlays for National Defense and Veterans Benefits and Services: 1950 to 1977.
5. Social Security Bulletin, Vol. 41, No. 7 (July 1978) Table M-5, "Old-age and Survivors Insurance Trust Fund: Status, 1940-78," p. 40.
6. U.S. Bureau of the Census, op. cit. Table No. 456, "All Governments -- Summary of Finances: 1950 to 1975."
7. Unpublished data acquired through telephone conversation with Gerry Keffer, U.S. Bureau of the Census, Suitland, Maryland.

Keeping in mind the weaknesses in longitudinal data about nursing homes, it is instructive to consider nursing home spending for one year. Nursing home care is especially expensive to the states and to the federal government. In no other major health sector does the government bear so high a proportion of the cost of care. Table II-C indicates total spending by sector in fiscal year 1977.

Table II-C also indicates the high state and local contribution to nursing home spending. This is noteworthy by contrast to the hospital sector, the other area of high public contribution. Further, the states' share of the state/local contribution to nursing home spending is markedly higher than is their share of hospital spending. This is because of the high costs of city-county acute care hospitals, and the absence of a comparable local function in long-term care. For these reasons, increases in nursing home spending are particularly visible to the states. Such visibility helps make the state especially sensitive to increased costs of nursing home care. This is seen particularly in the Medicaid program, in which nursing home spending looms very large. In 1977 the state share of total Medicaid spending of \$16.3 billion was 43.5%. Of the total, 39.2% was spent on nursing home care.¹

¹Robert M. Gibson and Charles R. Fisher, "National Health Expenditures, Fiscal Year 1977." Soc. Sec. Bulletin, Vol. 41, No. 7 (July 1978), Table 3.

Table II-C
Total and Public Spending by Health Sector, FY 1977

<u>Sector</u>	<u>Total Spending</u> <u>(\$ million)</u>	<u>Public %</u>	<u>Federal %</u>	<u>State/Local %</u>
Hospital Care	\$ 65,627	55.2%	39.2%	16.0%
Physicians' Services	32,184	24.3	18.0	6.3
Dentists' Services	10,020	5.0	3.1	1.9
Drugs	12,516	9.1	4.9	4.2
Nursing Home Care	<u>12,618</u>	<u>56.9</u>	<u>33.3</u>	<u>23.6</u>
TOTAL	<u>\$162,627</u>	<u>42.1%</u>	<u>28.6%</u>	<u>13.5%</u>

Source

Robert M. Gibson and Charles R. Fisher, "National Health Expenditures, Fiscal Year 1977." Soc. Sec. Bulletin, Vol. 41, No. 7 (July 1978), Table 2.

While nursing home spending increases over the past decades appear impressive, data problems noted earlier point to the need to ground longitudinal comparisons more firmly. Total long-term care bed changes, and changes in the bed/population ratios constitute yardsticks less elastic than nursing home spending. Data in Table II-D indicate a considerable increase in the total number of long-term care beds available to the elderly from 1939 to 1975. During this time, total beds rose by 452% and beds per 1000 aged 65 and above increased by 116%; beds per 1000 aged 75 and above increased by 68%. The marked reduction in the rates of increase in all measures during the years 1961 to 1975 points to possibilities that needs are being met or that controls on spending or admissions are constraining bed growth.

These data clearly modify the picture of long-term care spending and utilization which was formed by viewing nursing home spending alone. Assuming little change in occupancy rates, or in average cost per long-term care bed occasioned by the changed proportions of mental hospital, chronic hospital, and nursing home beds in the long-term care bed totals, it can be asserted that overall spending on institutional care has indeed increased markedly since 1939. In recent years, however, this increase has been relatively undramatic.

Another implication of this information should be noted. The deceleration of the rate of increase in long-term beds per thousand elderly, combined with the steady growth in the long-term care bed supply observed since 1939 would seem to indicate that the provision of

Table II-D

Estimated Number of Long-term Care Beds Available to the Elderly, 1939-1961-1975Thousands of Beds

<u>Institution</u>	<u>1939</u>	<u>1961</u>	<u>1975</u>	<u>% Change 1939-1975</u>	<u>% Change 1961-1975</u>
Nursing Homes ¹	25 ⁴	534 ⁷	1,330 ¹⁰	+5,220%	+149%
Long-term Hospitals ²	61 ⁵	71 ⁸	51 ⁸	- 16%	- 28%
<u>Mental Hospitals</u>	<u>182⁶</u>	<u>212⁹</u>	<u>99⁹</u>	- <u>46%</u>	- <u>53%</u>
TOTAL	268	817	1,480	+ 452%	+ 81%
Beds/1000 ≥65	30.6	47.8	66.1	+ 116%	+ 38%
Beds/1000 ≥75	103.4	140.4	173.6	+ 68%	+ 34%

Table II-D

SOURCES

1. 90% of nursing home beds are included, approximately the proportion of residents aged 65 and above. See U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Tables 163 and 166. "Nursing homes" are "places providing some form of nursing, personal care, or domiciliary care; standards vary widely among states." (ibid., Table 163.)
2. "Long-term general and other special" hospitals.
3. 30% of all mental hospital beds in Massachusetts were occupied by persons aged 65 and above in 1973. See a Massachusetts Department of Mental Health study cited in Massachusetts Long-term Care Task Force, Report, op. cit. Only 30% of all beds in mental hospitals are therefore included in all estimates of availability of mental hospital beds for the elderly.
4. L. Block, Hospital and Other Institutional Facilities and Services, 1939, Vital Statistics, Special Reports 13, Nos. 1-57, Washington: U.S. Bureau of the Census, 1942.
5. U.S. Bureau of the Census, Historical Statistics of the United States, Colonial Times to 1970, Part 1, Washington: USGPO, September 1975, Series B-328.
6. ibid, Series B-324.
7. H.B. Speir, "Characteristics of Nursing Homes and Related Facilities: Report of a 1961 Nationwide Inventory," U.S. Public Health Service Pub. No. 930-F-S, Washington: USGPO, 1963.
8. Historical Statistics, op. cit., Series B - 310.
9. ibid, Series B-312.
10. U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 163.

institutional long-term care is more than a recent artifact, purely a response to federal legislation of the past fifteen years. Rather, the nature of the growth of the long-term care bed supply points to a deep-seated pattern, one which might well prove difficult easily to reverse.

A final characteristic of public long-term care spending should be noted. This is the profound emphasis on institutional care. While, as Table II-E indicates, there was a slight increase in the proportion of public long-term care spending devoted to home care from 1970 to 1977, it still is the object of less than 12% of the total. As noted in chapter III, this small rise took place in an atmosphere of intense pressure for greater public support for home care.

This discussion of the extent and nature of increased long-term care spending has indicated that while the rise in nursing home spending overstates the true increase in the size of the institutional long-term care sector, examination of the number of long-term care beds available to the elderly does document a deep-seated steady increase. The growth of the nursing home as the site of care for the disabled elderly, combined with the financing of that care under Medicaid, has probably increased the visibility of institutional long-term care expenditures. Care of thousands of residents of mental hospitals, financed by the states, and of thousands of county infirm-ary and poor farm residents, financed by localities, became the responsibility of nursing homes. Under the Medicaid budget, the costs of this care are visible to both the federal government and

Table II-E

Distribution of Public (Federal, State, Local) Long-Term Care Spending
on the Elderly (Age 65 and Above)
(Fiscal Years, Except as Noted)

	<u>1970</u> (000)	<u>1977</u> (000)
<u>Nursing Home Spending</u>		
Medicare	\$ 249,911 ¹	\$ 288,597 ²
Medicaid*	<u>1,058,557³</u>	<u>4,902,890⁴</u>
Subtotal - nursing home spending	1,308,468	5,191,487
Nursing home percent of Total	91.9%	88.2%
 <u>Home Care Spending</u>		
<u>Medicare</u>		
Part A	\$ 46,539 ¹	\$ 217,718 ²
Part B	28,307 ⁵	90,360 ⁶
Medicaid	9,010 ³	141,514 ⁷
Title XX-Social Security Act	32,015 ⁸ (FY 1971)	229,446 ⁹
Title III - Older Americans Act	<u>NA¹⁰</u>	<u>16,908</u>
subtotal-home care spending	<u>115,871</u>	<u>695,946</u>
home care percent of Total	8.1%	11.8%
Total (nursing home plus home care)	<u>\$1,424,339</u>	<u>\$5,887,433</u>

Note:

*excludes ICF-MR

Table II-E

SOURCES

1. U.S. Social Security Administration, Social Security Bulletin, Vol. 33, No. 12, December 1970, Table M-18 and Vol. 34, No. 6, June 1971, Table M-18.
2. U.S. Social Security Administration, Social Security Bulletin, Vol. 41 No. 7, July 1978, Table M-18.
3. Calculated for CY 1970 from data in:
 - a. U.S. Department of H.E.W., Social and Rehabilitation Service, National Center for Social Statistics, Numbers of Recipients and Amounts of Payments Under Medicaid and Other Medical Programs Financed from Other Public Assistance Funds - 1970. DHEW Pub. No. (SRS) 73-03153, NCSS Report B-4 (CY 70), Tables 20, 21, and 22. October 1972.
 - b. U.S. Department of H.E.W., Social and Rehabilitation Service, National Center for Social Statistics, Findings of the 1970 AB Study, and Findings of the 1970 APTD Study, Part 1, Demographic and Program Statistics, Table 1. 1972.
4. U.S. Department of H.E.W., Health Care Financing Administration, Medicaid Statistics, June, 1977, Research Report B-1 (6/77), December 1977, Table Q1. Estimated payments for SNF's and ICF's (excluding mentally retarded) by summing Quarters October-December 1976, January-March 1977, and twice April-June 1977, subtracting 10% to allow for nursing population under age 65.
5. U.S. Social Security Administration, Social Security Bulletin, Vol. 33, No. 6, June 1970, Table M-20 and Vol. 34, No. 4, April 1971, Table M-20.
6. U.S. Social Security Administration, Social Security Bulletin, Vol. 41, No. 7, July 1978, Table M-20.
7. U.S. Department of H.E.W., Health Care Financing Administration Medicaid Statistics June 1977, Research Report B-1 (6/77), December 1977, Table Q1. Estimated payments for home health services for FY 1977 by summing Quarters October-December 1976, January-March 1977, and Twice April-June 1977, subtracting 20% to allow for services to those under age 65.
8. Figure estimated by:
 - a. Calculating percent of all Homemaker and Chore service

recipients in OAA, APTD, and AB categories (U.S. DHEW), Social and Rehabilitation Service, National Center for Social Statistics, Findings of the 1970 OAA Study, Part 1, Table 37, Findings of the 1970 APTD Study, Part 1, Tables 1 and 37, and Findings of the 1970 AB Study, Tables 1 and 37. 1972.

- b. Applying these percents to the total social service dollar figure expended for Homemaker and Chore services for adult titles, (OAA, APTD, AB) for FY 1971 (U.S. DHEW, Social and Rehabilitation Service, Cost Analysis of Social Services, Fiscal Year 1972; An Update of the Cost Analysis of Social Services for FY 1971, report prepared by Touche Ross & Co., Washington, D.C., February 1973. Exhibit 4.
 - c. Calculating percent of APTD and AB recipients age 65+ (OAA = 100% age 65+);
 - d. Applying these percents to the respective dollar figures derived in b;
 - e. Summing the final dollar figures derived in d.
9. Figures estimated by:
- a. Calculating average percent of home-based service dollar figure allocated to age 60+ according to a four-state survey (Benton, Bill Tracey Feild, and Rhona Millar, "State and Area Agency on Aging Intervention in Title XX," Working Paper 0990-24, Washington, D.C.: The Urban Institute, December 1977. Figs. 7, 9, 10, 13, 15.);
 - b. Reducing average percents by five to eliminate an amount estimated to be allocated to persons 60-64 years old;
 - c. Applying net percent to total estimated expenditures for home-based services for FY 1977 (Wolff, Eileen, Barbara E. Bird, Patricia L. Sullivan, Technical Notes; Summaries and Characteristics of States' Title XX Social Services Plans for Fiscal Year 1977, U.S. DHEW, Office of the Secretary, Washington, D.C., 1977, p. 89.)
10. Telephone conversation with Eleanor Sneed, Office of Program Operations, Administration on Aging, Washington, D.C.
11. U.S. Senate, Special Committee on Aging, Developments in Aging: 1977, Part 1, Report No. 95-771. Washington, D.C.: USGPO 1978, p. 120.

the states. Finally, the institutional emphasis of public long-term care spending, while modified slightly in recent years, remains profound.

The next section discusses the reasons for the increased provision of publicly-supported long-term care in this country; the following section explores the sources of this country's apparent preference for institutions as settings for the delivery of that care.

C. Explaining Increased Demand for Long-term Care.

Long-term care was defined earlier in this chapter as a set of activities designed to provide certain services in a variety of settings for individuals who have chronic physical or mental impairments. Until the early 1970's the major public policy concerns in long-term care involved organized, formal means of providing long-term care. In the last few years, there has been an increasing interest in strengthening informal supports for citizens in need of long-term care. This interest has grown for at least two reasons: 1) efforts to increase the supply of non-institutional alternatives for the long-term disabled elderly, working-aged disabled, mentally ill, mentally retarded, and others; and 2) recognition that for reasons of cost and effectiveness, formal long-term care programs must complement (or do as little as possible to undermine) informally provided help.

Three types of explanations for increased demand for organized long-term care services may be reasonably adduced. They are socio-demographic, economic, and epidemiologic. These explanations may be thought of

as acting in various ways both independently and synergistically. Certain forces in each area act to increase the overall demand for long-term care, no matter how provided; some of these forces act specifically to increase the demand for formally organized services and/or reduce the supply of informally provided services. Family behavior is terribly important because, as will be made clear below, small changes in patterns of family effort can powerfully affect demand for formal supports.

It should be noted at the outset of this discussion that no attempt will be made to assess comprehensively the relative importance of the various sources of higher demand for formally organized -- and, with increasing frequency, publically funded -- long-term care. Rather, the general size and direction of these sources will be set out. Further, no serious attempt will be made to resolve the question: has the family's willingness to care for its older dependent members declined? Family members -- spouses and adult children in particular -- have been castigated by some analysts and some advocates for the elderly as selfish, unfeeling, and worse when they place their relatives in nursing homes. Critics of the family point to the increase in the proportion and absolute number of the elderly residing in long-term care institutions, the greater proportion who die as residents of institutions, the well-publicized abuses of rights and dignity of institutional residents, and the general preference of the

elderly for home care.¹

In the face of these attacks, many have responded by asserting that the level of effort exerted by families to care for their dependent members has changed very little, and that family members continue to provide the great majority of the services required by the dependent elderly. Moroney's study of the family in Britain concludes that by most available measures, "there is no clear evidence that the state is assuming the primary responsibility for the care of the elderly."² Morris, Benedict and Maddox are among those who argue that the most reliable U.S. national data indicate that almost 80% of help received by older Americans is provided by related household members.³ Analysis by Shanas of data from a 1975

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See, for example, Claire Townsend, Old Age: The Last Segregation, New York: Grossman, 1971, pp. 133-135; also, those criticized by Donald P. Kent, "Aging-Fact or Fancy," The Gerontologist, vol. 5, no. 2 (June 1955), pp. 51-56.

2

Robert Moroney, The Family and the State: Considerations for Social Policy, London: Longman, 1976, p. 56.

3

Robert Morris, "Family Responsibility: Implications of Recent Demographic and Service Trends for a Natural Helping System," Waltham, Mass.: Levinson Policy Institute, Brandeis University, working paper, November 1977; George L. Maddox, "Families as Context and Resource in Chronic Illness," in Sylvia Sherwood, ed., Long-term Care, Holliswood, N.Y.: Spectrum, 1975, pp. 317-348; Robert Benedict, "The Family and Long-term Care Alternatives," Address to the 1978 Groves Conference on Marriage and the Family, Washington, D.C., April 28, 1978; National Center for Health Statistics, "Home Care for Persons Fifty-five and Over, United States, July 1966-June 1968, Vital and Health Statistics, Series 10, No. 73 (July 1972), p. 8 See also the discussion by Elaine M. Brody, "The Aging and the Family," Annals of the American Academy of Political and Social Sciences, Planning for the Elderly, Vol. 438 (July 1978) pp. 13-26.

national study further supports the contention that members of the household and non-resident children of non-institutionalized elderly bedfast Americans provide the great bulk of services needed.¹ The thrust of these arguments is that the place of the three-generation family in caring for the elderly may well have been exaggerated in almost mythical fashion.

Families do more than provide most of the care to those of their disabled members who reside at home; families also care for at least as many older Americans as do institutions. While it is certainly true that the average disabled older person residing at home requires less help than the average disabled older person residing in an institution, the needs of the former group are very considerable--particularly in as much as families' resources for care are fewer than those of typical institutions. Maddox notes that, of older Americans who receive care at home, "one-third require constant care over a long period of time." Surprisingly high proportions have been receiving help from family members for over one year.²

By some measures, some families may be viewed as abandoning their responsibilities to their dependent elderly members. By other measures,

¹Ethel Shanas, "The Family as a Social Support System in Old Age," A paper presented at the 30th Annual Meeting of the Gerontological Society, San Francisco, November 1977.

²George L. Maddox, "Community and Home Care: United States and United Kingdom," in A.N. Exton-Smith and J. Grimley Evans, eds., Care of the Elderly: Meeting the Challenge of Dependency, New York: Grune and Stratton, 1977, pp. 147-160.

families seem to be doing quite a good job. What is most important to public policy in long-term care, however, is not whether or not families are "discharging their responsibilities." Rather, it is the size and direction of marginal shifts in the level of family effort. Even after decades of growth in the use of institutional care, only a small proportion of those aged 65 and above reside in institutions. Families do provide most of the services needed by those who require help. Consequently, a small reduction in the level of family effort means a significantly larger percentage increase in the number of older Americans who require formal support in either the home or an institution. Understanding the variables which affect level of family effort over time should inform public attempts to buttress families. In the context of the present study, such understanding should also help explain differences in ability across families at the present time to provide help to relatives at home. Changes in ability, in turn, affect the demand for different types of paid, formally organized home care services.

Of the three forces affecting the demand and supply of informal support, epidemiologic changes have worked to increase the demand for long-term care generally. Socio-demographic and economic changes appear to have modulated this demand through their impacts on the availability and ability of family members to provide informal support for the elderly. A reduced supply of informal help, in relation to the number of elderly Americans needing long-term support, has resulted in increased demand for formal help. This formal help could be

provided either in homes or in institutions. Section D of this chapter seeks to explain why the institutional site has been more common.

Epidemiologic changes. Three epidemiologic forces affecting the demand for long-term care can be identified: Americans are living longer; the causes of death are changing; and the specific gap between male and female longevity is widening.

The proportion of the U.S. population aged 65 and above has increased markedly over the past 100 years. This is expected to continue. The rise in the proportion aged 75 and above is even greater, and is even more significant in explaining the increased demand for long-term care: Those aged 75 and above are especially likely to need and to use long-term care. As the data in Table II-F indicate, the proportion of the population institutionalized rises steadily with age. The Federal Council on Aging refers to those over 75 collectively as the "frail elderly," indicating that a "critical mass occurs within this age range which is worthy of national attention."¹

Age is correlated not only with nursing home use, but with home care use as well. Table II-G presents home care use under Medicare by age. The pattern of home care services' use increases with age in a manner different from that of institutional care. Home care use by

¹Federal Council on the Aging, Annual Report to the President-1976, Washington: USGPO, 1977, pp. 23-31.

Table II-F

Utilization of Nursing Homes - 1977

<u>Age</u>	<u>% of Population¹ (216,332,000)</u>	<u>% of Nursing Home² Residents</u>	<u>% of Age Group in Nursing Home</u>
under 65 yrs.	89.1%	14.7%	0.098%
65	10.9	85.3	4.7
65-74	6.7	15.7	1.4
75-84	3.2	36.6	6.9
85	1.0	33.0	20.5

Sources

¹ Administration on Aging, Office of Human Development Services, Statistical Notes from the National Clearinghouse on Aging, No. 2, August 1978, p. 3.

² National Center for Health Statistics, Advance Data from Vital and Health Statistics, No. 29, May 17, 1978, Table 1.

Table II-G
Utilization of Home Health Services under Medicare
Calendar Year 1975

Age	Visits ¹ (000)	% of Total Visits	Visits/1000 ^{1,2} Medicare population per each age group (000)	% of Enrolled ^{1,2} Medicare population by age group served by home care
Under 65	797	7.4%	368	1.4%
65	<u>10,007</u>	<u>92.6</u>	445	2.1
65-74	3,891	36.0	290	1.4
75-84	4,432	41.0	628	2.9
85	1,684	15.6	846	3.9
Total	<u>10,805</u>	<u>100.0%</u>		

¹Health Care Financing Administration, DHEW, Research and Statistics Note, No. 2, June 1978.

²Social Security Bulletin, Annual Statistical Supplement, 1975, Tables 138, 139.

the oldest group, that aged 85 and above, is proportionately less than use of institutional care. This reflects the present difficulty of organizing home services for the very disabled, who are likely to be relatively old.

Given that age correlates so strongly with use of long-term services, it is important to note the past and projected rise in the numbers and proportions of those over age 75--the very groups most likely to use long-term care. These data are set out in Table II-H.

Life expectancy at birth has increased along with the aged proportion of the population: from 49 years in 1900, to 63 years in 1940, to 71 years in 1970, and to 72.5 in 1975.¹ A further consequence of the growth of the elderly population, and of its aging, has been an increase in the likelihood that the adult children of parents in need of care would themselves be too frail to provide that care.

Americans are not only living longer; we are dying of different causes. Many of the illnesses which killed quickly in earlier years were infectious. Their importance, both absolutely and relatively, has been reduced. Influenza and pneumonia, the leading causes of death in 1900, have been replaced by heart disease and cancer. Both of the

¹National Center for Health Statistics, "Some Trends and Comparisons of United States Life-table Data: 1900-1971," U.S. Decennial Life Tables for 1969-71, Vol. 1, No. 4, Washington: USGPO, May 1975, Table 1; U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 94.

Table II-H

U.S. Elderly Population: 1870-2000 (in thousands)

year	total pop.	pop. ¹ / ₆₅	%	pop. ² / ₇₅	%	pop. ³ / ₈₅	%
1870 ¹	38,558	1,154	3.0%	² 325	0.84%	² 55	0.14%
1900	75,995	3,080	4.1	³ 899	1.2	³ 122	0.16
1930	122,775	6,634	5.4	³ 1,945	1.6	³ 272	0.22
1940	131,669	9,019	6.8	³ 2,664	2.0	³ 370	0.28
1950	150,697	12,270	8.1	³ 3,904	2.6	³ 590	0.39
1960	179,323	16,560	9.2	³ 5,621	3.1	³ 940	0.52
1970	203,211	20,066	10.0	³ 7,598	3.7	³ 1,432	0.70
1975	⁴ 213,540	⁴ 22,405	10.5	³ 8,527	4.0	³ 1,877	0.88
1980	222,159	24,927	11.2	9,434	4.2	2,294	1.0
1990	243,513	29,824	12.2	12,021	4.9	2,881	1.2
2000	260,378	31,822	12.2	24,368	5.5	3,756	1.4

Sources:

1. U.S. Bureau of the Census, Historical Statistics of the United States, Colonial Times to 1970, Washington: USGPO, 1975, Series A-119, 133 (total and 65, 1870-1970; U.S. Bureau of the Census, Projections of the Population of the United States: 1977 to 2050, Current Population Reports, Series P-25, No. 704, Washington: USGPO, July 1977, Table 8.
2. Statistical Atlas of the United States Based on the Results of the Ninth Census 1870 with Contributions from Many Eminent Men of Science and Several Departments of the Government. Compiled under Authority of Congress by Francis A. Walker, M.A. Superintendent of the 9th Census, Professor of Political Economy and History, Sheffield Scientific School of Yale College, Julius Bien, Lith. 1874, Table 1.
3. U.S. Bureau of the Census, Demographic Aspects of Aging and the Older Population in the United States, Current Population Reports, Special Studies, Series P-23, No. 59, Washington: USGPO, Jan 1978, Table 2-1.
4. U.S. Bureau of the Census, Statistical Abstract of the United States: 1977 (98th edition.) Washington, D.C. 1977, Table No. 3.

latter are degenerative diseases associated with the aging process.¹ "Degeneration" suggests not only deterioration of tissue and organ, but also reduction in functional capacity and independence. In addition, as more Americans live to be very old, the non-fatal infirmities of old age--arthritis, weakness, and the like--affect greater numbers of older people. Both types of illnesses, those associated with fatal and non-fatal diseases, lead to increased need for long-term care services by older Americans. Medical advances and improved real incomes have done more than change the causes of death. They have permitted large numbers of older citizens in all developed countries to survive although greatly disabled, and therefore requiring much care from others, often for a very long time.²

This is an important point, one often lost sight of. For example, Wegman has written that:

It is a truism to the point of being a cliché that the major way to cut health care costs is to prevent disease from occurring in the first place: so-called primary prevention, whether addressed to the individual or to the environment.³

¹Monroe Lerner, "When, Why and Where People Die, in Orville G. Brim, Jr., The Dying Patient, New York: Russell Sage Foundation, 1970, pp. 14-16.

²For a striking account, see Bernard Isaacs, Maureen Livingstone, and Yvonne Neville, Survival of the Unfittest: A Study of Geriatric Patients in Glasgow, London: Routledge and Kegan Paul, 1972. See also Elihu M. Gerson and Anselm L. Straus, "Time for Living: Problems in Chronic Illness Care," Social Policy, Vol. 6, No. 3 (November-December 1975), pp. 12-18.

³Myron E. Wegman, "Health Departments: Then and Now," editorial, American Journal of Public Health, Vol. 67, No. 10 (October 1977), pp. 913-914.

This is certainly true for non-fatal disease and, for a time, for fatal illnesses also. But it may well be false in the long run, regarding killing diseases. It is especially likely to be false in that prevention of some diseases may save certain costs for a time, especially in the acute medical care sector. But many of these savings are only postponements over time within the acute care sector and/or transfers of spending to the long-term care sector. The costs of treating illnesses may be put off for a time, until people become ill from something which we do not yet know how to prevent. Many of the cheap-to-treat illnesses have been prevented. It may be argued that increasing proportions of us now become sick and ultimately die from illnesses which linger and are expensive to treat.

(This is not an unmixed curse. It does signify that many Americans are living long enough to require long-term care. Further, it testifies to medicine's power to combat diseases such as influenza or pneumonia, once called the "old man's friend,"--diseases which quickly carried off many weak older persons and therefore reduced demand for long-term care.)

Analyses of U.S. data reveal striking secular changes in the relative longevity of men and women since the beginning of this century. Table II-I presents these changes. The considerable and growing gap between male and female longevity is reflected in the sex ratio of the elder population and in the different living arrangements and marital statuses of men and women.

Table II-I

Changes in Male and Female Longevity, 1900-1975

Period	<u>Life expectancy at birth (years)</u>		
	<u>male</u>	<u>female</u>	<u>gap (years)</u>
1900-1902	47.9	50.7	2.8
1949-1951	65.5	71.0	5.5
1969-1971	67.0	74.6	7.6
1975	68.7	76.5	7.8

Source:

National Center for Health Statistics, "Some Trends and Comparisons of United States Life-table Data: 1900-1971," U.S. Decennial Life Tables for 1969-71, Vol. 1, No. 4, Washington: USGPO, May 1975, Table 1; U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 94.

Table II-J indicates the relative size of the elderly U.S. male and female populations today. Overall, there are about 146 women for every 100 men aged 65 and above. In the age groups most vulnerable to requiring long-term care, those 75 and above, there are 186 women for every 100 men.

Differing living arrangements and marital status of men and women have a measurable effect both on the demand for long-term care and on the prospects for supplying it via informal supports. In 1975, only about 18% of men aged 75 and above were living alone; over 40% of all women were living alone. Table II-K indicates the marked increase over the past quarter-century in the proportions of older men, and (especially) of older women who live alone. Sixty-three percent of all men aged 75 and over lived with a spouse. These factors are reflected in different rates of institutionalization: 7.4% of men aged 75 and above lived in nursing homes or other institutions, while fully 10.0% of all women did so.¹ There is some evidence that one reason why women have been disproportionately obliged to enter institutions (few do so from choice)² is the absence of someone to care for them at

¹U. S. Bureau of the Census, "Demographic Aspects of Aging and the Older Populations in the United States," Current Population Statistics, Series P-23, No. 59, Washington: USGPO, May 1976, Table 6-2.

²William G. Bell and others, Community Care for the Elderly: An Alternative to Institutionalization, Tallahassee, Florida; Program in Social Planning and the Aged, Florida State University, June 1971.

Table II-J

Aged Men and Women in the United States, 1978

<u>age</u>	<u>aged population (thousands)</u>		
	<u>men</u>	<u>women</u>	<u>women/100 men</u>
65-69	3,786	4,773	126
70-74	2,680	3,676	137
75-79	1,627	2,531	156
80-84	791	1,763	223
85	671	1,463	218
65	9,735	14,207	146
75	3,089	5,757	186

Source:

U. S. Bureau of the Census, Projections of the Population of the United States: 1977-2050, Current Population Report, Series P-25, No. 704, Washington: USGPO, July 1977.

Table II-K

Population Aged 65 and Above Living Alone, 1950-1977
(thousands)

year	Total	living alone	% alone	Male	living alone	% alone	Female	living alone	% alone
1950	12,397 ¹	1,559 ²	12.6%	5,856 ¹	518 ²	8.8%	6,541 ¹	1,041 ²	15.9%
1960	16,560 ³	2,898 ⁴	17.5	7,503 ³	853 ⁴	11.4	9,056 ³	2,045 ⁴	22.6
1970	19,972 ³	5,071 ⁵	25.4	8,367 ³	1,174 ⁵	14.1	11,605 ³	3,897 ⁵	33.6
1977	23,431 ⁶	6,482 ⁵	27.7	9,545 ⁶	1,343 ⁵	14.1	13,885 ⁶	5,139 ⁵	37.0

Sources:

1. U.S. Bureau of the Census, Statistical Abstract of the United States, 1975, Washington: USGPO, 1975, Table 3.
2. U.S. Bureau of the Census, U.S. Census of Population: 1960, Vol. I, Characteristics of the Population. Part 1, U.S. Summary, USGPO, Washington, D.C. 1964. Table 185.
3. U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 28.
4. U.S. Bureau of the Census, Persons by Family Characteristics, Subject Reports, Final Report PC (2)-4B. U.S. Census of Population: 1960. Washington: USGPO, 1964, Table 3.
5. U.S. Bureau of the Census, "Household and Families by Type: March 1977 (Advance Report), Current Population Reports, Series P-20, No 313, Washington: USGPO, September 1977, Table 3.
6. U.S. Bureau of the Census, Projections of the Population of the United States: 1977-2050, Current Population Reports, Series P-25, No. 704, Washington: USGPO, 1977, Table 8.

Table II-K

Note

Note on figures for 1960, 1950: estimates of those living alone are based on data for primary unrelated individuals presented in sources 4 and 6. By definition (source 4, p. IX and U.S. Census of Population: 1950, Vol. IV, General Characteristics of Families, Washington: USGPO, 1955, pp. 2A-7 and 2A-10), a primary individual is a household head living alone or with non-relative only. Figures for 1960 indicate that 88.6 of all primary individuals live in a household of 1 person, while 91.8% of male primary individuals age 65 and above and 90.5% of female primary individuals age 65 and above live in a household of 1 person. Based on a statement in the 1950 census that "five out of every six primary individuals were living alone (as one-person households) in 1950" (op. cit. p. 2A-10), ratios were calculated of the 1960 percentages ($91.8/88.6$ and $90.5/88.6$), these ratios adjusted to account for a change between 1950 and 1960 in the percentage of 65 and above males (-0.9%) and 65 and above females (+5.5%) constituting the primary individual category, and the final ratios applied to the 1950 living-alone % (83.3) to estimate the percent of each sex group living alone in 1950. These percentages were then applied to the total primary individual figures for that age/sex group for 1950 and the resulting numbers used to estimate percentages of that total age/sex group living alone.

home when the need for help becomes pressing.¹ Table II-K presents striking data on the proportions of non-institutionalized older men and women who live alone. In 1977, the proportion of women over age 65 living alone was over two and one-half times that of men. The long-term trend, based on historic patterns, appears likely to be increasingly unfavorable to women.

The foregoing review of epidemiologic changes has set out three types of explanations of increased need for long-term help by older Americans as a group. In turn, the supply of long-term care by family members and other informal supports to meet this increased need, depends on the availability, ability, and willingness of these informal supports to help the elderly. Availability means that informal supports have the time, physical strength, skills, and energy necessary to provide needed help. Willingness indicates that the choice to help is made. Public attempts to enhance family support by manipulating choice or increasing skills in a particular case would be pointless--if availability were the real problem in that case. Conversely, it is clear that all three elements are required before informal support can be provided. In recent years, the supply of long-term care by family members--their availability and ability--has been affected by both economic and socio-demographic changes in American society.

¹National Center for Health Statistics, "Marital Status and Living Arrangements Before Admission to Nursing and Personal Care Homes, United States, May-June 1964," Vital and Health Statistics, Series 12, No. 12, Washington: USGPO, May 1969, Table 2.

Economic changes. Industrialization, in itself, seems to have reduced availability of family members to aid one another. Four consequences of industrialization--geographic mobility, rising real incomes, urbanization, and careers for women--seem to have acted in similar ways. Industrialization has meant a decline in the role of the family as a unit of production. Grandparents, parents, and children therefore no longer find it necessary to live with or near one another. They had more often lived together when farm or shop was the site of production.

Geographic mobility in the United States in recent years has been considerable. From 1970 to 1975 alone, over 41% of the U.S. population over age five moved to a different residence; over 17% moved to a different county or a different state.¹ It is not known how many older Americans who need help fail to receive it because family members live too far away to provide it regularly (or at all). Further, it is not known whether family are less or more available today than 200, 100, 50, or 10 years ago. What does seem clear is that adult children and other potential caregivers of the elderly often live hundreds of thousands of miles away. Some adult children leave the South and Appalachia for jobs in Northern and Midwest cities; others move from their parents' homes to settle in the cities where they attend college; still others seek work in California, Texas, and other regions of above-average rates of job creation. Older citizens move as well, principally as they retire, from cold to warm regions.

¹U. S. Bureau of the Census, Statistical Abstracts of the United States, 1977, Washington: USGPO, 1977, Table 46.

Rising real incomes of both the elderly and the non-elderly have permitted increasing proportions of Americans to live apart from their parents or children. (No position is taken here on how high this proportion was in the past or on how far it appears to have fallen.) As separate dwelling units are established, usually at a time of good health for members of both households, they may be located either near or far from one another. If far, availability of help for aged members of the family who subsequently require aid is reduced.

The growth of large American cities and suburbs has entailed more than the construction of buildings. It has also created the spatial and social setting for patterns which seem in some respects inimical to family support of elders. Spatially, in the years since World War II, residential land-use patterns in large older cities have often obliged young families seeking homes of their own to move many miles from the homes of their parents. This has been particularly true when incomes or lifestyles of the two generations have differed. To help families live together, more mixed-income, mixed-class neighborhoods would be desirable. Then, distant relocation would no longer need to be the price of income or life-style differences across generations. Racial and ethnic succession in cities has been accompanied by the disproportionate departure of the young and mobile, and the continued residence of elders. Large-scale public projects in many cities--urban renewal, public housing, highway construction--have displaced thousands, often into tight housing

markets which made difficult collective relocation of large families.¹ The effect of these events has probably been to reduce the availability of family support for older citizens.

Socially, the city has been the setting for changes accompanying urbanization and industrialization. Even when parents were not physically left behind by their children, parental authority was often set aside. There are many reasons: uprooting of traditional culture by the stress of international migration or the journey from farm to city, loss by the parents of land ownership as a source of control, and perceived obsolescence of traditional values and skills carried by parents.² Loss of parental authority has by no means meant a collapse of intergenerational support. It has reduced parents' ability to compel provision of aid by children. Other things being equal, it cannot be decided whether children are willing to do more or less for parents today than in past years.

Industrialization and urbanization have made it possible for increasing proportions of women to take jobs outside the home. This has reduced their availability as providers of care to older relatives who could not be left alone. (Women may work on the farm and work at

¹Herbert Gans, The Urban Villagers, New York: The Free Press, 1962, contains an account of the difficulties of large-scale relocation.

²For discussion of this pattern, see Harold L. Wolensky and Charles N. Lebeaux, Industrial Society and Social Welfare, New York: Free Press, 1965, especially, pp. 77-79; also Maurice R. Stein, The Eclipse of Community, Princeton, N.J.: Princeton University Press, 1960, ch. 1.

keeping house in cities, but are not counted as members of the "labor force" unless they are paid.) In 1940, 17% of all married women worked outside the home; by 1976, this figure had risen to 46%.¹

Taken together, the economic forces just discussed seem to have reduced the availability of families to care for their aged members. Several socio-demographic changes which have had similar consequences are now worthy of mention.

Socio-demographic changes. Three forces which seem to have affected availability, ability, and willingness of family members to care for their aged relatives are the decline in the number of children per family, the aging of potential providers of care, and the increase in the rates of divorce and re-marriage.

The number of children per aged patient is one of the most important variables influencing whether a dependent older person comes to live with a child and thereby avoids or postpones institutionalization.² The number of children born in each family has been declining. This

¹U.S. Bureau of the Census, Historical Statistics of the United States from Colonial Times to 1970, Washington: USGPO, 1975, Series D-60; U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 632.

²Marvin B. Sussman, "Family Life of Old People," in Robert Binstock and Ethel Shanas, eds., Handbook of Aging and the Social Sciences, New York: Van Nostrand, 1976, pp. 218-243; cites A. Chevan and J. H. Korson, "Living Arrangements of Widows in the United States and Israel," Demography, Vol. 12, pp. 505-518.

means that fewer children are available--even potentially--to care for aged parents. The decline has not been continuous. Neugarten notes that there will be almost 50% more children for each surviving 65 year old woman in the year 2000 than there are today.¹ The ratio will worsen again after the year 2000 as the children of the post-World War II baby boom are replaced as potential caregivers by the children born in recent years. This will mean that women now of childbearing age (and their husbands) will be able to draw on fewer children to provide that help that did preceding generations. Support for this contention is provided by the decline in the total fertility rate, one crudely standardized measure of the ratio of children born to women of childbearing age. It has dropped steadily from a post-World War II high of 3,690 births per 1000 women in 1955-1959 to only 1,799 per 1000 women in 1975.²

The age of adult children is also an important factor. As noted above, when very old parents come to need care, it must be expected that an appreciable number of children will be unable to provide that

¹Bernice L. Neugarten, "Commentary," in A.N. Exton-Smith and J. Grimley eds., Care of the Elderly; Meeting the Challenge of Dependency, New York: Grune and Stratton, 1977, pp. 102-104.

²U.S. Bureau of the Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, Table 76. See also Judith Treas, "Family Support Systems for the Aged: Some Social and Demographic Considerations," The Gerontologist, Vol. 17, No. 6 (December 1977), pp. 486-491.

help: they may be too ill or too frail to aid their parents. The same difficulty can impede help of one elderly spouse by another.

A related problem deserves mention here. Ability of family members to aid dependent older relatives is impaired not only by the frailty of potential providers, but also by the technical difficulty of rendering needed help. Advances in medicine and related fields have made more complex the tasks of home care for many dependent older persons. The proportion of home care services which can be provided by family members, in the absence of training or other skilled support from outside the home, has probably been reduced. Such training and support may well merit increased investment in the future.

Availability of family members to provide help--and perhaps their willingness to help--has very likely been impaired by rising rates of divorce and remarriage. A small proportion of the elderly are themselves divorced or separated; these former spouses are therefore unavailable to help each other. More often, older parents may divorce and remarry; their children may do the same. In either case, bonds of affection and obligation can become diffused. Children may be left uncertain about whom to care for. Children and step-children may find it more difficult to negotiate and allocate the jobs of caring than would children alone.

In considering epidemiologic, economic, and socio-demographic influences on the demand for long-term care and on the supply of informal support, important interactions between the sources of increased demand and reduced supply should be noted. For example, higher real incomes

have done much to improve longevity; at the same time, they have enabled the generations to live apart. Further, at least until very recently, different sex roles in the labor market may have helped increase the gap between male and female longevity. This is true of deaths caused by cancer and probably somewhat less true of deaths caused by cardio-vascular diseases. A second example lies in the decline in the number of children per family. This drop has been affected by the reduced importance of the family as a unit of production and the perceived availability of OASI to replace care by children. Attempts to enhance informal supports' availability, ability, or willingness to help the aged by manipulating individual variables should take these and similar interactions into account.

Just as secular changes in these variables seem to affect supply and demand for long-term services, so it may be hypothesized that the strength of the variables themselves, in individual cases, relates to the types and quantities of services required by the elderly and to the proportion of those services provided by families. Patient-related demand variables and family-related supply variables will be among those explored in this study.

In this regard, it is of vital importance to take note of the work of Sussman, who has explored the variables associated with families' willingness to care in their own homes for older persons. This research suggests that a number of important variables which could be influenced by public programs are most powerful influences on family willingness to

provide support.¹

Even better understanding of the forces affecting the availability, ability, and willingness of informal supports to care for the dependent elderly will inform possible public interventions to increase the supply of this type of care. Such understanding should also serve as a base for possible negotiations over division of responsibility between informal supports and formal providers.

This section has explored epidemiologic, economic, and socio-demographic reasons for the growth in reliance on formal supports and public financing for the provision of long-term care in this country. The next section examines the reason for the emphasis on institutional services in the provision of publicly-assisted long-term care.

D. Public Responses to Increased Demand for Long-term Care:
Institutional Preferences

Since the second half of the nineteenth century, a combination of social changes and public responses to those changes has induced a growing proportion of the elderly to live out their lives--and die--in hospitals, nursing homes and other institutions. Epidemiologic,

¹Marvin B. Sussman, "Social and Economic Supports and Family Environments for the Elderly," Final Report to the U.S. Administration on Aging, Grant 90-A-316, January 1979.

economic, and socio-demographic changes influencing the demand for formal long-term care supports were discussed in the previous section. Now, the nature of public response to these changes is presented and explained.

The origins of the modern nursing home. The pattern of entering hospitals for care of terminal (and other) illnesses spread during the 19th century from the poor to other groups in most industrial societies. Hospitals were founded during the Middle Ages as places for pilgrims and other travelers to rest, especially when ill. They evolved into sites of care for the dying poor.¹ With the advent of medical interventions which seemed to be of demonstrable benefit in assuaging pain or saving lives, construction of hospitals to serve all classes grew rapidly.

A U.S. Commission on Hospital Care identified five important factors which contributed to the growth of hospitals: advanced in medical science (especially through wars which resulted in rapid progress in surgical specialities, the focus of early hospital care), modern nursing, education for doctors and other personnel, religious and philanthropic impulses, and increased per capita income (permitting allocation of resources to hospital care without imperiling

¹See, "25 Years for Health," Cleveland Press, May 16, 1941; Ivan Belknap and John G. Steinle, The Community and Its Hospitals, Syracuse: Syracuse University Press, 1963, pp. 9-10; and Michael M. Davis, Clinics, Hospitals, and Health Centers, New York: Harpers, 1927, p. 17.

other areas of consumption).¹ Corwin pointed to two additional pressures leading to hospital expansion: increasing urbanization, which induced a recognition that health was not solely a personal matter, but in part a public concern as well; and a desire to conserve physicians' time by gathering patients conveniently together.² Belknap and Steinle endorse the argument that hospitals are because medical advances converted them into sites where special tools-- x-ray, antiseptic surgery, modern nursing, for examples--of diagnosis and treatment could be conveniently organized. They also emphasize the importance of economic and social factors supporting the founding and expanding of hospitals: the growth of industrial production in the U.S. after the Civil War; the accumulation of large surpluses in the hands of a wealthy few; and the widely received doctrine that philanthropy was as necessary to high status as was wealth.³

As the usefulness of hospital care became more visible, it came to be desired by all classes of the population. The hospital ceased being "principally a place for the transient ill, the poor, and the person with a communicable disease."⁴ Although some hospitals

¹

Commission on Hospital Care, Hospital Care in the United States, New York: Commonwealth Fund, 1947, pp. 43-51.

²

E.H.L. Corwin, The American Hospital, New York: Commonwealth Fund, 1946, pp. 9,11.

³

Belknap and Steinle, op. cit., p. 13.

⁴Belknap and Steinle, op. cit., pp. 9-10

began accepting some paying patients as early as 1850,¹ it was not until the turn of the century that all classes came to accept hospital care.²

The various reasons for the growth of hospitals changes in its services, and the patterns of its use by different populations will be contrasted below with the reasons for the later growth of nursing homes. The consequences of these differences for the long-term care system generally--and for home care particularly--will be explored.

Hospitals grew in number from only 178 in 1873 to 4359 in 1909 and to 6291 in 1940. The number of beds rose from 421,000 in 1909, and to 1,226,000 in 1940.³

It should be expected that an increase in the number of hospital beds would be associated with an increase in the proportion of the population dying in hospitals in 1955; by 1967, this population had

1

George Rosen, "The Hospital: Historical Sociology of a Community Institution," in Eliot Friedson, ed., The Hospital in Modern Society, New York: Free Press, 1963, pp.29-30

2

Until 1908, doctors at Massachusetts General Hospital could not charge fees; New York Hospital, Johns Hopkins, and the Pennsylvania Hospital did not organize special facilities for private patients until 1900-1910. See Belknap and Steinle, op. cit., pp. 9-10.

3

Corwin, op. cit., pp. 1,7 citing a study by J.M. Toner, "Statistics of Regular Medical Associations and Hospitals of the United States: Section II," Transactions of the American Medical Association, Vo. 24(1873), pp 314-33; and U.S. Bureau of the Census, Historical Statistics of the United States, Colonial Times to 1970, Part 1, Washington: USGPO, September 1975, Series B-345 and B-346.

risen to 67.3%.¹ There is every reason to believe, based on the increasing numbers of hospital beds in this country, that Lerner's data capture only the most recent segment of a trend beginning in the nineteenth century.

What is new in the years since World War II is the striking increase in the use of long-term care facilities by the elderly in the years before death. (The growth in total long-term beds available to the elderly was discussed in section B of this chapter.) The number of nursing homes alone increased from 1200 in 1939 to 16,701 in 1963, to 21,834 in 1973. At the same time, residents increased from below 25,000 in 1939 to 491,000 in 1963 to 1,198,000 in 1973.² By 1973, 5.0% of Americans aged 65 and above were residing in nursing homes.

1

Monroe Lerner, "When, Why, and Where People Die," in Orville G. Brim, Jr., and others, eds., The Dying Patient, New York: Russell Sage Foundation, 1970, Table 4. Lerner writes that the great majority of deaths in institutions in fact occurred in hospitals.

2

U.S. Bureau of Census, Statistical Abstract of the United States, 1977, Washington: USGPO, 1977, table 163; and Samuel Levey and Bernard A Stotsky, Nursing Homes in Massachusetts, Boston: Massachusetts Research Institute, Inc., March 1968 (mimeo), citing L. Block, "Hospital and Other Institutional Facilities and Services, 1939," Vital Statistics, Special Reports 13, Nos. 1-57, Washington: U.S. Bureau of the Census, 1942. The 1939 estimates of 1200 nursing homes and 25,000 residents may be low. Wrote Bigelow and Lombard, "In 1933, 'there were 435 nursing homes known to exist in the Commonwealth of Massachusetts, and the existence of others is suspected.'" (G.H. Bigelow and H.L. Lombard, Cancer and Other Chronic Diseases in Massachusetts, Boston: Houghton Mifflin, 1933, p.69, cited in Levey and Stotsky, op. cit., p.5.) It seems clear that varying definitions of "nursing homes" were used. Alternatively, Massachusetts may simply have been well-advanced in the provision of long-term care in "nursing homes."

The proportion receiving nursing home care during their last years was even greater. Lerner found that the percentage of all deaths occurring in nursing homes, homes for the aged, and similar facilities, increased dramatically from 1.6% in 1949 to somewhat under 6.0% in 1958.¹ More recent work by Kastenbaum and Candy² and Wershow³ shows that there has been a rapid increase in nursing home use during the last years of life.

Further, Kastenbaum and Candy criticized then-current use of population data which indicated that, at any time, only 4% of those over age 65 were in nursing homes or other long-term care facilities. They argued that application of these cross-sectional data seriously underestimated any older person's true chances of using such long-term care. By studying obituary notices, they estimated that 13.3% die in nursing homes; by studying death certificates, they found that 20.3% die in nursing homes and 23.7% die in nursing homes or other extended care facilities. These proportions were themselves thought to be underestimates in that they did

1

Lerner, op. cit., pp. 22-23.

2

Robert Kastenbaum and Sandra E. Candy, "The 4% Fallacy: A Methodological and Empirical Critique of Extended Care Facility Population Statistics," International Journal of Aging and Human Development, Vol. 4, No. 1 (1973), pp. 15-21.

3

Harold J. Wershow, "The Four Percent Fallacy: Some Further Evidence and Policy Implications," The Gerontologist, Vol. 16, No. 1, Pt. 1 (1976), pp. 52-55.

not include those short- and long-term residents of extended care facilities whose conditions became unstable, were transferred to hospitals, and died there.

Today's American pattern of providing long-term institutional care for the elderly did not emerge full-blown from the Medicare and Medicaid legislation of 1965. These laws did yield a significant increase in public funding for nursing home care. The regulations promulgated in Washington to carry out the laws did much to systematize what was formerly an inchoate and diverse group of facilities. Nonetheless, many of the characteristic assets and liabilities of today's system of long-term care represent a continuation of patterns long established. For these reasons, it is useful to review briefly the history of long-term institutional care for the elderly.

In many respects, nursing homes are the organizational descendants of early hospitals. Since the turn of the last century, hospitals have become progressively more distinct as sites of short-term intervention. Activities not requiring large doses of skilled help have for a variety of reasons been successively shed to long-term care facilities. These activities are generally performed today in skilled nursing facilities and, to a lesser extent, in the less medically and rehabilitatively oriented intermediate care facilities. To these SNF's and ICF's should be added a third type of institution, the rest home, which provides room, board, and very small amounts of direct supervision.¹ This discussion

¹Facilities are licensed under different names in different states. In New York, for example, ICF's are "health-related facilities," and rest homes are "domiciliaries."

will devote little attention to those long-term institutions denoted as hospitals. In general, a long-term institution is one in which patients' average stay is 30 days or more.¹ Many of these chronic and/or rehabilitation hospitals provide to the elderly care which is very similar to that of skilled nursing facilities. Others fall between SNF's and acute care hospitals in the sophistication and vigor of their patient care. The number of these hospitals is not great.

In the United States, early nursing homes were a heterogeneous lot. They had a variety of names and institutional origins, and housed diverse populations. In many cases, they were not easy to distinguish from other types of facilities.² The earliest sort of organization commonly housing the poor in the United States was the almshouse. The almshouse had origins in the 1601 English Poor Law. This civil institution was the product of two events. The first was the suppression by Henry VIII of Roman Catholic institutions for the care of the frail poor and the second was the perceived need to manage the large numbers of dispossessed subjects driven to towns and cities by enclosures of common land or attracted there by the prospect of employment. The almshouse was

¹See U. S. Bureau of the Census, 1976 Survey of Institutionalized Persons: A Study of Persons Receiving Long-Term Care, Current Population Reports Series P-23, No. 69, June 1978, technical note.

²The following discussion draws heavily on Levey and Stotsky, op. cit., pp. 1-5; and on Robert M. Moroney and Norman R. Kurtz, "The Evolution of Long-Term Care Institutions," in Sylvia Sherwood, ed., Long-Term Care: A Handbook for Researchers, Planners, and Providers, New York: Spectrum (Wiley), especially pp. 81-89.

transplanted to the American colonies in the 17th century. Housing an undifferentiated population, it often provided little in the way of decent care to the elderly. By contrast, the earliest hospitals--- Pennsylvania, Philadelphia General, New York, and Bellevue--all evolved from infirmaries of almshouses but can be seen as an expression of charitable impulses toward the frail and chronically ill elderly. Possibly because early hospitals were designed to house solely those who could not work, the standard of living which they offered the elderly was usually higher than that of the almshouse.

By the late nineteenth century, distinctions between the two institutions of the almshouse (or "poor house" or "county infirmary") and the hospital were becoming increasingly clear. Hospitals were for treatment of medical and surgical problems, for recuperation, and for the isolation of contagious diseases. Most early hospitals were owned by voluntary, non-profit, philanthropic corporations; this pattern prevailed also during the period of explosive hospital growth which began during the final quarter of the nineteenth century. In the almshouse resided a diverse group of citizens thought unable to live in the community. In some states, the insane and the victims of communicable diseases like tuberculosis were placed in segregated institutions; usually, however, the frail elderly were housed alongside the diseased, the retarded, the blind, orphans, and criminals. The overwhelming majority of these facilities were publicly owned and operated. They varied considerably in the quantity and quality of nursing and physician services offered.

During the last quarter of the nineteenth century, hospitals became recognizable as increasingly different from the almshouses for the impoverished, disabled or incurable elderly. Acute care hospitals provided active treatment and recuperation for all classes, usually under voluntary non-profit auspices. Publicly owned county infirmaries, or poor farms, continued as institutions of last resort for the elderly.

During the 1920's, a new long-term care facility became visible. This was the convalescent home, offering post-surgery and other recuperative care to those unable to return directly home from the hospital and able to pay for their room, board, and the varying quantities and quality of nursing care available. The convalescent home, usually privately owned and operated to earn a profit, can be seen as the most direct ancestor of the typical skilled nursing home today. Another institution, the non-profit "home for the aged," grew around the same time as the convalescent home. Its residents seem to have remained longer than those of the convalescent home.

It can be seen that hospitals shed first the function of caring for the frail elderly, and second that of housing convalescents. Specialized long-term care facilities arose to perform these tasks on behalf of the different social groups: the poor to live in almshouses and those who could pay to recuperate in convalescent homes or to reside in homes for the aged. (It should be noted that the almshouse itself was engaged in a similar shedding as the "insane" were placed in asylums and the "criminals" were placed in penitentiaries.) It is not known either what proportions of the population these institutions served or how well

they cared for their residents. It does seem likely that most frail older persons lived out their years cared for at home by their families, and that others--fewer in number--suffered unnecessarily and died prematurely because they lacked help to live in their homes but could not or would not enter an institution.

Similarly, the quality of institutional care was uncertain. Some almshouses, though publicly owned, were managed under contract by individuals whose incomes depended on keeping costs low and/or selling the services of residents. Locally financed from property taxes, almshouses were seldom run so as to encourage marginal optional admissions. Utilization and taxes were controlled in part by making it clear to the elderly that these unattractive institutions were clearly a last resort, that the almshouses housed those who failed, who had not worked hard enough, who had not saved enough, who were "morally defective." In some cities, where almshouses came to be run by local political machines as welfare benefits, the quality of life for the elderly may have been somewhat better than the average. In contrast to almshouses, convalescent homes cared for a paying population and probably felt some competitive pressures to satisfy their residents.

With the passage of Titles I and II of the Social Security Act in 1935 came national programs of old-age assistance (building on earlier state legislation) and also of federal old age and survivors' insurance.¹

¹See Edwin Witte, The Development of the Social Security Act, Madison: University of Wisconsin Press, 1963; and The Social Security Act, Public Law 74-271 (14 August 1935), 49 Stat. 620.

These programs raised the incomes of most elderly Americans and immediately placed cash in the hands of many who had formerly been destitute.

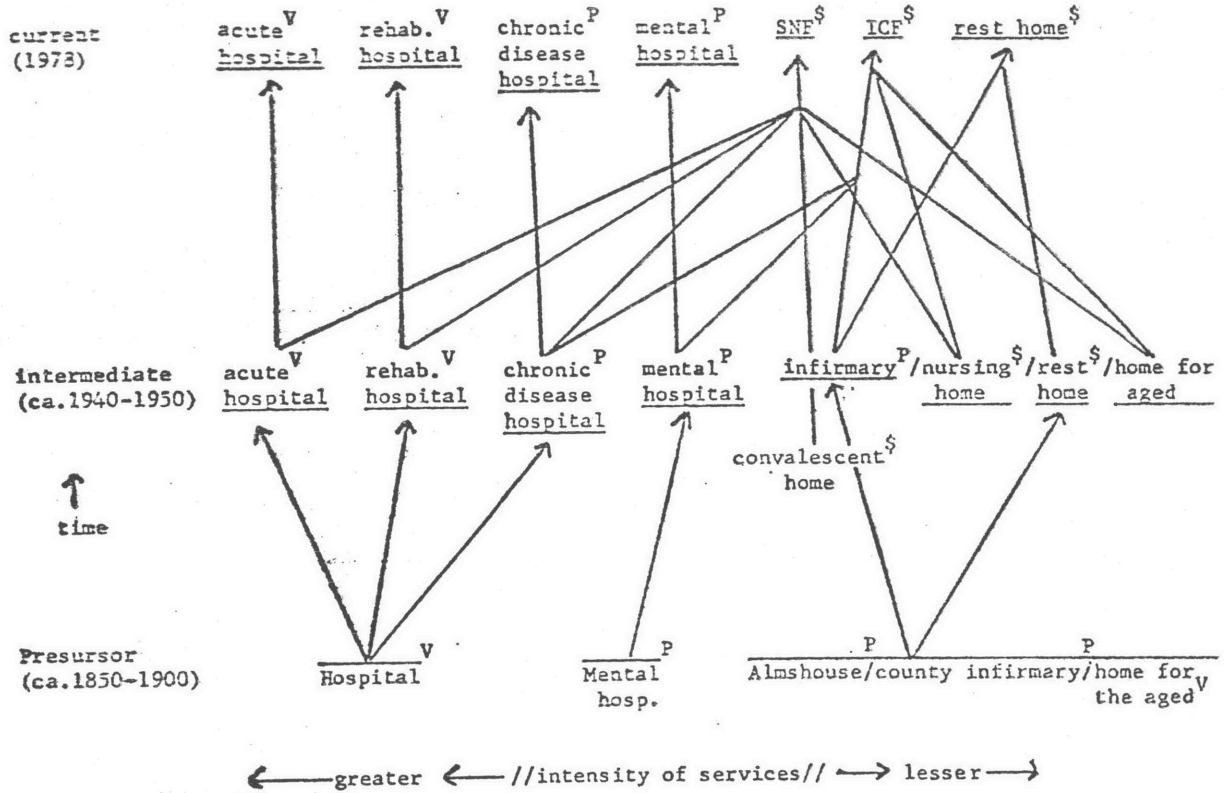
The availability of these funds affected decisions by both the elderly and their families. Those elderly citizens who had desired to live apart from their children, now had the wherewithall to do so. Those spouses or adult children who had been unable or unwilling to continue to care for their husbands, wives, or parents at home, but had not been prepared to make the decision--widely perceived as shameful--to place them in the poor house, now saw old age assistance and retirement or survivors' insurance as the means with which to pay for institutional care.

During the 1940's and 1950's, these alternatives slowly grew. Boarding homes, homes for the aged, nursing homes, rest homes, and other facilities were founded in increasing numbers. Names used were often arbitrary or simply followed the licensing requirements of those states which had enacted such. Reliable national data on the numbers of facilities of different types, and on the services provided are lacking because of inconsistent nomenclature and fragmented regulation. It does seem that they were generally small and offered relatively few services beyond room and board. Many resembled crudely the foster care programs rediscovered in recent years: an elderly couple or widow might take in 2-5 boarders. Skilled nursing or rehabilitative services were generally lacking.

Figure II-A portrays in general terms, the evolution of functions and

Figure II-A

Institutional Antecedents of Today's Long-term Care Facilities



Code: dominant control: V= Voluntary, non-profit
P= Public
\$= Proprietary

organizations in the institutional long-term care field from the last half of the nineteenth century through today. While only a crude representation, it serves several useful purposes: First, it indicates the diverse origins of today's long-term care facilities. Long-term care facilities today range from the intensive help provided in rehabilitation hospitals to the low level of support offered in rest homes. These facilities have evolved as successors to several types of earlier institutions. They acquired some of the functions successively sloughed off by acute and other hospitals; they reorganized into more-or-less systematic levels of care the heterogeneous functions of antecedent facilities.

Second, this figure indicates that there exists today a logical framework for viewing the functions of long-term care facilities. Perhaps until the passage of Medicare and Medicaid, non-hospital institutions were distinguished more by their source of revenue than by the types and intensity of services they provided their patients. (Despite the regulations accompanying federal financing, which have systemized the services federally reimbursed, many of the vagaries of the older system survive. For example, life safety codes may prevent some county infirmaries from obtaining certification as intermediate care facilities, even though they provide that level of care.)

Public programs which pay for long-term care have grown in different ways from both common and diverse sources. The nature of this growth, and the reasons for it help explain the current debate over

increased public funding for home care--which generated the present study.

Public financing for institutional care. In the United States, the first public funds for institutional care supported poor houses, almshouses, and similar facilities. With the construction of proprietary nursing and convalescent homes and non-profit homes for the aged during the first decades of this century, non-stigmatizing alternatives to public facilities became visible. Passage of the Social Security Act made available to the elderly Old Age Assistance "welfare" funds and retirement and survivors' "pension" funds. Both types of money could be spent on institutional care, and each could be regarded in a sense as public spending, in-as-much-as it was collected through taxation and disbursed out of proportion to any funded contributory scheme. It was only in 1940 that any spending on nursing home care was identified by federal statistics. This sum, \$33 million, was thought to have been spent entirely by private consumers. Local public spending and philanthropic contributions were not included.¹

The first federal program of direct vendor payments to nursing homes was authorized by the Social Security amendments of 1950. By 1952, the final pre-Medicaid year, public nursing home spending was \$502 million;

¹Office of Research and Statistics, Social Security Administration, Compendium of National Health Expenditures Data, Washington: USGPO, 1973, Table 6.

this was almost entirely federal-state medical vendor payments. These payments were made both under a 50% federal match (Old Age Assistance) and under a 50-80% federal match (Kerr-Mills Medical Assistance to the Aged).¹ In 1965, 60% of all patients in nursing homes received partial or full support under one of these two welfare programs.² Table II-A of this chapter summarized the growth of absolute and proportionate public nursing home spending. By fiscal year 1977, total spending had risen to \$12,618,000,000; the public share was 56.9%.

A series of legislative changes helped underwrite this increase in funding. Medicare directly covered for the first time long-term institutional care without a means test. This was---and is---available only for short post-hospital recuperative stays, and amounts to only a small share of public nursing home spending today, but it may prove an important precedent. The Kerr-Mills Medical Assistance to the Aged and the Medicaid programs represented departures from the Old Age Assistance medical vendor payment schemes for skilled nursing facility care. They increased the federal share of nursing home spending in many states and removed the cap on the maximum daily rate in which the federal government would share. It is worth noting in passing that the enactment of Medicaid itself should

¹Robert J. Myers, Medicare, Homewood, Ill.: Irwin, 1970, pp. 40-41.

²National Center for Health Statistics, "Chronic Illness Among Residents of Nursing and Personal Care Homes, United States, May-June 1964, PHS Pub. No. 1000, Series 12, No. 7, Washington: USGPO, 1967; cited in Robert M. Moroney and Norman R. Kurtz, "The Evolution of Long-term Care Institutions," op. cit.

not be held responsible for any meaningful acceleration of the rate of public spending on nursing home care. This public spending increased 152% from 1961 to 1965, under the combined Old Age Assistance medical vendor payment and Kerr-Mills Medical Assistance to the Aged authorizations; it increased 167% from 1966 to 1970 under Medicaid.¹ Finally, the Social Security Amendments of 1972 expanded coverage under the Medicaid program beyond skilled nursing facility care to include intermediate care facilities.

Public financing for home care. Three major programs currently fund home care services for the elderly. In two other areas, small programs have this year won Congressional appropriations; they may grow. Presently, Medicare, Medicaid, and Title XX finance in-home services for the elderly. Medicare will pay for post-hospital care under Part A and other skilled care under Part B. In both cases, services are limited to patients requiring short-term, intermittent assistance from a registered nurse or physical or speech therapist. The patient must be homebound. Some assistance by a home health aide may be reimbursed, but this is limited to medically-related services. The home health aide may perform incidental housekeeping tasks, such as cooking or cleaning, only if such performance does not substantially increase the time spent in the home. General homemaker services are not covered. In sum, Medicare

¹Office of Research and Statistics, Social Security Administration, Compendium of National Health Expenditures Data, Washington: USGPO, 1973, Table 6.

pays almost exclusively for skilled, short-term home care.¹

The state-federal Medicaid program is free from the legal and regulatory strictures of Medicare. Since 1970, home health care has been a mandated benefit, and states seem in practice free to write and administer Medicaid plans to reimburse a wide range of services to those eligible for the program. Patients need neither be homebound nor in need of skilled services. Covered benefits may extend beyond those permitted by Medicare to include homemaking and chore services. Nonetheless, viewed nationally, the Medicaid home health program must be considered a profound disappointment. It is not really a national program: in calendar 1976, for example, of total Medicaid spending of \$151 million, \$123 million (81.5%) was spent in New York State.² The United States, then, can be thought of as having not a national Medicaid home health program, but rather a one-city program. Other jurisdictions forego the opportunity of federal matching funds; they are probably out of compliance with federal mandate to provide home care services to eligible Medicaid beneficiaries.

¹For careful summaries of these issues, see Comptroller General of the United States, "Report to the Congress: Home Health Care Benefits Under Medicare and Medicaid," Report B-164031 (3), Washington: General Accounting Office, July 9, 1974, pp. 16-18; also, Judy LaVor, "Long-term Care: Challenge to Service Systems," Washington: Office of the Assistant Secretary for Planning and Evaluation, DHEW, April 1977, p. 49.

²National Center for Social Statistics, "Medicaid Statistics, December 1976," NCSS Report B-1, Washington: NCSS, April 1977, Table A-3.

Title XX of the Social Security Act is the third major source of public funding for home care. Home-based services for the elderly consume a large proportion of funds allocated under most states' Title XX plans. Home care helps support attainment of most of the federally legislated goals of Title XX: aiding families in becoming or remaining self-sufficient and self-supporting, protecting older citizens who are unable to care for themselves, and helping individuals avoid institutionalization.¹

Two new programs legislated in the 95th Congress will provide a measure of help to support the elderly at home. The first is federal funding for social services in housing projects for the elderly ("congregate housing"). The second is federal funding for meals-on-wheels programs of home-delivered food. Either or both of these programs may grow and contribute measurably to sustaining aged Americans at home. Recent consolidations and re-focusing of programs under the Older Americans Act may yield similar results.

Explaining the institutional preference in long-term care funding.

Earlier in this chapter, Table II-E summarized public spending for nursing home and home care. The latter is markedly greater. What accounts for this difference? Perhaps the most useful way to begin answering this question is to compare nursing home and home care spending under Medicaid.

¹Candace Mueller and Eileen Wolff, "Home Based Services," Title XX CASP Plans, Technical Note No. 10, Washington: Office of Assistant Secretary for Planning and Evaluation, DHEW, February 20, 1976 (multilith).

This program pays for more long-term care than any other. By contrast, Medicare's focus is clearly on acute care. Medicaid is a means tested program. If an older person has the income or assets to support normal life at home, but comes to require supporting home care services from another individual, Medicaid will not pay the bill unless the person in need of service "spends down" to levels of Medicaid eligibility. This may mean depleting assets or income necessary for ordinary maintenance at home. Or, more likely, home care services under Medicaid simply are not available. The older person's alternative then is to enter a nursing home, spend down assets (or sometimes, illegally, dispose of them), and rely on Medicaid to pay for long-term institutional care. In one sense, then, the incentive to enter a long-term care facility follows from the difficulty of coordinating personal and public resources to sustain oneself at home. In a larger sense, two questions should be asked: why was this difficulty legislated into place? Why is it so hard to obtain the services of a Medicaid home care provider and relatively easy to enter a nursing home?

The second question is more simple, and helps suggest answers to the first. Medicaid's long-term care program seems to have been designed to support institutional care. Despite Congress's mandating provision of home care in 1970, there seems to be a desire manifested in the administration of the Medicaid program--either in the states, the federal government, or both--to constrain home care spending. Circumstances in both the home care and nursing home industries supported this purpose. Home care has been fragmented and delivered by non-profit and governmental

providers. Nursing home care has increasingly been delivered by proprietary providers who have entered the field in response to opportunities for profit. Not only providers, but services as well, have been more easily mobilized in the institutional arena.

When Medicaid was legislated, there were relatively few organized providers of home care. Most were voluntary, non-profit groups like visiting nurse associations, or public units like branches of county health departments. No evidence of the existence of either mid- or large-size proprietary home care providers can be found by this writer. Many individuals, such as private duty nurses and companions, provided home care as independent contractors; small agencies to furnish such workers could be found in many cities. In the years since the passage of Medicaid, some organized providers of in-home services have become large enough to attain national visibility. Homemakers-Upjohn is one example. Under both Medicare and Medicaid, proprietary home care agencies may be reimbursed only if licensed by the state in which they operate. By 1975, only sixteen states had done so.¹

Not only were home care providers badly organized as a lobbying force and lacking in the ability to identify and serve (and perhaps mobilize) populations in need of care, but home care suffered the further weakness of being difficult to organize on behalf of individual patients in need.

¹For a discussion of this issues, see Department of Health, Education, and Welfare, "Home Health Care: Report on the Regional Public Hearings," Washington: DHEW, October 29, 1975 (multilith), especially pp. 40-42.

In part, this follows from some of the same reasons why home care providers were difficult to bring together as a lobbying force. Home care providers typically were (and are) small organizations, each servicing only some of the home care needs of people residing in a fairly small geographic area. Disabled older people residing at home frequently require a complex set of goods, income support, and services delivered by many types of trained and untrained individual providers and by public agencies. In only a very small number of communities in this country are all needed services available today; when available, they are still difficult to organize. Several promising administrative devices have been explored in recent years to attempt to overcome fragmentation.¹

A related difficulty faced by home care in past years cannot be ignored. As physicians became increasingly reluctant to visit patients at home, the setting of medical care for the chronically ill elderly shifted increasingly to the acute hospital and the nursing home. Recent developments in the use of nurse practitioners and physician assistants may do much to decentralize long-term care once again.

Below the logistical difficulty of coordinating home care services, and the funding under Medicaid of established institutional care lie more fundamental explanations for the preference in this country for allocating public funds to institutional long-term care.

¹Two of the best are described in James J. Callahan, Jr., "Single Agency Option for Long-term Care," Waltham, Mass.: University Health Policy Consortium, February, 1979; and Dennis F. Beatrice, "Case Management: A Policy Option for Long-term Care," Waltham, Mass.: University Health Policy Consortium, February 1979.

A first explanation follows from a desire to control utilization and spending. Home care, preferred by the elderly, appears to some as an attractive benefit. Many older--and not so old--persons might desire the regular help of a homemaker, a helper whose tasks resemble those of a servant, especially if publicly paid. It is hard initially to decide appropriate levels of help for a given person, and to adjust those levels from day to day as patient needs change. Further, it might be feared that help currently provided by family members and other informal supports would be displaced. Some family members might tire of the job of providing care, and fall back on a public service. Others might resent their own continued efforts in the face of publicly provided substitutes for their neighbors. Allocation of public services in a fashion that would encourage sustained family provision while meeting court tests of not being arbitrary or capricious would be a difficult task. Total utilization would consequently be hard to control.

By contrast, public funding for long-term care which emphasizes institutional services appears to offer a number of advantages. Total utilization can be restricted to equal the number of beds built or licensed. The type of care is itself relatively unattractive, feared, and stigmatizing. Institutional care appears unattractive to many older Americans because it entails a loss of freedom, of control over such daily activities as when to eat or wake up. This loss is particularly important because it often comes at a time of loss of control in other spheres due to reduced income, mobility, and other factors. In addition, many nursing homes are unpleasant; some are monstrous. Entry

into the nursing home is feared by some older citizens because it is perceived as the last step before the grave. Entry is stigmatizing to those who see the nursing home as the successor to the almshouse: the site of residence of the improvident or unworthy. Public funding of non-medical services in nursing homes, principally room and board and personal care, should be viewed as the descendent of funding for the almshouse.

Payment for medical services in long-term care facilities has another origin. Funding for chronically ill or convalescing patients extruded from acute care hospitals follows in part from medical insurance principles of paying for those services thought to have a low and unpredictable chance of being needed, and because it was costly when required. It has been realized increasingly that little in the health care field adheres to these principles. Utilization often is predictable and manipulable; consequently, frequency of use may rise above levels predicted by skilled actuaries. Nursing home care is no exception. A second reason for funding skilled and intermediate care is that they were thought to be cheaper substitutes for hospital and skilled nursing home care, respectively. (Home care has been promoted by some as a less costly substitute for nursing home care; questions about the savings realized by past substitution have made legislators and administrators wary of promises of new cost reductions.)

Another reason for the emphasis on institutional care in public programs follows from their medical thrust. Skilled and intermediate care facilities reimbursed under Medicare and Medicaid are designed for patients with substantial medical problems. Home care funding under

Medicare is similarly a short-term, medically-related benefit. Only Medicaid is permitted to pay for a wide range of home care services; its low rates of spending, noted above, testify to the states' probable views that social services in the home are less important to fund than medically-related services in institutions.

It should be noted also that the medical emphasis of nursing homes initially appeared to be a welcome alternative to the non-medical, disorganized, and often inadequate patterns of boarding home and adult foster care which had been common until the 1950's and perhaps until the early 1960's.¹ Medical and nursing supervision seemed to promote responsible supervision of dependent older persons. It seems that the present pattern of long-term care in this country, with its profound institutional emphasis, became firmly established with the passage of the Medicaid legislation in 1965. At that time, little concrete evidence of the argued evils of institutional care had become visible to legislators. If the evidence--such as it was--was available, it seems not to have been forcibly presented during consideration of nursing home funding. Additionally, little of the subsequent pressure for de-institutionalization which has arisen in related sectors--care of the retarded, juvenile delinquents and adult criminals, and other incarcerated groups--seems to have been visible in 1965.

¹And which, to an unfortunate extent, persist today. Witness both the large numbers of older persons killed annually in hotel and boarding home fires, and the quality of care in many non-medical boarding homes. See, for example, Pearl R. Roberts, "Human Warehouses: A Boarding Home Study," American Journal of Public Health, Vol. 64, No. 3 (March 1974), pp. 277-282.

A useful parallel to the need to provide non-institutional care for the disabled elderly had appeared in the exodus from mental hospitals. Indeed, the Community Mental Health Center Act of 1962 did appear to signal increased federal interest in non-institutional care of a group whose needs closely paralleled those of the frail elderly. For a number of reasons, this parallel was not visible to Congress in 1965: new medications had been largely responsible for permitting de-institutionalization of many mental hospital residents, and no similar opportunity seemed present in the case of the elderly. Further, it may have been clear to some in Congress that nursing homes would need increased funding to care for many of those whose discharge from mental hospitals only meant re-institutionalization in nursing homes. Had the horrors of other institutions and the perils of de-institutionalization from mental hospitals been documented and made visible to legislators, they might have affected the Medicaid legislation itself. But, as Bruce Vladeck notes of federal policy-making in long-term care generally, "By and large, nursing home policy has been made not only with limited foresight, but largely by people who, at the time, were primarily concerned with doing something different."¹ This pattern continues today. As the following section will note, current efforts to improve long-term care delivery and expand the range of available benefits are being made within

¹Bruce C. Vladeck, My Strength Faileth: Nursing Homes and Public Policy, forthcoming, Chapter 3.

contexts of national health insurance debates and demands to balance the federal budget by constraining spending.

A final explanation for the emphasis on institutional funding may follow from a desire to serve those most in need in what is perceived to be the more efficient site. Patients most in need of long-term care may be viewed as those requiring the most help. Some evidence exists that these are the persons likeliest to be cheaper to care for in institutions.¹ This follows from the efficiency of organizing such services in a common site and perhaps from the lower standard of living which many institutions provide. Evidence on the possible cost advantages of institutional care will be taken up in Chapter III.

To sum up: this section has considered the origins of the nursing home, reviewed public financing for home and institutional care. It concluded by trying to explain the pronounced preference to spend public funds on institutional care. The section which now follows begins by examining the arguments in favor of a more balanced long-term care spending policy. It reviews recent developments in that policy in Washington, and then closes by discussing the needs to consolidate existing evidence about the comparative costs of home and institutional care (the subject of Chapter III) and to develop new evidence (the subject of this thesis).

¹General Accounting Office, "Home Health--The Need for a National Policy to Better Provide for the Elderly," A Report to the Congress, HRD-78-19, December 30, 1977.

E. Advocacy of Home Care and Consumer Sovereignty in the Context of Current Federal Long-Term Care Policy

Earlier sections of this chapter have discussed the steady increase in the use of formally organized long-term care services-- particularly in institutions; the reasons for this increase and why they appear well-established and likely to persist for some time; and explanations for the disproportionate public spending on institutional services.

In light of this history, and of other considerations, it is not surprising to find a large number of vocal advocates of increased public funding for non-institutional care.¹ Observing both past trends and the evidence suggesting that the need by the elderly for long-term care is going to grow in coming years, these advocates have put forth several arguments in favor of greater funding for a variety of non-institutional alternatives.

¹By the mid-1979's, the depth of this advocacy warranted compilation of two useful bibliographies. One, a Council of Planning Librarians Exchange Bibliography, contains over 300 entries. Another, prepared at the University of Illinois, has some 500 entries. See Liz Karnes, "Alternatives to Institutionalization for the Aged: An Overview and Bibliography," Council of Planning Librarians Exchange Bibliography No. 877, September 1975; Wendy Garen, Monica Lindeman, Leslie Lareau, and Leonard Herman, "Alternatives to Institutionalization: An Annotated Research Bibliography on Housing and Service for the Aged," Housing Research and Development, University of Illinois at Urbana-Champaign, July 1976.

(While this thesis will discuss only home care as an alternative to the nursing home, this writer believes that many of the arguments for home care also tend to support such other alternatives as adult foster care, day care, and a variety of congregate and other intermediate housing arrangements. It should also be understood in what follows that the terms "institution" and "nursing home" are used interchangeably unless special distinctions are made. Thus, "nursing homes" also refers to non-medical rest homes or homes for the aged, as well as such more intensive centers of care as the rehabilitation or chronic disease hospital.)

Proponents of greater public spending for home care of older Americans have made their case variously on three principal grounds: quality and effectiveness, consumer choice and cost. This section presents the first two of these grounds and then considers how recent federal policy has dealt with them; it closes by pointing to the need for a clearer understanding of the comparative costs of home and institutional care for the elderly. This is considered in Chapter III.

Arguments in favor of higher home care spending. Some have asserted that problems of both quality-effectiveness and cost in long-term care can be ameliorated by increased home care funding. They argue that home care can be both better and cheaper for many older people than the nursing home care they would otherwise receive. If this is true, they argue further, legislators should at the very least be indifferent to where

long-term care is delivered, and permit older patients to choose the site of their care. (This further assumes that outcome is not made worse by the process of choice.) For clarity of exposition, these three related arguments in favor of higher home care spending will be considered separately.

Quality and effectiveness of long-term care should be discussed distinctly. Quality refers to the process of care: are patients treated humanely and decently, and are services delivered competently? Effectiveness refers to the outcome of long-term care: how do similar populations cared for at home and in institutions compare in their morbidity and mortality rates, in changes in their level of independent functioning in activities of daily living, and in their psycho-social functioning and morale?

In the face of the difficulties of conducting reliable research on these questions (a problem plaguing cost comparisons as well), and the consequent paucity of reliable data, home care advocates have generally tried to make their case largely in a journalistic or impressionistic manner. Because of the dramatic---frequently tragic---content of these journalistic accounts, they seem to have had a considerable impact on public and legislative attitudes, if not on actual behavior. Since research difficulties make difficult an assessment of the comparative quality and effectiveness of home and nursing home care, an attempt will be made here both to set out the lines on which home care

advocates attach over-dependence on institutional care, and to indicate available evidence on quality and effectiveness.

Quality of care in nursing homes has frequently been denounced. Among the reported types of abuse of patients are beatings, torture, intimidation, over-drugging, deprivation of freedom, inadequate or dangerous food, inadequate heat and ventilation, filth and squalor, and lack of fire precautions.¹

It is impossible to know how widespread these abuses are. They appear common, in view of their causes, discussed below, and of the frequency with which they are reported. Because so little home care is provided in this country, particularly to people as dependent as typical nursing home residents, it is difficult to decide if home care is or would be open to the same sorts of patient abuse.

It can be argued, on one hand, that home care recipients would find it easier than would nursing home residents to change providers if they

¹Journalistic accounts are common. Newspaper articles which seem to number in the hundreds touch on one or more of these areas. See, for example, Jack Newfield, "The Last Unspeakable Nursing Home," Village Voice, 18 September 1978. For overviews, see Frank E. Moss and Val. J. Halamandaris, Too Old, Too Sick, Too Bad, Germantown, Md.: Aspen, 1977; Mary Adelaide Mendelson, Tender, Loving Greed, New York: Knopf, 1974; New York State Moreland Act Commission, Regulating Nursing Home Care: The Paper Tigers, New York: The Commission, October 1975. An important new work is Carol A. Delany and Kathleen A. Davies, Nursing Home Ombudsman Report: The Pennsylvania Experience, Harrisburg, Pennsylvania Advocates for Better Care, January 1979.

suffered harm. At home, a phone call will yield a change in provider; in the nursing home case, the patient must be relocated. This is often difficult and sometimes dangerous. On the side of the nursing home, it should be noted that abuses may be easier to detect; one family visitor or state inspector may bring to light a collective problem. A nursing home administrator is able to supervise employees with less difficulty than is the case under the decentralized provision of home care. Finally, if a home care recipient's family is committing the abuse, the patient may lack any one to whom to appeal. This is a subject for speculation because this writer has seen no investigation of the protection of rights of similar patients by home and institutional care providers.¹

It should be asked whether abuse of dependent older patients may not be a generic problem, difficult to solve by manipulating site of care. Certainly, reports of abuse of foster children and children generally, mental patients, and the frail elderly are all common. These citizens have common problems: they are weak and depend on others; those others are sometimes not able, trained, or motivated to provide good care. Usually, formal providers of care to the dependent are poorly trained and poorly paid. They face a difficult, dirty, and often unpleasant job. Those they care for are not always pleasant;

¹A suggestion of some of the decency assurance problems under home care is offered in Susan K. Kinoy, "Discussion of Problems Concerning the Selection of Home Attendants by Patients of Their Families," Testimony before the United State Senate Special Committee on Aging, Washington, D.C., 16 May 1977.

sometimes recipients are abusive. In the face of these likely barriers to good care, supervision is often difficult or lacking. Rewards either for good direct service or good supervision are difficult to provide.

Opportunities do exist for improving the quality of long-term care. Kane and others describe a care-giving team which both improves the conditions of patients' lives and saves money.¹ A Veterans Administration committee has described a number of useful measures of patients' rights and dignity. These include a place to be alone; a stable environment--one which encourages choice in realms such as time to go to sleep, clothing, and several other areas which can be operationalized.² Barney has called for increased visiting and other involvement in nursing homes as means of improving quality.³ Visitability of family and visitors doubtless influences the quality of all forms of service--from public education to hospital, nursing home, and home care. Friedman and others

¹Robert L. Kane, Lou Ann Jorgensen, Barbara Teteberg, and Jean Kuwahara, "Is Good Nursing-Home Care Feasible?" Journal of the American Medical Association, Vol. 235, No. 5 (2 February 1976), pp. 516-519.

²The Quality of Life Committee, Draft Report, Washington: V.A., 15 July 1977 (mimeo).

³Jane Lockwood Barney, "Community Presence as a Key to Quality of Life in Nursing Homes," American Journal of Public Health, Vol. 64, No.3 (March 1974), pp. 265-268.

present practical steps toward improvement of in-home services.¹

Many--perhaps most--nursing homes could diminish abuse of their patients' rights. To do so may well prove difficult. Some opportunities are emerging, but assuring decent provision of publicly-funded home care on a large scale may face obstacles similar to those confronting today's institutions.

Despite the weak and mixed evidence on the comparative quality and decency of home and institutional care today, home care advocates have made the argument that a more balanced long-term care system, one which made more freely available the option of home care, would induce providers in both settings to monitor quality more carefully.

It may be feared, however, that those who attempt to buttress claims of the desirability of home care by pointing to quality problems of nursing homes are paying insufficient attention to generic problems of assuring the quality of long-term care. The history of long-term care policy in this country offers several examples of spasmodic change produced by reaction to visible evil, absent careful consideration of the value of alternatives proposed.

Advocates of home care should be more mindful both of past events in the evolution of institutional long-term care for the elderly and of

¹Susan Rosenfeld Friedman, Lenard Kaye, and Sharon Farago, "Maximizing the Quality of Homecare Services for the Elderly," a paper presented at the 30th Scientific Meeting of the Gerontological Society, San Francisco, 21 November 1977.

recent changes in the long-term care of other groups of disabled people. Historically, it should be recalled that institutions arose in response to identified needs, and were themselves seen as improvements over earlier forms of care. Mental hospitals¹ and nursing homes² themselves were designed and funded in response to identified abuses of the forms of care that preceded them.

Proponents of home care should bear in mind also recent difficulties encountered in the course of de-institutionalization of mental hospital patients. Non-institutional care may be promoted only as an excuse to close expensive facilities; "community alternatives" are often not established in sufficient numbers. In the mental hospital case, it is by no means clear that the de-institutionalization movement has yielded any net benefit to those discharged or to those denied admission under new policies.³

¹See David Rothman, The Discovery of the Asylum, Boston: Little, Brown, 1971.

²As discussed in section D of this chapter.

³Ellen L. Bassuk and Samuel Gerson, "Deinstitutionalization and Mental Health Services," Scientific American, Vol. 238, No. 2 (February 1978), pp. 46-53; Kim Hopper, Review of Andrew T. Scull, Decarceration: Community Treatment of the Deviant - A Radical View, Health PAC Bulletin, No. 78 (Sept.-Oct. 1977), pp. 24-31; Leona L. Bachrach, "Deinstitutionalization: An Analytical Review and Sociological Perspective," National Institute of Mental Health, Series D, No. 4, DHEW Pub. No. (ADM) 76-351, Washington: USGPO, 1976.

The effects or outcomes of long-term care are at least as difficult to measure as the quality or process of that care. This problem highlights the importance of good long-term care planning. Issues of major concern in this thesis--the comparative costs of home and institutional care, and who should design plans of care--would be far easier to resolve if outcomes could conveniently be measured. The difficulty of gauging the outcomes of care of comparable populations in the two different settings impede efforts to decide what services are necessary and who should allocate them. Consequently, costs of in-home and institutional care are difficult to compare, because if outcomes can not easily be measured they cannot easily be controlled. This difficulty is further compounded by the practical and ethical problems of controlling for the characteristics of the members of the two samples (those receiving home and institutional care). This triad of problems, in sum, makes it difficult to establish benchmarks, yardsticks, or other devices by which to learn confidently the relative benefits and costs of home and institutional care. As a result, this thesis will seek a variety of indirect measures of the effectiveness of long-term care.

It is difficult to measure the effects of long-term care in any one site. This is one reason why it is hard to compare the efforts of in-home and nursing home care. The task of learning the effects of care in these two sites is further complicated by methodological problems which stand in the way of obtaining comparable populations. These problems will be taken up in the next chapter, as part of the discussion of cost comparisons.

Proponents of home care sometimes argue that nursing home care is relatively ineffective, in that admission to the nursing home is associated with mortality rates which appear very high.¹ Kasl, after a careful review of this literature, has argued that little is indeed known about whether nursing home admission is the cause or correlate of higher mortality rates.² He notes that most studies of "unexpected" mortality at nursing home admission fail to control for the age, physical frailty, or medical instability of nursing home entrants. It is possible that a regression to agnosticism is taking place. Outcomes of nursing home care are unclear. They may not be as bad as often feared. On the home care side, reanalysis by Bigot and his associates³ of findings and data generated by Nielsen and others⁴ suggests that first indications of the negative impact of home care on mortality should be discounted because of methodological uncertainties in early analyses.

¹J.P. Costello and G.M. Tanaka, "Mortality and Morbidity in Long-Term Institutional Care of the Aged," Journal of the American Geriatric Society, Vol. 9 (1961), pp. 959 ff; M. A. Lieberman, "Relationship of Mortality Rates to Entrance to a Home for the Aged," Geriatrics, Vol. 16 (October 1961), pp. 515-519 are two examples.

²Stanislav V. Kasl, "Physical and Mental Health Effects of Involuntary Relocation and Institutionalization on the Elderly--A Review," American Journal of Public Health, Vol. 62, No. 3 (March 1972), pp. 377-384.

³Arthur Bigot, "Protective Services for Older People: A Reanalysis of a Controversial Demonstration Project," a paper presented at the 31st Scientific Meeting of the Gerontological Society, Dallas, 17 November 1978.

⁴Margaret Nielsen, "Home Aide Service and the Aged; A Controlled Study," Part 1, Cleveland: Benjamin Rose Institute, August 1970.

This climate of agnosticism has probably been reinforced by the failure to develop a large set of reliable evidence on the comparative effects of home and institutional care. Mitchell's study of outcomes of long-term care in three Veterans Administration settings is a valuable oasis in this field.¹ While patients in this study could not be randomly assigned to treatment sites, multivariate techniques were used to control for patient characteristics. Holding other variables constant, home care patients typically enjoyed greater improvement than did patients in two types of nursing homes. Improvement was measured by an index of functional health status.

Another carefully designed study, by Katz and others,² considers only the effect of home care. Half of a group of older patients discharged from a short-term rehabilitation hospital received home care services from a visiting nurse association. After two years, a major finding was that "the avoidance of deterioration was...the most consistent favorable effect, and that even this result could be achieved only with the younger and less disabled patients." This constitutes a cautious endorsement of home care.

¹Janet B. Mitchell, "Patient Outcomes in Alternative Long-Term Care Settings," Medical Care, Vol. 16, No. 6 (June 1978), pp. 439--452. For a more detailed view, see Janet B. Mitchell, "Alternatives in Extended Medical care," Unpublished doctoral dissertation, Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, July 1976.

²Sidney Katz, Amasa B. Ford, Thomas D. Downs, Mary Adams, and Dorothy I. Rusby, "Effects of Continued Care: A Study of Chronic Illness in the Home," DHEW Pub.No. (HSM) 73-3010, Washington: National Center for Health Services Research and Development, December 1972.

Despite the methodological uncertainties alluded to earlier, the work by Nielsen and her associates also stands as an important effort to learn the effects of home care. Through a randomized trial, home care was shown to produce higher levels of contentment, fewer long-term care admissions, and fewer long-term care patient-days than its absence.¹

Why are the effects of long-term care so difficult to measure, such that we have relatively few good studies either of the outcome of care in one site or of the comparative outcomes of care in two sites? The problem of comparable samples will be taken up in the next chapter. For the present, it should be noted that there exist large gaps in our ability to conceptualize and measure the impact of long-term care.

While these problems affect acute care as well, they are probably more serious in long-term care. It is therefore somewhat discouraging to read McAuliffe's critique of outcome measures.² Should these assertions withstand the replies they are likely to draw, they may induce re-assessment of efforts to develop reliable, valid, and easily secured

¹Margaret Nielsen, Margaret Blenkner, Martin Bloom, Thomas Downs, and Helen Beggs, "Older Persons After Hospitalization: A Controlled Study of Home Health Aide Services," American Journal of Public Health, Vol. 62, No. 8 (August 1972), pp. 1094-1101.

²William E. McAuliffe, "Measuring the Quality of Medical Care: Process Versus Outcome," Milbank Memorial Fund Quarterly: Health and Society, Vol. 57, No. 1 (Winter 1979), pp. 118-152.

outcome measures in long-term care. Further, if arguments of McKinlay and McKinlay,¹ Illich,² and Carlson³ are accorded weight, the goals and methods of acute care itself may merit closer looks.

Some of the major difficulties of measuring outcome in long-term care can best be introduced by contrast with acute care. In acute care, measured events are clearer and it is probably easier to relate interventions to changes in patient status. In acute care, mortality, morbidity, and pain are outcomes to avoid. Identified goods, services, and techniques aim to forestall or prevent these outcomes.

The goals and desired outcomes of long-term care are by no means as clear. Good health and restoration of full functional ability are not possible in many cases. Often, the goal is to slow a decline, but no minimum expectable rate of decline has been established for most conditions. Frequently, chronically ill patients suffer from more than one problem, making prognosis difficult to set.

The relation of long-term care services to outcomes poses a particularly difficult problem. In both nursing homes and home care, most services are non-medical. The great preponderance of effort is devoted

¹John B. McKinlay and Sonja M. McKinlay, "The Questionable Contribution of Medical Measures to the Decline of Mortality in the United States in the Twentieth Century," Milbank Memorial Fund Quarterly: Health and Society, Vol. 55, No. 3 (Summer 1977), pp. 405-428.

²Ivan Illich, Medical Nemesis, New York: Pantheon, 1976.

³Rick J. Carlson, The End of Medicine, New York: Wiley, 1975.

to compensating or substituting for deficits in functional ability (to perform activities of daily living like bathing, dressing, and the like) and in such instrumental activities as shopping, cooking, and cleaning. Measures of functional ability, discussed in Chapter IV, are used to predict need for such compensating services. But changes recorded by functional ability measures usually cannot be expected to reflect the effectiveness of these compensatory services. That is, an older woman's functional independence, for example, does not improve because a home health aide bathes her daily. Rather, she is cleaner.

Thus, measures of outcome of long-term care must attend to personal and household cleanliness, personal mobility and nutritional levels, and the like. Some services may be devoted to preventing, slowing, or reversing medical or functional or social-psychological deterioration. Reliable and valid instruments exist in some of these areas but must be developed in others.

Comprehensive assessment of outcomes in all these realms is a difficult, costly, and time-consuming job. Instruments to do this job are being advanced. When available, these devices will prove to be invaluable benchmarks for assessing the effectiveness of long-term care.¹ For

¹Among the work in this area is that recorded in Battelle Human Affairs Research Centers, "Evaluation of the Outcomes of Nursing Home Care," prepared for the National Center for Health Services Research, Seattle: Battelle, October 1976 (NTIS PB 266-301); Alan S. Rosenfield and Milton F. Bornstein, "Quality of Life and Care in Long Term Care Institutions: An Empirical Study," Worcester, Mass.: Commission on Elder Affairs, 1978; Laurence G. Branch, "Understanding the Health and Social Service Needs of People Over Age 65," Boston: Center for Survey Research of the University of Massachusetts, 1977; and Alan Sager, "Decision-making for Home Care,"

the present, the weakness of our ability to measure the outcomes of long-term care, combined with our desire to learn the cost of "comparable" care in homes and institutions, obliges that thoughtful consideration be given to the process of planning long-term care. Now follows a discussion of consumer choice in long-term care, which will be shown to be one aspect of the care planning process. In Chapter III, the reliability of decision-making by professionals will be taken up. Taken together, these two treatments introduce the problem of care planning in the setting of long-term care cost comparisons.

Choice and consumer sovereignty constitute the second argument advanced by proponents of higher federal home care spending. For some, the right of the elderly to choose the site in which they receive long-term care seems to be posed almost as an ethical issue.¹ Others assert this right as a practical matter: Older people may know best what is in their interest and/or being permitted to choose, to avoid compulsory institutionalization (or remaining at home) is itself so beneficial as to outweigh the ill effects produced by choice of a site of care believed by professionals to be relatively ineffective. In either case, it is

Interim Report to the U. S. Administration on Aging, Waltham, Mass. ;
Levinson Policy Institute, Brandeis University, March 1979

¹U.S. House of Representatives, Select Committee on Aging, Subcommittee on Health and Long-term Care, "New Perspectives in Health Care for Older Americans," Washington: USGPO, January 1976.

argued, the consequence of choice is preferable to the consequence of compulsion.¹

In long-term care, a wide variety in the range of choice to be permitted to patients has been endorsed. In one context, it is insisted that patient choice as to which nursing home to enter, combined with a greater bed supply, would help improve the quality of institutional care.² Greater choice would be permitted by those who would grant the elderly some measure of influence on whether they would be cared for at home or in an institution.³ Others go further and assert that the elderly can

¹Budd N. Shenkin, "Stalking the Irrational," Review Essay, Journal of Health Politics, Policy, and Law, Vol. 1, No. 3 (Fall 1976), pp. 355-371; Nelida A. Ferrari, "Freedom of Choice," Social Work, Vol. 8, No. 4 (October 1963), pp. 104-106; Anne R. Somers and Florence M. Moore, "Homemaker Services--Essential Option for the Elderly," Public Health Reports, Vol. 91, No. 4 (July-August 1976), pp. 354-359; M. Powell Lawton, "Social and Structural Aspects of Prosthetic Environments for Older People," paper presented at the Third Annual Institute on Man's Adjustment to a Complex Environment, V.A. Hospital, Brocksville, Ohio, 1963, cited in Institute of Medicine, The Elderly and Functional Dependency: A Policy Statement, Washington: National Academy of Sciences, 1977, p. 9.

²Amitai Etzioni, Alfred J. Kahn, and Sheila B. Kamerman, "Public Management of Health and Home Care for the Aged and Disabled," Position Paper, New York: Center for Policy Research, January 1975.

³Institute of Medicine, The Elderly and Functional Dependency: A Policy Statement, Washington: National Academy of Science, 1977, p. 9. State Communities Aid Association, "Report of the Arden House Institute on Continuity of Long Term Care," New York: The Association, 1978, p.8.

and should be permitted to make "necessary decisions regarding such major changes in their lives as being moved to an institution for needed care."¹ Significant judicial support for the right of disabled groups other than the elderly to obtain care in the "least restrictive" setting has been developed. This has been especially true for the mentally retarded.² One decision, that of Sheldon v. Tucker,³ noted that a "'purpose cannot be pursued by means that broadly stifle personal liberties when the end can be more narrowly achieved.'"⁴ This principle is of great importance. It may be extended logically to groups other than the retarded.⁵

¹Institute of Medicine, op. cit., p. 9; see also American Public Welfare Association, "Report on Long-Term Care," Washington: The Association, November 1978.

²For a general discussion, see The President's Commission on Mental Retardation, The Mentally Retarded Citizen and the Law, New York: The Free Press, 1976, especially pp. 234-5.

³364 U.S. 479, 488 (1960).

⁴Cited in The President's Commission on Mental Retardation, op. cit.

⁵A suit to compel more generous provision of home care to present and prospective residents of intermediate care facilities in Massachusetts is contemplated. Robert C. Benedict, "Emerging Trends in Social Policy for Older People," Presented at the 1977 National Round Table Conference, American Public Welfare Association, Washington, 9 December 1977, supports the right to the least restrictive form of care.

Calls for choice in site or provider of service is by no means limited to care of the elderly or the mentally retarded. Women who desire to give birth at home, attended by a physician or other caregiver, raise this issue as well.¹ If the effect of freedom of choice in long-term care on outcome were strong, it might be possible to improve both autonomy and safety. This would be particularly true if patients were able to make decisions as well as typical professionals.

Greater choice in site of care of the elderly should not be restricted to long-term care. Trades between acute and long-term care should be considered as well. Indeed, one possible source of funds for greater choice in long-term care--to permit more care at home--would be to divert funds now spent on acute care. The "death with dignity" movement raises clearly the possible choice, for some people, between quality of the last days or years of life and the length of life itself. In part, this movement springs from medical advances which permit many of the very ill or disabled to live longer today than in earlier years. These treatments are usually fully reimbursed for the elderly by Medicare or Medicaid. Tubiana argues that "doctors...must learn to give up their relentless right-to-live therapies and end the laughable lies that surround the dying...".² The hospice as a device for in-patient and in-home delivery of services to the terminally ill, seems designed to

¹George J. Annas, "Homebirth: Autonomy vs. Safety," Hastings Center Report, Vol. 8, No. 4 (August 1978), pp. 19-20.

²Maurice Tubiana, cited in Francois Dupuis, "France: Restoring Dignity to Death," Washington Post, 23 May 1974

deliver balanced care and elicit and then respect the preferences of those who are dying.

The principle of care in the least restrictive environment may also be extended logically, for the elderly, to making available choice about the content of care in a given site. Freedom over both site and content of care would be supported by a general extension to all the disabled of the scheme of cash payments, "the aid and attendance allowance," devised for disabled veterans.¹ A generous, if somewhat more narrow, range of choice would be permitted by voucher schemes such as those advocated in the field of public education.

Cash benefits, such as the aid and attendance allowance, and vouchers make it clear that choice by the disabled is to be permitted. This would permit selection of a more restrictive site of care, if the patient desired. While guarantees would be needed to prevent inappropriate pressure by families or professionals to induce patients to enter institutions, Brody's position "that the service to be provided is the least restrictive alternative"² may itself remove desirable elements of freedom. Increasingly, it appears that the right to choose a more restrictive setting

¹American Foundation for the Blind, Washington Report, December 1977, p. 2.

²Stanley J. Brody, "Testimony on 'Health Care for Older Americans: The Alternative Issue, '" before the U. S. Senate Special Committee on Aging, 17 May 1977.

of care is being denied in principle by home care advocates. To protect the elderly who may prefer or who may require institutional care from judges desiring to mandate freedom or administrators and legislators desiring to save money, the right to choose institutional care should probably be guaranteed.

Brody's position can perhaps best be understood as a reflection of a general dislike for all institutions. There seems to have been a growing feeling that schools do not educate (or even teach); hospitals do not prolong life (or even improve health); corrective institutions do not correct (or even deter). The validity of this impression is unclear; it does seem widespread today. Its strength may diminish in the future if established institutions come to be seen again as bulwarks against instability--not as obstacles to freedom.

The right of older patients to have wider latitude to exercise their preferences for setting of long-term care has received a fair measure of attention only in recent years. Guttman has noted that:

"The study of decision-making in old age, with regard to resource utilization is a relatively new and uncharted territory as far as social gerontology is concerned. In contrast to the overwhelming literature on young adults, studies on decision-making of older adults are relatively scanty."¹

¹David Guttman, "Seekers, Takers, and Users--The Elderly as Decision Makers," A paper presented at the 30th Scientific Meeting of the Gerontological Society, San Francisco, November 1977.

Davis¹ and Schulz and Hanusa² have begun the job of testing practical methods to increase older dependent citizens' choice and control.

Proclaimed rights of the elderly to select the site in which they will receive long-term care, and the practical work to support such a right seems to have had little impact. In a Florida study, Bell found that over 80% of mentally alert Medicaid recipients of nursing home care and over 80% of those at home "would prefer to live out the remaining years of their lives at home and not in an institution."³ Nonetheless, as Barney⁴ has noted and the data on proportionate spending on home and institutional care confirm, the option of choosing home care is usually denied.

There are several reasons for this. One is the fear that to permit greater choice of site of care would lead to a considerable increase in

¹Marcella Z. Davis, "The Organizational-Interactional Structure of Patient Participation in Continuity of Care: A Framework for Staff Intervention," a paper presented at the 30th Annual Scientific Meeting of the Gerontological Society, San Francisco, November 1977.

²Richard Schulz and Barbara Hartman Hanusa, "Long-Term Effects of Control and Predictability Enhancing Interventions: Findings and Ethical Issues," Pittsburgh: Carnegie-Mellon University Department of Psychology, 1977 (mimeo).

³William G. Bell, "Community Care for the Elderly: An Alternative to Institutionalization," Tallahassee: Program in Social Policy and the Aging, Florida State University, June 1971.

⁴Jane L. Barney, "The Prerogative of Choice in Long-Term Care," The Gerontologist, Vol. 17, No. 4 (July 1977), pp. 309-314.

long-term care spending: As noted in section D of this chapter, many of the services covered under the heading of home care are to many people quite desirable in themselves, especially in contrast to institutional long-term care.

Beyond this visible pattern in long-term care looms a general problem in social services, medical care, and perhaps publicly funded goods and services generally. In the face of the need to ration resources in medical care itself, Mechanic foresees a growth in bureaucratic power. This could scarcely work to yield greater autonomy for patients.¹

A problem beyond cost may stand in the way of granting patient control over long-term care site and services. This is that some (the proportion is not known) consumers may really prefer not to choose. Neuhauser describes the often positive role of the placebo effect on acute care patients, owing to blind trust in authoritative decisions.²

It may be imagined reasonably, by some, that older patients should not be trusted to choose the setting in which they will receive care or the services to be delivered to them. Perhaps they will ask for far more than they need, ruining budgets and leading to avoidable overdependence. Conversely, it may be feared that some older patients

¹David Mechanic, "The Growth of Medical Technology and Bureaucracy: Implications for Medical Care," Milbank Memorial Fund Quarterly: Health and Society, Vol. 55, No. 1 (Winter 1977), pp. 61-78.

²Duncan Neuhauser, "The Really Effective Health Delivery System," Health Care Management Review, Vol. 1, No. 1 (Winter 1976), pp. 25-32.

heroically--but inappropriately--insist that they "can manage fine" with levels of assistance so low that preventable harm is suffered: bedsores, falls, malnutrition, or other damage. These considerations should be borne in mind in evaluating the data presented in part three of this thesis.

Reasonable responses to these positions might be to permit choice by only those patients who desire it. A process for identifying and protecting others would have to be devised. Further, costs could be constrained by permitting choice only to a population which, in total, could be cared for at the same cost in institutions or in their homes.

There are several positive reasons to offer in favor of permitting choice to patients. First, to permit choice may in itself improve outcome of care. Long-term services are delivered principally to compensate for losses in functional ability. Physically, these losses reduce in varying degrees the freedom of action enjoyed by the person when young. In this context, to be compelled to accept care in an institution can be demoralizing.

Second, patients may typically be able to select settings and types of services which objectively yield outcomes superior to those of settings and services selected by professionals. Most long-term care services are non-technical in nature, involving help with personal care, house-keeping, and related functions. Older people may indeed have excellent ideas of what help they require. For technical matters, such as monitoring vital signs or special nursing or therapeutic procedures,

advice from expert professionals should be provided and, hopefully, used. Devices for accomplishing joint care planning in a cooperative atmosphere would have to be devised. What would have to be constrained, therefore, is the defining of long-term care as a medical problem. For, "When medicalization is based on the problems of living and the determination of the 'quality' of one's life, the limits of social control seem boundless."¹

To permit patients choice in this area follows common patterns, in virtually all societies, of permitting consumers to spend their disposable incomes as they wish. Consumers are considered competent to do this unless they harm themselves. Means are needed to determine which older persons could safely exercise varying degrees of influence or control over the settings and types of services they receive.

This pragmatic argument for permitting patients some measure of freedom to decide their long-term care services will be considered in this study. It will be considered in the contexts of difficulties of measuring outcomes, discussed earlier in this section; difficulties of comparing the costs of in-home and institutional care, taken up in section C of Chapter III; and uncertainties surrounding the reliability of decision-making by professionals, explored in section D of Chapter III.

¹Arnold Arluke (Department of Sociology, Northwestern University) and John Peterson, "Old Age as Illness: Notes on Accidental Medicalization," delivered at the annual meeting of the Society for Applied Anthropology, San Diego, California, April 6-9, 1977.

The discussion to this point has considered only the types of arguments advanced on behalf of greater choice by patients. But patients are not usually the only consumers of long-term home care: families receive it as well. This is especially true when the patient lives with family members who provide much care, supplemented by paid providers. Families are not compelled to deliver care, either in their own home or in the separate home of an older relative. If they feel that the types and/or quantities of paid, formal home care support are inadequate and that, consequently, they are carrying too heavy a burden, they may give up their work and seek to have their relative institutionalized.

Thus, three types of actors can be seen to have possible roles in the home care planning process: patients, their families, and different professionals. In part three of this thesis, the views on home care (requested services) of members of the three groups will be examined, and the consequences for cost and outcome of home care will be suggested.

This section now closes with examinations of how federal long-term care policy has responded to the advocates of greater choice in long-term care, and of why it has responded in these ways.

Federal policy on long-term care for the elderly today: a description and an explanation. Response by Congress and the federal bureaucracy to the advocates of more generous provision of in-home benefits has consisted principally of hearings, proposals, legislative activity,

and rhetoric. There has, in addition, been a small but measurable increase in home care spending (see Table II-E). Significant programmatic initiatives, such as improved eligibility or significant expansion of benefits, have not been seen. There are several reasons for this: the weaknesses of the advocates of better home care; the widespread dissatisfaction in Washington with how federally-aided programs in both home care and nursing home care work; and, in the contexts of interest in national acute medical care insurance and perceived real budget tightness, the powerful fear that new home care benefits would be uncontrollably costly. Now, home care initiatives are described and all but the last of the reasons for their failure are analyzed. The cost question is examined in section C of Chapter III.

The advocates of increased home care funding have not been silent, and they have not been without allies in the U.S. Congress. In the 94th Congress, for example, over 80 bills to expand home care benefits were filed.¹ This includes only legislation which would specifically fund home care, and omits bills that would make more money for home care available under such general approaches as raising the Title XX federal ceiling.

A variety of approaches to finance and organize a broader range of in-home services for more older Americans have been advocated. Most would make possible public payment for non-medical, non-technical in-home services of the sorts not well covered under Medicare, Medicaid,

¹Letters to this writer from Ms. Janet Kline, Legislative Analyst, Congressional Research Service, Library of Congress, 6 March 1976.

or Title XX today. At present, federal home care funding is hamstrung in several ways: Spending and eligibility under Medicare are open, (there is no budget ceiling), but personal care and house-keeping services are not covered. Medicaid does permit payment for non-technical services, but it is both means-tested and subject to varying state policies. Most of these policies in practice restrict Medicaid home care spending to very small sums in all but a few states. Title XX funds can pay for all non-technical care, but it is means-tested and has a budget ceiling on federal participation as well. Finally, Titles III and VII of the Older Americans Act have supported many forms of care to help older citizens remain at home. While not means-tested, these funds are targeted toward low-income older people; a budget ceiling is present as well.

These patterns are disappointing in view of the aims proclaimed for these programs by Congress. Medicaid, Title XX, and the Older Americans Act all include carefully spelled out mandates to fund and promote home care widely.¹

Legislative approaches to carrying out these aims have been several. Improvements in Medicare's home care benefit package has been the most frequently sought end. In the 95th Congress, active efforts were made to eliminate the 100 visit limitation under Part A and Part B,

¹For Medicaid, see 45 CFR 249.10(b)(15)(i)(A); 42 USC 1396 a(13), (19), (20), (21). For Title XX, see 42 USC 1397. For the Older Americans Act, see 42 USC 3001.

to eliminate the homebound and skilled nursing requirement for eligibility, and to add a homemaker benefit. None of these efforts succeeded--not even those whose cost would have been so low that their success would have been almost entirely symbolic.¹

Attempts to reorganize the delivery of home care have taken several forms. Some would make available project money for "case management" services to coordinate existing benefits. Others would go so far as to establish a new Part under Medicare, which would become the funding source for virtually all federal spending on long-term care services. The most common approach here would be to make available flexible block grants to states and sub-state regions.²

Why have efforts to increase federal funding for in-home services fared so poorly in Congress? An expression of the difficulty is found in the aging committees of the two houses. Each lack legislative authority to send bills to the floor of its house. Both hold hearings and attract a considerable amount of attention.³ Neither could be abolished

¹For one pertinent bill, see HR 10738 (95th Congress).

²One of the best examples is HR 2268 (94th Congress).

³See, for example, the House Aging Committee's Subcommittee on Long-Term Care's report on "New Perspectives in Health Care for Older Americans," Washington: USGPO, January 1976; and the Senate Aging Committee's series of hearings on "Health Care for Older Americans: The 'Alternatives' Issues," Washington: USGPO, 1979.

in recent Congressional reorganization, although serious attempts to do so were made in the Senate. Still, both are usually forced to remain on the periphery of the legislative process.

In the Department of Health, Education, and Welfare also, the forces for higher home care funding are not strong. A report on home care which Congress ordered HEW to complete by October of 1978 had not been released six months later. It appears that the major reason for the delay is the desire to remove from the report recommendations for new initiatives.

Given the extent of dissatisfaction with nursing homes in this country today, and the seeming attractiveness of home care as an alternative, why have the advocates of home care fared so poorly?

First, it seems that advocates have not been able to bring to bear on Congress a concentrated lobbying force. Why is this? The frail or medically unstable disabled older person can only, with difficulty, act as an effective self-advocate. Further, although, as noted above, perhaps 25% of older Americans will live in a nursing home before they die, and most say they fear or dislike the prospect, older persons who do not yet need long-term care do not seem to have been able or (in some cases) willing to invest a great deal of their political assets

in improved long-term care. As Binstock¹ and Hudson² have agreed, the elderly and their allies have been unable to secure enactment of legislation to reduce the severe unbalance in quality of life that exists between those older Americans who are well-off and those who are very old, poor, dependent, ill, and alone. They have been far more successful in gaining higher Social Security payments. This behavior may perhaps be explained in part by self-interest and in part by denial of the prospect of (much feared) dependence. Finally, those who care for the disabled elderly may themselves be old, frail, and ill. This contrasts with the position of parents and others who advocate better programs for the developmentally disabled.

A second set of obstacles to increased home care funding seems to lie in the general dissatisfaction with long-term care generally: nursing home cost and charges of fraud, problems in assuring nursing home quality, and fears that these will pervade new or expanded home care programs as well. Early evidence in support of these suspicions has already appeared.³ In recent years in Washington and perhaps for

¹R. H. Binstock, "Interest Group Liberalism and the Politics of Aging," The Gerontologist, Vol. 12, No. 3 (Autumn 1972), pp. 265-280.

²Robert B. Hudson, "The 'Graying' of the Federal Budget and Its Consequences for Old-age Policy," The Gerontologist, Vol. 18, No. 5, Part 1 (October 1978), pp. 428-440.

³U.S. Senate, Committee on Government Operations, Subcommittee on Federal Spending Practices, Efficiency, and Open Government, "Problems Associated with Home Health Agencies and Medicare Program in the State of Florida," Washington: USGPO, August 1976, U.S. House of Representatives, Select Committee on Aging, "New York Home Care Abuse," Comm. Pub. No. 95-145, Washington: USGPO, 1978.

some time to come, it may be difficult to secure an objective assessment of home care's merits and liabilities.

Third, the fear that problems which have been associated with nursing home care will spill over to home care should be viewed within a larger legislative context. This begins with the interest in devising a national health insurance program (for acute care only) and the comparative disinterest in long-term care. It continues with suspicions that the elderly already receive more than their fair share of federal funds.¹ And it concludes within the perceived national mood of tax and spending limits: seemingly, it is feared that new home care benefits' costs would be unpredictable and uncontrollable.

If Congress and HEW could be more confident about the comparative effectiveness of home and nursing home care (difficult to calculate for reasons discussed earlier in this section) and about the comparative costs of care in the two sites (taken up in the next chapter), the future of home care could be legislated and administered with greater confidence.

¹See evidence cited by Robert B. Hudson, op. cit.

F. Summary

This chapter has covered a good deal of ground. It began by noting the extent and nature of increased long-term care spending in this country. Then, the sources of increased demand for formal long-term care by the elderly were explored, along with the reasons for disproportionate public funding for institutional care. Three of the principal arguments employed by advocates of higher home care spending--quality, effectiveness, and choice--were examined. Difficulties in measuring effectiveness and the consequence of these difficulties for research and policy were noted. This theme of method will be carried to Chapters III and IV as they discuss how to measure comparative costs of care at home and in institutions. Finally, the present setting of federal long-term care policy was discussed. This served as the final piece of the foundation for assessing the evidence on the comparative costs of home and institutional care.

Chapter III

THE EVIDENCE ON COMPARATIVE COSTS; ITS WEAK FOUNDATIONS

A. Introduction

Section E of Chapter II examined a first difficulty in comparing the costs of home and institutional care: problems in controlling for outcomes or effectiveness of long-term care. This chapter has two principal sections. In each, yet another difficulty in comparing costs is discussed. Section B begins by presenting a summary of available evidence on comparative costs. It then indicates limitations of most of the studies which developed this evidence: lack of real control on groups or samples whose initial characteristics are dissimilar. Sources of these limitations are discussed.

In the face of problems of controlling for initial characteristics and measuring outcomes, section C considers an alternative to the use of experimental and control groups to compare the cost of home and institutional care. This is to let a sample serve as its own control. Patients are actually cared for in only one setting. The hypothetical cost of their care at a defined level of effectiveness, in the other setting is estimated by health and social service professionals. Reliability of professional views about the costs of care in the hypothetical setting would inspire confidence that recommends services were

indeed of the effectiveness specified. But, if the types, quantities, and providers of home care services -- and their costs -- recommended by different professionals were quite divergent, this would tend to call into question professionals' capacity to design long-term care plans of defined effectiveness.

In light of research findings about the reliability of professional judgment in several fields, and of the discussion of consumer sovereignty in long-term care in Chapter II, section C closes by pointing toward the method used in the present study to prepare a foundation on which to compare the costs of home and nursing home care.

B. Evidence on the Comparative Cost of Home and Institutional Care

The total cost of a new home care program, like any other, is the product of its utilization and on the average cost of care received by those helped. Because, at the time the present study was designed, it appears that relatively good estimates were available of the size of the population needing home care but not receiving it, and relatively poor estimates were available of the average cost per person of home care, it was decided to learn more about the latter.¹ Although this

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For useful material on the population in need, see Laurence G. Branch and Floyd J. Fowler, Jr., The Health Care Needs of the Elderly and Chronically Disabled in Massachusetts, Boston: Survey Research Program of the University of Massachusetts, March 1975; Laurence G. Branch, Understanding the Health and Social Service Needs of People over Age 65, Boston: Survey Research Program of the University of Massachusetts, 1977; Levinson Policy Institute, Alternatives to Nursing Home Care: A Proposal

study will concentrate on cost of care for individuals and pay little attention to system costs, Chapter VII will consider the effect on system costs of various types of diversion of nursing home residents to home care.

Comparing costs by four methods. One customary approach to comparing the costs of home and institutional care has been to introduce a new home care service, measure its costs, and then compare these with the savings thought realized by shortening or eliminating institutional stays. The sample serves, in a sense, as its own control. This approach has been applied to home care as a substitute for various types of nursing home and hospital care. Studies which take this approach usually show that the introduction of an in-home benefit leads to a net reduction in cost of care. Such results have reinforced the arguments of those who propose increased public home care funding on grounds of quality and effectiveness.

Among the compilations of data which take this approach are those of the home care programs of Blue Cross of Greater Philadelphia and Associated Hospital Service of New York.¹ Both of these programs appear to have been well run, but neither seems to have been designed principally to obtain

prepared for the U.S. Senate Special Committee on Aging, Washington: USGPO, 1971, stock no. 5270-1248; American Public Welfare Association, "Report on Long-Term Care," Washington: The Association, November 1978.

¹ Brahna Trager, "Home Health Services in the United States," A Report to the U.S. Senate, Special Committee on Aging, Washington: USGPO, April 1972, Appendix 3, Items 1-2, pp. 82-114.

data on comparative long-term care costs. This is common: As La Vor and

Callender note:

Most of the available literature on cost effectiveness of home care has resulted from the application of certain criteria to already existing programs that were not designed to be research studies....¹

It appears that this first method presents at least six problems:

- 1) Seldom is any evidence offered of reduction in nursing home costs -- or even of reduction in the rate of increase of those costs. Beds emptied may be quickly filled. Is this new use marginal and discretionary, or does it represent a legitimate demand for beds which are in too-short supply?
- 2) The question of whether the patients receiving home care would have required the duration of institutional care thought "saved" is often addressed inadequately. The assumption is usually made by a professional on the scene that a given patient would have required n days of institutional care. The present study is designed in part to address the reliability of similar types of professional judgement, in this case, about needed home care services.
- 3) The home care benefit investigated is usually for short-term recuperation from an acute illness. Seldom is funding included for even short-term custodial care in the home. The costs of these services are therefore usually excluded.
- 4) Savings from institutional care foregone are taken at the average cost of institutional care. If these patients were less ill than the average resident of the institutions concerned, the

¹ Judith La Vor and Marie Callender, "Home Health Cost Effectiveness: What Are We Measuring?" Medical Care, Vol. 14, No. 10 (October 1976), pp. 866-872.

real cost of nursing home care for these patients would be below average.

5) Are all the substitute home care services needed? Are additional services appropriate? 6) As presented, these studies seldom provide adequate descriptions of their patient samples. This information would help answer some of the questions just raised.

This first approach to learning the cost of a home alternative seeks to learn the savings which accrue from appropriate de-institutionalization. A second common method, a mirror image of the first, has been to examine the individual and program costs of removing from nursing homes those "inappropriately institutionalized." Here, too, the sample serves as its own control. Regrettably, the word "inappropriately" is not always tightly defined. In some reports, it seems to refer to patients who do not require some or all of the services in their facility or at their level of care. In others, it signifies patients who, it is thought for some reason, could be cared for more cheaply in other settings. Further, it sometimes means all patients wrongly placed, receiving too much care or too little; at other times, only those receiving too much care. Methods of determining who is wrongly placed vary with these definitions.¹

¹ The literature on this subject is quite large. See among others, Kathleen Connelly, Philip K. Cohen, and Diana Chapman Walsh, "Periodic Medical Review: Assessing the Quality and Appropriateness of Care in Skilled Nursing Facilities," New England Journal of Medicine, Vol. 296, No.15 (April 1977), pp. 878-880; Alan C. Beckman, Linda S. Noelker, and Debra David, "PEER REVIEW: Overt and Covert Factors in the Decision to Institutionalize," Cleveland: Benjamin Rose Institute, 1977, paper presented at the 1977 meeting of the Gerontological Society; and John Halahan and Bruce Stuart, "The Extent and Cost of Unnecessary and Inappropriate Utilization," in Chapter II of Controlling Medicaid Utilization Patterns, Vol. II, Washington: Urban Institute, 1977, U.R.I. 17700.

Estimates by different methods in different places and at different levels of institutional care not surprisingly reveal a wide variation in the proportion of patients considered wrongly placed. A useful compilation by the Congressional Budget Office identifies estimates that 6% to 65-76% of various institutional populations are inappropriately placed.¹

The present study adopts some of the methods embodied in these two approaches to cost comparisons. It seeks to learn what proportion of certain new nursing home residents are being "inappropriately institutionalized" in that they could be cared for more cheaply at home. Therefore, it must face up to the problems just identified. This task is attempted in Chapter IV.

A third method for comparing the costs of home and institutional care involves a natural experiment, using retrospective selection of matched samples. Here, clients of home care agencies are matched with residents of nursing homes who have similar medical, functional, psychosocial, demographic, and environmental characteristics. By observing the variety of current practice with an open-mind, the presumption of selecting people and designing service packages for experimentation is avoided.

Retrospective matching suffers from practical and conceptual problems. Matching is difficult to accomplish when the patients served in the two settings are generally dissimilar. This seems to have been the experience

¹ Congressional Budget Office, Long-Term Care for the Elderly and Disabled, Washington: USGPO, 1977, Appendix B.

of a recent project in Minnesota.¹ Reports by the Congressional Budget Office and by Smyer, however, argue that there does exist a group in the community which is similar to a fraction of institutionalized patients.²

On the conceptual level, Campbell and Stanley offer a set of methodological arguments against retrospective matching.³ Greenberg has recently asserted that if it is possible to model the basis on which patients ultimately received care in two settings, it is possible to adjust for the different characteristics of the two groups.⁴ When this can be done it promises to be a useful tool in comparing the costs of long-term care in different settings.

The three approaches to comparing costs have been used in long-term care as second-best substitutes for controlled experiments. The best way to measure the costs of different services is to conduct a prospective randomized clinical trial (RCT). Cochrane has offered several arguments in favor of this approach, which would apply in the controlled experiment to

¹ Nancy N. Anderson and others, "A Comparison of In-home and Nursing Home Care for older Persons in Minnesota," U.S. Administration on Aging Project No. 90-A-682. See also Frederick W. Seidl, Kevin D. Mahoney, and Carol D. Austin, "Providing and Evaluating Home Care: Issues of Targetting," paper presented at the Gerontological Society's 31st Scientific Meeting, Dallas, 20 November 1978.

² Congressional Budget Office, Long-Term Care for the Elderly and Disabled, Washington: USGPO, p. 62; Michael E. Smyer, "Differential Usage and Differential Effects of Services for Impaired Elderly," Advances in Research (Duke University Center for the Study of Aging and Human Development) Vol. 1, No. 4 (Winter 1977).

³ Donald T. Campbell and Julian C. Stanley, Experimental and Quasi-experimental Designs for Research, Chicago: Rand-McNally, 1966, pp. 15, 47-49.

⁴ Jay Greenberg, "The Determinants of Bias in Observational Studies: A

health and social services.¹

When the RCT can be used, it is the most persuasive of any comparative evaluation of cost. In long-term care, however, the RCT has two distinct liabilities. One is that sample size must be considerable to permit measurement of the effects of all the variables being manipulated -- sites, types, quantities, and providers of services. This seems to be true of any facet of acute care if its impact on health status is indeed small.²

It may be true of long-term care for the same reason. Moreover, in long-term care, effects themselves are relatively difficult to measure and/or imprecise conceptually: contrast morale and functional ability with mortality.

The need to control for secular changes in the status of recipients of long-term care probably tends to increase desired sample size. If the number of variables being manipulated under any one cost comparison could be limited, needed sample size would shrink accordingly. Regrettably, the number of variables seems difficult to limit. Patient characteristics -- medical, functional, demographic, psychosocial, and environmental -- all appear to influence needed services. In addition, they interact. Treatment variables -- setting, types, quantities, and providers of care -- are on ethical grounds, difficult to specify in advance. Finally, if the number

Simulation Study and a Long-term Care Example," Unpublished Doctoral Dissertation, Harvard School of Public Health, Boston, 1978.

¹ A.L.Cochrane, Effectiveness and Efficiency, London: Nuffield Provincial Hospital Trust, 1972.

² John M. McKinlay and Sonja M. McKinlay, "The Questionable Contributions of Medical Measures to the Decline of Mortality in the United States in the Twentieth Century," Milbank Memorial Fund Quarterly: Health and Society, Vol. 55, No. 3 (Summer 1977), pp. 405-428.

of variables is successfully restricted in the interest of controlling sample size, the generalizability of the findings is likely to be restricted as well.

The second general liability of the RCT lies in the ethical hazard of requesting informed consent for experimental manipulation of care, and in the practical difficulty of securing that consent. The traditional RCT begins with: (1) an accepted treatment for a problem; (2) an alternative; and (3) evidence for suspecting that (2) is better than (1). In some cases, belief in the accepted treatment is so strong that innovators find it hard even to win the right to test their alternative. Witness Fisher's efforts to gain the right to measure the effectiveness of more conservative treatments for breast cancer.¹

In other instances, such as many areas of long-term care, (1), (2), and (3) are lacking. While there seems to be no validated treatment for individual problems, there are accepted modes of practice. Most publicly-supported long-term care is delivered in nursing homes. This site appears to be the safest, in conventional medical respects, in as much as the traditional devices of medical intervention -- trained workers and sophisticated machinery -- can, in some circumstances, be brought to bear sooner. In comparing the costs of care in different sites, it would probably be desirable to manipulate inputs -- types, quantities, and providers of services -- and learn thereby the costs of delivering to similar patients care of equal effectiveness. To upset established patterns with an experiment requires seeking

¹ Victor Cohn, "Science Comes to Medicine -- Slowly," Technology Review, December 1974, pp. 8-9.

informed consent. Human subjects protection committees now demand that consent forms contain information revealing expected benefits and risks of established and experimental treatments. This is difficult to offer in long-term care. For these reasons, and probably for others as well, the RCT appears never to have been used to compare the costs of home and institutional care.

A study is planned¹ to help assess benefits and risks. It will first compare several sets of professional views of the home care needs of a sample of 100 patients. Then, the possible validity of these views will be measured by contrasting actual patient outcomes with professionals' plans for desired services. Professional prescriptions will be compared with patient and family requests for services. On the foundation of these two analyses, alternatives for service delivery will be specified for possible subsequent testing under a RCT.

What is known about comparative costs? In the face of the difficulties of comparing the costs of home and institutional care, it is not surprising that most recent reviews of empirical studies conclude that little is reliably known and that more careful research is indicated. A review by Robinson and others of the comparative costs of home and institutional care concluded that:

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"Decision-making for Long-Term Care," Levinson Policy Institute, Heller School, Brandeis University, 1978-1980.

The available data support the thesis that homemaker-home health aide services, when provided alone or as one of an array of in-home services, are usually less costly than any of the out-of-home alternatives.¹

On the whole, however, as the authors of this review indicate, most of the data summarized derive from studies which do not control patient characteristics or outcome measures. A similar difficulty plagues a review of home care costs studies by Homemakers Upjohn.² Both of these efforts call attention to the need to consider separately home care as an alternative to hospital care and to short- or long-term nursing home care. One of the dominant findings in this literature seems to be that home care for many convalescents costs less than hospital care -- taking the hospital cost to be the per diem charge.

A 1975 General Accounting Office review of 20 studies of home and nursing home costs concluded that nineteen "presented data which supported the proposition that home health care can be less expensive under some circumstances than alternative institutional care."³ Several problems in making cost comparisons were noted: finding samples of similar patients

¹ Nancy Robinson, Eugene Shinn, Esther Adam, and Florence Moore, "Costs of Homemaker-Home Health Aide and Alternative Forms of Service: A Survey of the Literature," New York: National Council for Homemaker-Home Health Aide Services, Inc., 1974.

²"Cost Analysis: Home Health Care as an Alternative to Institutional Care," Kalamazoo, Michigan: Homemakers Upjohn, October 1975.

³ General Accounting Office, letter to Rep. Edward I. Koch, MWD-76-30, B-164031(3), 17 September 1975.

who receive similar services, relying on charges (which may be arbitrary) as surrogates for cost, and relying on average institutional costs as measures of the costs for particular patients.

Three other reviews have been more critical in their judgments of the methods and findings of comparative and other studies of the costs and effects of home and institutional care for the elderly. The three had some reasons in common; other reasons were individual. Each decided that research and demonstration projects were, in sum, inconclusive.

Craig's 1975 analysis of twenty-three studies of home care reported three general barriers to the accumulation of systematic knowledge: (1) individual efforts varied in their objectives; (2) client populations and program environments were not controlled; and (3) benefits and their administration were widely dissimilar.¹

The firm of Applied Management Sciences completed in 1976 a review of several alternatives to nursing home care, including home care and adult day care. Only eight studies were located which investigated the costs, efficiency and/or effectiveness of these alternatives. AMS concluded that "The available evidence is insufficient either to refute or support the assertion that in-home care is cost-efficient and/or

¹ John Craig, "Cost Issues in Home Health Care," in Marie Callender and Judy LaVor, Home Health Development, Problems, and Potential, Washington: Disability and Long-term Care Study, Office of the Assistant Secretary for Planning and Evaluation, Department of Health, Education and Welfare, April 1975, pp. 48-55.

effective for all elderly persons."¹ This can hardly have been a surprising finding; Care in any one site could not be thought best, by all or any measures, for "all elderly persons." AMS did identify certain sub-populations for whom in-home care might be preferable.

AMS faulted individual studies of alternatives to institutionalization on several grounds: sampling methods were thought inadequate; samples were too small; patients were followed for too short a time; cost data were not sufficiently detailed; and evaluators were typically themselves numbered among the direct service providers.

Collectively, several major demonstrations were criticized for their failure to adopt common methods. Outcome measures, patient variables, and services offered exhibited considerable differences. Most projects developed their own instruments for gauging outcomes; in only a few cases were standard measures, such as the Katz ADL score, used. AMS further criticized five major demonstration projects then in process because all were located in the northeast and all but one were in urban areas. According to this argument, failure to standardize some variables, such as experimental services, is an error; but standardization of other variables -- is also an error. It would appear difficult for researchers to tread a safe path amid these charges.

¹ Applied Management Sciences, "Evaluation of Personal Care Organizations and other In-Home Alternatives to Nursing Home Care for the Elderly and Long-term Disabled," Final Report and Executive Summary (Revised), Contract HEW-OS-74-294, Silver Spring, Maryland: AMS, 1 May 1976.

Based on its assessment of the inadequacies of past efforts, AMS recommended a \$58 million demonstration program to test four administrative arrangements, and four financing and four reimbursement mechanisms's utility in six delivery systems.

A contrary plan was put forth by the Office of Social Services and Human Development, in the Office of the Assistant Secretary for Planning and Evaluation, DHEW.¹ An evaluation of 25 experimental non-institutional long-term care projects for their enhancement of clients' daily functioning and their effectiveness in preventing institutionalization was extremely critical of both research procedures and results. Therefore, it was recommended that "New Experimental Research Should Be Proceeded by Development of Theory and by Non-experimental Research."

In the face of these assessments, and those of such other authorities in the field of long-term care as LaVor and Callender² and Doherty et al,³ the prospects for soon obtaining data on the comparative costs of home and institutional care for the elderly do not appear bright. Thus, it seems likely that home care advocates will be obliged to continue to argue without the support that cost data might provide.

A noteworthy exception to this generalization may shortly materialize.

¹ "Critical Review of Research on Long-term Care Alternatives Sponsored by the Department of Health, Education, and Welfare," Washington: ASPE, DHEW, June 1977.

² Judy LaVor and Marie Callender, op cit.

³ Neville Doherty, J. Segal, and Barbara Hicks, "Alternatives to Institutionalization for the Aged," Aged Care and Services Review, Vol. 1, No. 1 (1978), pp. 1-16.

Careful work by the U.S. General Accounting Office in Cleveland, using Duke's OARS instrument seems to have developed measures of the cost of home care for a large sample. If estimates of the average cost of comparable levels of institutional care for the members of this sample can be developed, a useful device for assessing cost differences will have been produced.¹

In view of the difficulties of experimentally controlling -- either prospectively or retrospectively -- for the initial characteristics of patients receiving home and institutional care, and in view of the general difficulties of measuring the outcomes of long-term care, the present study seeks to compare the costs of the two types of care hypothetically. The sample is actually cared for only in one site: the nursing home. Thus, the sample serves as its own control and the problem of comparability of initial characteristics is avoided.

This leaves only the problem of estimating what would have been the costs and outcomes of care in both sites. The cost of nursing home care is known. This study, by means of a series of pre-planned and adaptive devices, has sought descriptions of the home care service packages which are in general at least as effective as the institutional services actually provided.

¹ For work to-date, see Controller General of the United States, "Report to the Congress on Home Health -- The Need for a National Policy to Provide Better Care to the Elderly," Washington: General Accounting Office, HRO 78-19, 30 December 1977; William F. Laurie, "Employing the Duke OARS Methodology in Cost Comparisons: Home Services and Institutionalization," in Multidimensional Functional Assessment: The OARS Methodology, 2nd ed., Durham, N.C.: Center for the Study of Aging and Human Development of Duke University, 1978, ch. 12, pp. 110-120.

It is believed that this condition has been met. (The devices for so doing are described in Chapters IV and V.)

The remaining problem is to learn whose views of the hypothetical cost of home care should be compared with the actual cost of institutional care. Who can be trusted to know what package of home care services is "appropriate"? Whose views can be taken to be valid, in that they recommend not so much care that patients become dependent nor so little home care that they suffer avoidable harm. Since home care services are not actually provided, the general difficulty in long-term care of measuring outcome is compounded in the present study. Consequently, the quality of the care planning process and the reliability and validity of care planners views are of prime importance.

Two general approaches, described in part three, try to learn whose views of home care needs -- and therefore of the cost of home care -- should be accepted. These are to relate recommended home care service units to certain patient characteristics, and to test by a variety of devices the consistency of professional views about needed services.

There are several conceivable candidates for the position of planner of home care services: patients themselves, their families, and various professionals. Claims of patients and their families were described in Chapter II; those of different professionals will be taken up shortly. If professionals' views of patients' home care needs were generally consistent or reliable, this would arguably strengthen the case that professionals should control allocation of home care resources. It was suspected, however, that professionals would not agree very well among one

another about patient's needs. A considerable literature, principally in other fields, but touching on long-term care as well, generated this suspicion. Section C now reviews the relevant literature on professional agreement.

C. Planning Care: The Reliability of Professional Views

This section examines the extent of agreement among professionals about what patients or other people need. Reliability, or consistency, should be seen as a prerequisite for validity. That is, if professionals do not agree very well with one another about the needs of an individual patient, they cannot be expected to produce effective or valid plans of care. Reliability is not enough in itself to ensure validity. Professionals may agree with one another, but they may all be wrong. Nonetheless, confidence in professionals is greater if their views are consistent. How much consistency is "enough" is hard to say, but, other things equal, more is better.

In this thesis, it was decided to have many views about the home care needs of individual patients because the literature on professional decision-making, reviewed shortly, does not inspire a great deal of confidence in the general reliability of professionals and because the special circumstances of long-term care seem likely to increase the chance of disagreement. The general literature on decision-making is important also because it places possible disagreement in perspective. That is, given circumstances disposing to disagreement in long-term care, and the disagreement

in other professional fields, to discover a measure of disagreement in long-term care would not discredit the field as an object for funding.

This section now examines the reliability of professional views in home care, nursing home care, acute medical care, and several other fields. It will close with a discussion of the sources of disagreement in general and of the peculiar circumstances in long-term care in particular.

A note on definitions is important. The process of obtaining professional views of patient need will be referred to as "care planning." The products of this process will be called "care plans," "prescriptions," "professional recommendations," and the like. Thus, deciding what people need will be distinguished from describing their past or current physical, medical, functional, psycho-social and/or other status. The latter task will be referred to as "assessment." Assessment, to produce a timely and objective (insofar as possible) view of patient status is only a foundation for deciding needed care.

All too frequently, care planning and assessment are confused, or it is thought that they are identical, or that the content of the care plan flows smoothly and inevitably from an understanding of current condition. This view appears, for example, in the generally excellent report on long-term care by a task force of the National Conference on Social Welfare:

Once a functional capability assessment of a sample base of the population is obtained, the data can be translated into service[s]..., costs can be determined, standards established and the technology moved into place to serve the needs. Interventions

and therapies are readily related to functional levels.¹

In opposition to this outlook, the opinion seems to be widely held that "There is no set of criteria matching levels and combinations of disability with appropriate types of institutional or noninstitutional treatment"² and that "We lack methods to ... relate the assessment of a patient's medical condition to the quality of care and types of LTC services they receive ..."³

The difficulty of making this linkage is by no means restricted to long-term care. It is a problem, of debated dimensions, in acute care as well.⁴ That such a debate should occur signals a departure from Weber's view of the professional as a rational cog. The judge, for example:

in the bureaucratic state with its rational laws
is more or less an automation of paragraphs: the
legal documents together with the costs and fees

¹ National Conference on Social Welfare, "The Future of Long-term Care in the United States," The Report of the Task Force, Washington: The Conference, February 1977 (multilith).

² Congressional Budget Office, Long-term Care for the Elderly and Disabled, Washington: CBO, February 1977, p.33.

³ Health Care Financing Administration, "Memorandum for July 14, 1978 Briefing, Major Initiative: Long-term Care/Community Service," Washington: HCFA, 1978, Appendix 9.

⁴ For one side of the agreement see HCFA, op.cit. and David A. Hamburg and Sarah Spaght Brown, "The Science Base and Social Context of Health Maintenance: An Overview," Science, Vol. 200, No. 4344 (26 May 1978) pp. 847849; for the opposing view, see John Lister, "Training for What? -- Winter of Discontent," London Post, New England Journal of Medicine, Vol. 300, No. 12 (22 March 1979), pp. 656-658.

are dropped in at the top with the expectation that the judgment will emerge at the bottom together with more or less sound agreements -- an apparatus, that is, whose functioning is by and large calculable and predictable.¹

Critics of professionals today may on occasion state their case more forcefully than the available evidence warrants. This may be in part a reaction to descriptions, such as that by Weber, of professionals as disinterested truth processors. In part also, they may be reactions to claims that competent professionals, such as doctors, simply did their best, and that objective standards for judging their ability were unavailable. An example of this view is the definition of good medical care put forth by Lee and Jones in 1933 (and asserted often today). It is " 'the kind of medicine practiced and taught by the recognized leaders of the medical profession at a given time or period ...' "²

Hamburg and Spaght,³ and Cochrane,⁴ have been among those calling for better outcome measures in acute care; Kane and Kane⁵ have argued similarly

¹ Max Weber, Parliament and Government in Germany, Appendix 2, "Bureaucracy and Political Leadership," in Guenther Roth and Claus Wittich, eds., Economy and Society: An Outline of Interpretive Sociology, (Guenther Roth and Claus Wittich, eds., New York: Bedminster Press, 1968, p. 1395.

² R.I.Lee and L.W.Jones, The Fundamentals of Good Medical Care, Chicago: Press, 1933, cited in David M. Kessner, "Quality Assessment and Assurance: Early Signs of Cognitive Dissonance," New England Journal of Medicine, Vol. 298, No. 7 (16 February 1978), pp. 381-386.

³ op.cit.

⁴ A.L.Cochrane, Effectiveness and Efficiency, London: Nuffield Provincial Hospital Trust, 1972.

⁵ Robert L. Kane and Rosalie A. Kane, "Care of the Aged: Old Problems in Need of New Solutions," Science, Vol. 200, No. 4344 (26 May 1978) pp. 913-919.

in long-term care. Difficulties in measuring outcome¹ have led to renewed interest in grounding medical therapy in process or in consensus among experts.² It is likely, however, that critics of health professionals will regard other than outcome measures as clearly second-best.

Critics of professionals' ability -- that they have unique access to special knowledge -- and of their motives in seeking control over knowledge, resources, or decisions, has been linked by Glazer to critics of institutions themselves.³ The latter argument was taken up in Chapter II, Section E. The present purpose, however, is not to decide if professionals are generally wise or ignorant, concerned with promoting competence or restricting competition. Rather, this section seeks to report evidence on how well professionals seem to agree with one another.

In home care itself, the care planning process which underpins resource allocation appears to have been the subject of only one detailed study.⁴

¹ William C. McAuliffe, "Measuring the Quality of Medical Care: Process versus Outcome," Milbank Memorial Fund Quarterly: Health and Society, Vol. 57, No. 1 (Winter 1979), pp. 118-152.

² Witness the large-scale Research Development Consensus Project of the National Institutes of Health, conducted during 1977-1979.

³ Nathan Glazer, "The Attack on the Professions," Commentary, Vol. 66, No. 5 (November 1978), pp. 34-41.

⁴ Bay Area Welfare Consortium, Final Report of the Homemaker-Chore Study, Berkeley: University of California School of Social Welfare, September, 1977. See also U.S. Congress, "Proprietary Home/Health Care," Joint Hearing Before Subcommittee on Long-term Care of U.S. Senate Special Committee on Aging and Subcommittee on Health and Long-term Care of Select Committee on Aging of U.S. House of Representatives, 28 October 1975, Washington: USGPO, 1976.

This investigation found a considerable measure of both horizontal and vertical inequity: clients with similar needs were frequently treated differently, and clients with different levels of disability frequently did not receive services commensurate with their requirements. Moreover, patterns of care varied by county of residence and by procedure for assessment and care planning. Like reliability of planning, equity would point toward validity. Consistent plans could prescribe inappropriate services, and equitable plans could be ineffective or wasteful, but they carry a greater presumption of thoughtful consideration of clients needs.

In view of these results, and others presented below, certain assumptions made by federal institutional long-term care regulators should be carefully examined. These assumptions are visible in two areas: PSRO monitoring of nursing home care, and the drafts of proposed conditions of participation for skilled and intermediate care facilities in Medicare and Medicaid. Similar thoughts are not manifest in home care, probably because it has not yet been the object of significant regulation.

One of the three components of pilot PSRO review of nursing home care is "medical care evaluation." This is the component most closely related to patient care. Nonetheless, medical care evaluation does not review the content of care against validated standards. Rather, it calls for the completion of procedures reasonably thought to be necessary (but not sufficient) for good care: did the physician complete a plan of care, did medications relate to diagnoses, were goals of care recorded? Unlike the PSRO medical audit for acute care, which does attempt to rely on a broad consensus among physicians about what constitutes acceptable care, PSRO review of long-term care lacks a firm scientific base. In part, this follows from

PSRO's control by physicians, who generally are less interested in long-term care than in acute care. Physician domination of PSRO's nonetheless limits the latitude of knowledgeable and interested nurses, social workers, and other professionals in helping to prepare standards for long-term care.

Further, less certainty in diagnosis or treatment of long-term care problems can typically be expected, in comparison to acute care problems. The nature of chronic problems themselves, the likelihood of multiple diagnoses, and the relative lack of data on outcomes in long-term care may well contribute to this.¹

Nonetheless, optimistic assumption about the efficacy of regulation of long-term care appears in the draft conditions of participation for skilled and intermediate care facilities in Medicare and Medicaid. This draft is the basis for public hearings held during the summer of 1978. One major option being considered is to de-emphasize certification of nursing homes' policies and capacities and, instead, stress "quality of care and services provided to patients."² One revised condition of participation designed to effect this option is that for patient care management. This would call for detailed assessment shortly after admission, revised assessments as appropriate, discharge planning, if appropriate, and patient care planning. Assessment would include "social and background data, diagnoses, physical impairments, functional impairments, behavior, special procedures, care being provided, drug regimen reviews, and an estimate of discharge potential." These items are the union of data called

¹ Health Care Financing Administration, "Long-term Care Quality Assurance," Memorandum, 24 June 1978 (draft).

² Health Care Financing Administration, DHEW, "New Directions for Skilled Nursing and Intermediate Care Facilities," Notice of Public Meetings, N.d.

for in PSRO nursing home medical care evaluations and in the patient appraisal and care evaluation (PACE) form. As in the case of the PSRO medical care evaluations, gathering the data required to perform patient assessment is a necessary, but far from sufficient, condition for good long-term care.

Patient care planning is required by the draft conditions of participation; individualized care plans must be written and revised, at least quarterly. To require nursing homes to engage in care planning will formalize what is often done intuitively today. Greater thoughtfulness and consistency may ensue. But the benefits of this requirement are difficult to gauge, in the absence of valid evidence about the needs of individual patients and how to meet them.

A final issue in institutional care pertains to placement of patients at the correct levels. After reviewing this problem, the Moreland Act Commission found only a weak relation between patient needs and level of care.¹ A point system for patient classification which was introduced in response to the Commission's criticisms was itself attacked as capricious and insensitive to important differences in individual needs.² After reviewing issues in assigning institutional long-term patients to proper levels of care, Lawson concluded that this task "far exceeds known observer reliability with regard to a simpler situation, such as reading electrocardiograms

¹ New York State Moreland Act Commission, Reimbursing Operating Costs and Assessment and Placement: Anything Goes, Reports 5 and 6, New York: The Commission, March 1976.

² Peter Kihss, "Point System of Reclassifying Nursing-Home Patients is Under Attack," New York Times, December 20, 1977.

or feeling arterial pulses. It will, therefore, not support the observer agreement that is required."¹

The reported evidence on this question seems somewhat mixed. Wenkert and others found that

Physician-nurse teams using common concepts of levels of patient care can make replicable judgments with respect to the care needs and proper placements of statistically random samples of patients seen in different settings.²

Bell, on the other hand, found a considerable range of difference in the estimates by physicians, nurses, and social workers about the proportion of newly admitted nursing home residents who could have been sustained in the community had certain in-home services been available.³

Similarly, Seidl and others, learned that actual home care case managers judged a substantially higher proportion of their clients to be at risk of institutionalization than did a disinterested panel.⁴ Similar

¹ Ian R. Lawson, "The Antithesis Between Fiscal and Clinical Systems in Geriatric Care," in Edward J. Hinman, ed., Advanced Medical Systems: The Third Century, Miami: Medical Books, 1977, pp. 93-101.

² Walter Wenkert, John G. Hill, and Robert L. Berg, "Concepts and Methodology in Planning Patient Care Services," Medical Care, Vol. 7, No. 4 (July-August 1969), pp. 327-331.

³ William G. Bell, Community Care for the Elderly: An Alternative to Institutionalization, Tallahassee: Program in Social Policy and the Aging, Florida State University, June 1971.

⁴ Frederick W. Seidl, Kevin D. Mahoney, and Carol D. Austin, "Providing and Evaluating Home Care: Issues of Targetting a paper presented at the 31st Annual Scientific Meeting of the Gerontological Society, Dallas, 20 November 1978.

sorts of evidence appears in the work of Pollak¹ and of Williams and others².

In the realm of long-term care generally, the apparent importance of consulting professionals from a number of different fields further complicates the task of learning what care is appropriate for patients with various problems. Such consultation is desirable given the variety of professions assisting the elderly in meeting their multi-faceted needs. The frequently-reported disinterest by physicians in many of the problems of the aged³ appears to have led to a disjunction among knowledge, interest, and power. This has probably slowed reduction in the disparity of views about both the requirements of this population and how to meet them. Fragmentation of funding sources has probably had the same effect.

If Lawson is correct regarding the greater difficulty of making accurate clinical judgments in such complex areas of long-term care as level of nursing home placement, how much better is inter-rater reliability in the more straightforward realms of acute care? Koran's comprehensive examination of this subject constitutes a moderately chilling

¹ William Pollak, "Utilization of Alternative Care Settings by the Elderly: Normative Estimates and Current Patterns," Washington: Urban Institute, 13 March 1973, Working Paper 963-12.

² T. Franklin Williams, John G. Hill, Matthew C. Fairbank, and Kenneth G. Knox, "Appropriate Placement of the Chronically Ill and Aged," Journal of the American Medical Association, Vol. 226, No. 11 (10 December 1973), pp. 1332-1335.

³ See for example, Patricia Lee Kasschau and Vern L. Bengston, "The New American Dilemma: Decision-makers View Aging and Social Policy," Los Angeles: University of Southern California, Andrus Gerontology Center, August 1977.

indictment of physician decision making. After reviewing over 50 reports, he concluded that "if the results of these studies are representative of the reliability of clinical data, methods, and judgments, there is little room for complacency."¹ The work of Dunn and Conrath² reinforces this conclusion.

Koran was willing to offer tentative conclusions about factors influencing physician agreement. One was that "the less severe an abnormality, the lower the inter-observer agreement rate will be." Care planning for patients with chronic conditions, or suffering general frailty and who are in need of long-term care, is likely to suffer from this difficulty. Indeed, Koran's finding parallels that noted in part three of this study regarding decision making for home care: within this group of long-term care patients, the number of hours of care needed by the least ill and disabled patients were most difficult for professionals to agree

¹ Lorrin M. Koran, "The Reliability of Clinical Methods, Data, and Judgments," New England Journal of Medicine, Vol. 293, No. 13 (25 September 1975), pp. 642-646, and Vol. 293, No. 14 (2 October 1975), pp. 695-701.

² Carl V. Dunn and David W. Conrath, "Primary Care: Clinical Judgment and Reliability," New York State Journal of Medicine, Vol. 77, No. 4 (April 1977), pp. 748-754; see also, Robert H. Brook and Francis A. Appel, "Quality-of-Care Assessment: Choosing a method for Peer Review," New England Journal of Medicine, Vol. 288, No. 25 (21 June 1977), pp. 1323-1329; and Ward Casscells, Arno Schoenberger, and Thomas B. Graboys, "Interpretation by Physicians of Clinical Laboratory Results," New England Journal of Medicine, Vol. 299, No. 18 (2 November 1978), pp. 999-1001.

about.¹ Further evidence regarding inconsistent decisions by professionals working in areas removed from acute care is found in Liebman's review of disability determinations under federal income maintenance programs.²

Characteristics of patient's problems are not the sole influence on how well professionals agree with one another. Characteristics of professionals' training, experience, and information available may be expected to matter as well. It might reasonably be hypothesized, for example, that more and better information would be associated with greater inter-rater reliability, in that sources of uncertainty, requiring assumptions or guesses, would be removed. It is surprising, therefore, to learn that agreement about diagnosis or treatment in one study of ambulatory care did not improve as more information was provided.³

Other reasonable hypotheses are that professionals with similar training and experience, filling similar roles, are likelier to agree with one another. Inter-profession agreement is particularly important in long-term care, because, while many different professions' skills seem relevant to patients' problems, budgets are finite. In Chapters IX and X

¹ An interesting exception to this pattern, in the field of mental retardation, is reported by Priscilla Pitt Jones and Kenneth J. Jones, "Costs of Ideal Services to the Developmentally Disabled Under Varying Levels of Adequacy," Waltham, Mass.: Heller School, Brandeis University, 1 July 1976.

² Lance Liebman, "The Definition of Disability in Social Security and Supplemental Security Income: Drawing the Bounds of Social Welfare Estates," Harvard Law Review, Vol. 89, No. 5 (March 1976), pp. 833-867. Determinations are particularly important under SSDI and SSI because they are yes/no affairs. No gradations are possible, to provide a margin of safety against error.

³ Earl V. Dunn and David W. Conrath, "Primary Care: Clinical Judgment and Reliability," New York State Journal of Medicine, Vol. 77, No. 4 (April 1977), pp. 748-754.

of part three, the association of these variables with different levels of agreement about recommended hours of home care will be examined.

In an area related to inter-professional reliability, how well professionals agreed with certain standards, Shapiro found that more clinical experience was associated with better predictive ability.¹ Perrin and Goodman, in a study comparing ability of three groups of professionals to obtain appropriate information and make appropriate suggestions about therapy,² found that nurse practitioners generally did better than either house officers or practicing pediatricians. Further, more experience and training did not seem to be associated with house officers' performance.

Looking beyond long-term care and acute somatic medicine, it is of interest to note that Ennis and Litwack, in an evaluation of the reliability and validity of psychiatrists' judgment, argue that psychiatrists disagree so badly and predict outcomes so poorly that they should be denied any diagnostic, judgmental, or predictive role in civil commitment proceedings. Judges and juries "could function quite adequately...without 'expert' opinion."³

But how reliable are judges' views? Partridge and Eldridge report

¹ Alan R. Shapiro, "The Evaluation of Clinical Prediction," New England Journal of Medicine, Vol. 296, No. 26 (30 June 1977), pp. 1509-1514.

² Ellen C. Perrin and Helen C. Goodman, "Telephone Management of Acute Pediatric Illnesses," New England Journal of Medicine, Vol. 298, No. 3 (19 January 1978), pp. 130-135.

³ Bruce J. Ennis and Thomas R. Litwack, "Psychiatry and the Presumption of Expertise: Flipping Coins in the Courtroom," California Law Review, Vol. 62, (1974), pp. 693-752. See also, "Psychiatrists' Views Found Inconsistent," New York Times, May 30, 1978; and Earl V. Dunn and David W. Conrath, op.cit.

striking inter-rate dissimilarities in a study of 50 federal judges' hypothetical sentences of 20 defendants.¹ For example, large differences were found in lengths of prison sentences imposed in the same case; in 16 of 20 cases, judges were not unanimous in deciding if any prison sentence was appropriate; and no evidence was found that experience as a judge tended to moderate disparity.

Professionals, Patients, and Families. An examination has been made of the reliability of decision-making by professionals in home care, institutional long-term care for the elderly, other areas of long-term care, acute medical care, and other fields. Findings in these areas indicate that before professional views of the hypothetical cost of a home alternative to institutional care can reliably be compared with the cost of institutional care, differences in the consistency of those professional views should be examined,

Further, in the larger context, that of who should be permitted to control the allocation of home care and other long-term care resources, a finding that professionals' evaluations of patients' home care needs disagree considerably would seem to open the door to greater influence over resources by patients and/or families.

Using the terms presented by Bradshaw, disagreement among professionals would weaken the case for permitting standards of "normative need," experts' views, to prevail. Were this to happen, need felt or expressed

¹ Anthony Partridge and William B. Eldridge, "The Second Circuit Sentencing Study: A Report to the Judges of the Second Circuit, "New York: Federal Judiciary Center, August 1974.

by patients and/or families would seem more important. So too, might comparative measure of need: lacking a zero point, it might still be possible to decide who should have more help and who should have less.¹

In this regard, it is interesting to examine two contrasting findings. Keith identified a considerable divergence between elderly patients' and public health nurses' rankings of the importance of various services.² Nagi, by contrast, found high congruence between medical and self-assessment of disability in several types of activities.³ It will be of interest to learn which pattern will prevail in hypothetical home care planning.

Because who controls the allocation or planning of in home services may be imagined to affect the cost of that care and its effectiveness, it would be well to learn if professionals agree among one another about what is required to sustain an elderly person at home. Further, it would be well to learn if professionals, on average, agree with patients and their families. (When "agreement" shades off into "disagreement" must of course be decided.)

Section D now summarizes the argument to this point.

¹ Jonathan Bradshaw, "The Concept of Social Need," New Society, 30 March 1972, pp. 640-644.

² Pat M. Keith, "A Preliminary Investigation of the Role of the Public Health Nurse in Evaluation of Services for the Aged," American Journal of Public Health, Vol. 66, No. 4 (April 1976), pp. 379-381.

³ Saad Nagi, "Congruency in Medical and Self-Assessment of Disability," Industrial Medicine, Vol. 38, No. 3 (March 1969), pp. 27-36.

D. Summary of Part One

This chapter has been built on several of the earlier discussions in Chapter II. That chapter began by documenting the steady use in public long-term care spending in this country over the past 25 years. By placing nursing home use in the context of institutional long-term care generally, it noted that the high rate of increase in public spending cannot be attributed solely to the Medicaid program. Rather, high nursing home spending under Medicaid captures the effects of shifts in publicly-funded care from a variety of self-paid, voluntary, and local and state government efforts to a highly visible state-federal program. To a lesser but still important extent, high nursing home spending also captures the effects of increased utilization of institutional long-term care by the elderly.

Chapter II continued by noting the types of explanations for increased demand for formal, paid long-term care support and why this support has been delivered in this country principally in institutions. The reasons for increased demand for formal supports are most important. The epidemiologic and socio-demographic forces identified are likely to persist for the foreseeable future. Given that only a small percentage of older persons receive formal support at any one time, it is clear that a slight reduction in the proportion of older Americans able to reside at home, either independently or by means of the informal support of their families and friends, will result in a large proportionate increase in the number requiring formal support of some type. Thus, slow and barely visible changes in disability levels, in the age and sex composition of the elderly population, and in the availability or ability of families to provide help can have very considerable

impact on demand for publicly-funded formal supports.

After setting out the reasons why institutional settings for publicly-supported long-term care has been preferred, Chapter II described three of the arguments (quality, effectiveness, and choice) used by advocates of greater public funding for alternatives -- among them home care -- to institutional services. In the course of the discussion of effectiveness, the difficulty of measuring outcomes of long-term care was explained, along with some important consequences of this difficulty for policy and research. Chapter II closed by indicating the importance of better knowledge of the comparative costs of home care and institutional care to legislators and bureaucrats.

Chapter III has presented four methods for comparing costs of home and institutional care and has indicated some of the reasons why, together, they have not yielded conclusive results.

It has been argued that, in view of the difficulties both in controlling for initial characteristics of experimental and control groups and in measuring the outcomes of care in home and institutional settings, a method of "hypothetical diversion" might be a sensible method of uncovering useful information about comparative costs. It avoids entirely the problem of controlling for initial characteristics and, in a less satisfactory but still adequate manner (described in Chapter IV) controls for differences in outcome.

But since outcome or cost of home care cannot be observed and directly measured, because patients are diverted from institutional care only hypothetically, whose views of the types, quantities, and providers of needed

home care services should be accepted? Clearly, the costs and effects of home care depend on the services provided. Who really knows what patients need to live at home safely? In Chapter II, several of the arguments advanced by advocates of permitting patients and/or family members varying degrees of influence over the site in which long-term care is delivered. It was noted that generally they apply as well to influence over which services -- and how much of them -- are delivered in a given site.

Chapter III reviewed evidence on the reliability of professional views in several fields. This served several purposes. It suggested that professional reliability is not usually so good that it could be assumed that long-term care professionals would automatically agree well about the contents of hypothetical home care plans. Further, the special characteristics of long-term care suggest that consistency of professional views may prove particularly difficult to obtain. The review of the literature on reliability suggested also several variables which may be associated with greater or lesser agreement. This association will be examined in chapter IX of part three.

Lacking strong reasons for relying exclusively on patients', families', or various professionals' views of need, this study will seek to assess by two indirect methods the reasonableness of granting to the different parties control over the allocation of home care services.

Part two now presents the specific goals, methods, and history of the study.

P A R T T W O

STUDY GOALS, METHODS, AND EXECUTION

CHAPTER IV

DESIGN OF THE STUDY

A. Introduction

This chapter sets out the goals of the study and the methods by which it was planned to execute them. Modification of certain methods, discussed in chapter V, became necessary in several areas. These modifications, while obliging changes in some plans for analysis and weakening the strength of other analyses, basically left intact the structure of the study as originally intended.

Diversion is a theme which runs through several aspects of long-term care policy and research today. The present study was planned during the spring of 1976. At that time, there was a considerable amount of interest in the U.S. Congress¹ in expanding public funding for home care benefits. Proposals to increase the scope of home care services under Medicare and Medicaid were particularly numerous. Many bills called for Medicare and Medicaid to go beyond their traditional emphasis on skilled, medically related services and offer coverage of social, personal care services. Many advocates of home care were concerned about the costs of a new public program. In the 94th Congress, one approach considered was that of authorizing an expansion in the range of non-medical home care services to include homemaker, personal care, and other non-technical services only to those older citizens who faced

¹Over 80 pieces of legislation to expand home care benefits had been filed in the 94th Congress. Letter to this writer from Ms. Janet Kline, Legislative Analyst, Education and Public Welfare Division, Congressional Research Service, Library of Congress, 5 March 1976.

institutionalization, and for whom home care would cost no more than institutional care about to be delivered.¹ In effect, this approach was designed to allow a marginal increase in freedom of choice of site of long-term care for those about to enter nursing homes, while attempting to hold harmless federal and state fiscal liabilities. (It is acknowledged that such a policy presents several problems. For example, efforts to control costs would have failed if large numbers of older Americans suddenly presented themselves as candidates for nursing home care only in the ultimate hope of receiving non-technical home care services.)

This particular legislative strategy, permitting more generous federal funding of home care benefits for patients about to enter nursing homes, if the cost of home care were no greater than that of institutional care, parallels the method for comparing the costs of home and institutional care derived in chapters II and III. The method is appropriate for estimating the costs per person of such a new home care benefit. Cost estimation via hypothetical diversion is a sensible way to evaluate the costs per person of real diversion.

Hypothetical diversion is desirable in that it avoids the problem of controlling for initial patient characteristics and can deal with the problem of measuring outcomes. Further, it relies on the real-world costs of institutional care, delivered by an established industry, but

¹Pertinent bills in the 94th Congress were Representative Pike's H.R. 4869, Representative Koch's H.R. 10422, and Senator Bentsen's S.2591.

deliberately does not take as given the real-world costs of home care. Home care, in most parts of this country today, is not well coordinated. Physician, home health, and social services are fragmented. In many areas, vital services are not available. Daily service around the clock often cannot be obtained. Finally, until outcomes can be measured, we will really not know with confidence what services people require to live at home safely. Without this knowledge, comparisons of the cost of in-home and institutional care are extremely difficult to conduct.

Therefore, if the hypothetical costs of home care are to be compared with the real costs of institutional care, it must be decided whose views of types, quantities, and providers of home care--and therefore its cost--should be employed.

Patients, families, or various professionals are the logical candidates. Each offers advantages. For patients, influence or control over care planning may be good in itself, in that greater choice about services, at a time of declining autonomy in other realms, may directly improve health, functional ability, or morale. Further, most services are non-technical, so patients may know themselves and their needs best, and perhaps can be trusted to request only those services needed.

Families, alternatively, may be more able to be objective about patients' needs. Especially if they reside with the patient, they will be familiar with his or her needs. In addition, if families are providing help prior to receipt of formal support, it will be most important that they are content with the level of that support, or they

may refuse to continue their share of the burden.

There are several arguments in favor of professionals as decision makers in home care: they may be trusted to be objective; by virtue of training and experience they can both supply technical information when needed (about rehabilitation potential and techniques, opportunities for training for independence, need for medical monitoring or special nursing procedures, and the like) and, make the inter-patient comparisons necessary to equity.

Control by members of each group also carries, in theory, possible disadvantages. Because the non-technical home care services could be attractive in themselves to many patients, they might demand inappropriately high volumes of help. Consequently, costs would be higher than necessary. Well-being could suffer also if patients become avoidably dependent and passive. (Some patients might prefer passivity; inappropriately placing values on "objective" behaviors and outcomes in long-term care is all too easy.) Alternatively, patients might err in the other direction, and seek less than needed to permit them to live at home safely. Being unduly optimistic, they might suffer harm. Patients might find it difficult to gauge how much care is actually required to accomplish what they desire.

Families, given control, might seek more than the help needed to support their own efforts and thereby slough off onto paid providers' jobs which they could reasonably be expected to continue to do.

Finally, professionals might inappropriately assign too high a proportion of home care effort to skilled curative services and too little effort to supportive caring services. They might dispute boundaries of control: In which areas of home care are nurses expert? physicians? physical or occupational therapists? social workers? What if they disagree markedly within or across lines of training? Who then should control the allocation of in-home services? Perhaps professionals might in general be too cautious or too prone to take risks. If so, how might it be decided which is the case?

B. Goals

The goals of the present study emerge from the considerations just discussed. If for political reasons a policy of more generous funding for home care services were chosen, on the condition that only patients for whom home care was no more costly would be eligible; and if, for reasons of method, there are advantages to learning the costs of a hypothetical alternative to institutional care; then a base is necessary on which to estimate the cost of the in-home services. Many possible candidates could be asked their views of the cost of home care for people about to enter nursing homes. This study seeks the recommendations of most of the potential candidates.

This study has four principal goals. They are now presented and the techniques of analysis used to reach them in part three are sketched. Plans for gathering the data which serve as grist for these techniques are described in the next section of this chapter.

Goal I is to learn the extent of agreement among patients, their families, and various professionals about the types, quantities, and providers of hypothetical home care services needed to sustain patients--individually and collectively--at home. This is done by examining closely the service requests of members of the three groups. Results are not presented in the same order as goals in the interest of enhancing comprehensibility of the findings. Goal I is taken up in Chapter VIII.

Goal II is to assess whose views of home care need seem more valid, should patients, their families, and professionals disagree about needed services. This goal will be pursued in two ways. First, correlation and multiple regression will be used to gauge the relation of objective patient characteristics to the types of services recommended by members of the three groups (chapter VIII). Second, the extent of agreement among professionals themselves will be explored. The term "agreement" itself will be examined from a variety of directions. Analysis of variance, Kendall's W, Cronbach's Alpha, and factor analysis--supplemented by descriptive statistics--will be used to gauge the extent of agreement within and across professional lines (Chapter IX).

Goal III is to learn how the various views of hypothetical home care cost compare with the actual cost of institutional care, and what

proportion of the patients could be cared for at home at no greater expense. Further, by applying savings, achieved through diversions of some patients to home care, to subsidizing other patients for whom institutional care is marginally cheaper, how many could be maintained at home with no increase in system cost (chapter VII)?

Goal IV is to learn more about both long-term care policy and planning for individuals' needs by mining the by-products of data generated to reach Goals I-III. The data suggest opportunities for establishing a cooperative model for home care planning, incorporating views of patients, families, and professionals. It appears that the cost of care plans generated through such a model would be reasonable and affordable (chapter X).

Disagreement about the control or influence of dependent older persons, their families, and various professionals over long-term services has been in part a product of uncertainties about the goals of those services, their costs and effects, and the legitimacy of professional knowledge. These uncertainties interact. For example, if the principal goal of long-term care is to maximize longevity, physicians and/or related professionals might be best able to allocate funds. Should these professionals disagree about allocation, or should they agree but their prescribed services prove of little effect, the legitimacy of their control over resources is called into question.

Alternatively, patients, families, and professionals might begin with different goals. In a particular case, the patient, understanding

her condition to be terminal, might choose to live at home in relative comfort and reject life-prolonging interventions. Her family might be unwilling to continue to care for her at home and therefore prefer immediate nursing home entry. The patient's physician might argue for aggressive therapy and rehabilitation in hospital. Full real costs or benefits of any choice are not borne by, or even visible to, any party. To decide who should have the right to choose setting or type of care involves medical, ethical, legal and social considerations. What, for example, is a patient's right to choose home care if her family cannot provide it and adequate formal supports are not available? What should a hospital do when its continuing care department believes home care to be unsafe but a patient declines to enter an institution? What are the rights of patient, family, and physician to seek care that is very costly, when funds are limited?

Depending on the goal(s) of long-term care for a particular person, the patient, family, or one or more professionals can be supposed best able to allocate available resources to reach the chosen end(s). Today, given poor articulation of goals, various restrictions on spending, and setting of care, and often such exigencies as the need to empty a hospital bed, professionals generally choose sites and quantities of care usually after little consultation with patients.

Possibly, better goal articulation and cooperative planning should not even be pursued if costs are likely to preclude real choice. This would be regrettable because greater autonomy in long-term decision

making is important to aged persons, particularly to those whose freedom of action generally is contracting. Given the non-technical nature of most long-term care services, the potential for a greater measure of consumer sovereignty certainly exists. Should the three groups disagree, devices are needed to reconcile patient, family, and professional preferences and budget limits.

To help lay a firmer foundation for home care planning for individual patients, the following information should prove to be of help: data on the characteristics of patients about whom professional agreement is relatively good or bad; on which patients are thought to need more or less home care; on which services and providers agreement is best; and on which services and providers are thought most useful for which patients by which professionals. Finally, the effects of various types of information on professional prescriptions is measured in the hope that it will shed some light on what constitutes appropriate care planning and utilization review procedures (Chapters VIII and IX).

Absent outcomes measures and given the widespread belief that the long-term care system works badly (care is inefficient and of low quality, fraud is common, patients are misplaced, outcome is poor), a better care planning process--one which seems equitable, reasonable, and reliable--may help to convince legislators and bureaucrats that higher appropriations for long-term care in general and for home care in particular would not simply amount to "throwing

money at problems."¹

C. Study Methods

The method adopted by the present study was to identify a group of patients about to enter nursing homes. There would be no interference in placement or provision of services. These patients would be admitted into nursing homes. The average per diem costs of their institutional care would be measured. But, before entering nursing homes, they would receive a full functional, medical, and psychosocial assessment. Based on this assessment and other information, a group of health and social services professionals--physicians, hospital discharge planners, and home health agency care planners--would individually design detailed home care plans for each patient included in the study.

Data-gathering was planned to be accomplished in four phases. These were to: (1) compile the study sample at four Massachusetts hospitals, (2) assess patients, (3) interview patients and a member of their families, and (4) obtain professional home care plans.

¹It is believed, in sum, that these goals would, if attained, help respond to many of the concerns raised in Anthony Lenzer and Avedis Donabedian, "Needed...Research in Home Care," Nursing Outlook, Vol. 10, No. 10 (October 1967), pp. 42-45.

The sample. A total sample of 100 patients was sought for the study: 30 from a Boston-area teaching hospital, 20 from a Boston-area community hospital, 20 from a teaching hospital elsewhere in the state, and 30 from a community hospital elsewhere in the state. These proportions were based on those types of hospitals' 1975 share of total Massachusetts total acute hospital discharges by institutions of 150 beds or more. Hospitals were to represent only this class of institution because, it was felt, only large facilities could generate the volume of discharges needed to complete the sample in adequate time. Of all patients admitted to nursing homes in 1973-1974, 34.8% had "resided" in acute care hospitals before entry into the home.¹ The study sample, therefore, represents this group, allowing for differences in types of patients cared for at large versus small hospitals.

Hospitals were to be selected on several grounds. The first was their location and type of facility. The second was whether they seemed typical of their class. A hospital specializing in care of a certain type of illness had to be excluded. The third was whether the pertinent staffs and boards of the hospital were willing to grant permission. For the Boston area hospitals, a fourth criterion was added, that the facilities be convenient to consultants who would be briefly visiting patients.

¹National Center for Health Statistics, "Characteristics, Social Contacts, and Activities of Nursing Home Residents, United States 1973-1974," National Nursing Home Survey, Vital and Health Statistics, Series 13, No. 27 (May 1977), Washington: USGPO.

The screening process. To be included in the study, patients had to meet several requirements. First, they had to have resided in the "community," not in an institution, prior to the hospital admission. This condition was set to assure that, when interviewed about their own home care service requirements, patients had a recent source of information about those requirements.

Patients about to enter nursing homes from the community were preferred to patients already in institutions for another reason. The former plan would be likelier to better mimic real-world policy conditions--making available home care services for patients about to enter institutions. It is relatively difficult to deinstitutionalize older patients who have lived for a long time in nursing homes and lose their housing and other roots in their neighborhoods.¹

Second, the discharge planner--social worker or continuing care nurse--in the hospital had to decide that the patient would be discharged to a long-term care facility--rehabilitation hospital, chronic disease hospital, skilled nursing facility, intermediate care facility, or rest home--for a stay of not less than two months. (The stay in a first facility could be less than two months, if it was expected that the patient would subsequently be discharged to another long-term care facility, yielding a stay in both institutions of over

¹On the difficulties of deinstitutionalization, see Barry Siegel and Judith Lasker, "Deinstitutionalizing Elderly Patients: A Program of Resocialization," The Gerontologist, Vol. 18, No. 3 (June 1978), pp. 293-300.

two months.)

Third, the patient's physician was asked to permit participation in the study. No patient was approached and asked to participate without this permission. Fourth, the hospital discharge planner was asked to decide if the patient was competent to understand the nature of the study, respond to questions, and give informed consent. Patients judged not competent were not approached.

Fifth, the hospital discharge planner was asked to decide if the patient could cope well enough with the emotional stress of thinking about home care, at the time of discharge to a long-term care institution, to permit participation in the study. Patients judged unable to cope were excluded. Finally, patients and the members of their families who knew the patient best (the "caregiver") were approached separately and asked if they were willing to participate in the study. Consent was desired from both patient and caregiver, because each would be interviewed.

Because delays arose in the course of executing this plan, changes were made in the type of patients who could be included, the hospitals they were drawn from, and the size of the sample. These delays, and the reasons for them, will be discussed in chapter IV. The remainder of the study design, which now follows, was not modified.

Patients who were excluded from the study for any of the reasons noted above were not ignored. The reason(s) for their hospital admissions, their medical diagnoses and disabling conditions, their

known hospital and long-term care facility admissions, their socio-demographic characteristics (age, sex, race, ethnicity, religion, education, marital status, living arrangement, occupation, and employment status) were recorded. Based on this information, it was possible to measure how similar the study sample--those screened into the study--is to those screened out of the study; see chapter VI.

The patient assessment form. Once a patient was included in the study, an assessment form was completed. This included, in addition to the data just described, information about the patient's: (1) functional ability to manage activities of daily living (walking, transferring, dressing, bowel and bladder function, and the like); (2) independence in such instrumental activities of daily living as shopping and housework; (3) architectural barriers in the home; (4) composition of household; (5) capacity of informal support system; (6) psychosocial characteristics; (7) impairments and limb motion; (8) abnormal medical signs; (9) medications; (10) special nursing procedures; and (11) special personality, family, cultural or other characteristics.

The purpose of the assessment form was to assemble objective data about patients, to be used by consulting professionals as the base on which to design home care plans. Summary data were not presented to consultants, only information observed about patients in hospital, recorded from their medical records, or reported by them and/or their families.

Uninterpreted, objective data were presented to professionals to provide a common base for planning individual patients' services. In this way, one potential source of disagreement regarding needed services, patients' characteristics, would be eliminated. Nonetheless, three other sources of disagreement remain. This should be borne in mind when interpreting the meaning of the levels of agreement reported in chapters IX and X.

Given knowledge of patients' history and current status, professions might differ in their views of prognosis absent services.¹ Given agreement about status and prognosis, choice of different goals could lead to service packages of varying size or composition. Finally, even given unanimity about status, prognosis, and goals, professionals might still differ in their estimation of the efficacy of various services and, therefore, in recommended types, quantities, or providers of care.

The patient assessment form is a version of the patient appraisal and care evaluation (PACE) form. The form was adapted to home care planning by the addition of information about architectural barriers, household composition, and similar variables.² The advantages of the

¹Robert H. Brook and Francis A. Appel, "Quality-of-Care Assessment: Choosing a Method for Peer Review," New England Journal of Medicine, Vol. 288, No. 25 (21 June 1973), pp. 1323-1329; and Margaret W. Linn, Lee Gurel, and Bernard S. Linn, "Patient Outcome as a Measure of Quality of Nursing Home Care," American Journal of Public Health, Vol. 67, No. 4 (April 1977), pp. 337-344 offer evidence on disagreement about prognosis.

²The PACE is the product of collaboration among workers at four universities. See Ellen W. Jones, Barbara J. McNitt, and Eleanor M. McKnight, Patient Classification for Long-term Care: User's Manual, Department of

PACE form were thought to be several. First, it seemed at the time that the PACE was going to be extensively used to evaluate federally supported long-term care programs. Study data would, therefore, be comparable with those of large-scale efforts. Second, it presented data about patients in discrete, undigested form, allowing professionals to assimilate information as they wished. Finally, the bulk of the information would be observed and recorded by health care and social service professionals who were well acquainted with patients. The PACE form was designed to perform many functions, among them research. It seems to fill most of the general requirements for good assessment forms.¹

Several other assessment vehicles were reviewed before the PACE was selected. The one given most serious consideration was the Older American Resource and Services (OARS) inventory.² The OARS form had several important assets. It was carefully developed with extensive support, and it appeared likely to be used in a variety of research

Health, Education, and Welfare Pub. No. HRA 74-3107 (Washington, D.C.: Bureau of Health Services Research and Evaluation, December 1973).

¹These requirements are described in: Institute of Medicine, The Elderly and Functional Dependency: A Policy Statement (Washington, D.C.: National Academy of Sciences, June 1977), pp. 16-17; M. Lawton Powell, "The Functional Assessment of Elderly People," Journal of the American Geriatric Society, Vol. 19, No. 6 (December 1971), pp. 465-481.

²Eric Pfeiffer, ed., Multidimensional Functional Assessment: The OARS Methodology (Durham, N.C.: Duke University Center for the Study of Aging and Human Development, 1975).

settings--as indeed it has been.¹ Further, the reliability and internal validity of its components were being measured, and they appeared high. The OARS was ultimately rejected because, first, most data had to be obtained from the patient. It was felt that, under the patients' circumstances in this study, too much time would be demanded. Also, to obtain so much data directly from patients might weaken its validity.² Second, the OARS seemed more applicable to a population less ill and disabled than that expected to be included in this study's sample: little detailed data on medical status or nursing deeds were called for. Third, it was feared that the OARS was not compact enough to permit the study's consultants to review its raw data in detail, in sufficient time to make its use economical.

After data collection for the present study was completed, findings were reported which suggest that medical records, an important source of certain PACE data, are inadequate in some respects. While this presents some difficulty for the present study, the problem is not serious because care plans are only hypothetical. To rely on similar sources for real-world care planning presents the danger of

¹Duke University Center for the Study of Aging and Human Development, Multidimensional Functional Assessment: The OARS Methodology (Durham, N.C.: The Center, 1978), Appendix C.

²Janet Plant, "Various Approaches Proposed to Assess Quality in Long-Term Care," Hospitals, Vol. 51, No. 17 (September 1977), pp. 93-98.

harming patients by providing them with too little care or too much.¹

Patient and caregiver interviews. The second source of data acquired for the study was to be obtained by conducting separate interviews with patients and with their principle "caregivers." The latter was the family member, friend, or neighbor who would help the patient the most, and who was consequently familiar with his or her needs.

In view of the apparent importance to well-being of older people of ability to make decisions for themselves, it was thought useful to ask patients, hypothetically, what services they would need to live at home in a "safe, adequate, and dignified" manner. Such questions go beyond patient choice about site of care; they open the door to learning more about how older people regard their needs for service. If patients' control over setting of long-term care is judged important, it seems reasonable to consider control over level of service to be important as well.

It was thought useful to learn several things. First, in what areas did patients see themselves as needing help? Patients would be asked, service by service, for 41 separate areas, whether they needed assistance and, if so, how many times per week they would need that help. These services included several in the area of personal

¹Linda K. Demlo, Paul M. Campbell, and Sarah Spaght Brown, "Reliability of Information Abstracted from Patients' Medical Records," Medical Care, Vol. 16, No. 12 (December 1978), pp. 995-1005.

care, such as bathing and dressing; several housekeeping services, such as cooking and cleaning; a range of nursing services; and a set of medical and therapeutic services. A full list of all services is appended to this chapter. In addition, patients were asked how many times per week they thought an unpaid provider would be able to render assistance in each service area. The difference between the total number of episodes of help sought and the number of unpaid episodes would be the number of paid episodes for which formally organized services would be required.

Based on these data, comparisons could be made between patients, between patient and caregiver, and among patient, caregiver, and professionals regarding the types of services where help was thought necessary, how many episodes were requested, and the breakdown of requests into paid and unpaid help. Similar comparisons could be made for total episodes of help sought and for each of the four categories--personal care, housekeeping, nursing, and medical-therapeutic--just mentioned.

Patients' views were sought for several reasons. If patients were to have some sovereignty as consumers of long-term care services, it would be useful to compare what types of help, and how much they thought necessary, with the views of caregivers and professionals. This would make it possible to compare, in a rough way, the potential costs of the help requested by patients with that thought necessary by caregivers or professionals.

Episodes of help were the only items requested from patients or family members. Professionals were asked as well to indicate the duration of each episode and the preferred provider(s) of care. In this way, the cost of professional plans could be estimated with fair accuracy, but professional-caregiver-patient plans could be compared only using episodes. (This decision was made to shorten the interview with patients and caregivers to 15-20 minutes to reduce stress on them.)

If, for example, patients requested many more episodes of help than did caregivers or professionals, it might be feared that the costs of providing the care sought by patients would be unjustifiably great. The reverse is also possible. Patients might request fewer hours of care than other groups thought necessary. It could then seem that patients were too overconfident about their ability, or too self-denying; or that the other groups were too pessimistic about patients' capacity to care for themselves. In this case, if patients were to have control over service, total cost would be reduced.

Agreement among patients, caregivers, and professionals would, as a signal of reliability, induce confidence that the services requested were the services needed. Reliability points to validity. This is not enough to insure validity, but without it, validity (or confidence that selected services would be effective services) is impossible. If there is disagreement among patients, caregivers, and professionals, it must be decided who should be permitted to allocate

services. There are several goals to try to reach in making this decision. They include the importance of choice itself to many patients; the need to support caregivers, to sustain their efforts; and the desire to provide the services which will do the most to enhance medical, functional, and emotional well-being of the patient. Patient, caregiver, and one or more professionals, respectively, might be thought the best decision makers.

In sum, patients were interviewed to learn what services they thought they needed to live at home in a safe, adequate, and dignified manner. The volume of help they sought--paid and unpaid--would be compared to that prescribed by other groups. Caregivers were to be interviewed for many of the same reasons as were patients: to learn their views of patients' needs, and to be able to compare these views with those of patients and professionals. In particular, caregivers were thought best able to gauge the availability, ability, and willingness of unpaid, informal supports to provide help. Congruence between patients' and caregivers' views would be examined to learn if they agreed in their estimate of the number and proportion of total hours which informal supports might provide.

Professional care plans. Each of eighteen professionals was asked to write a detailed care plan for each patient in the study sample. The care plan was designed to be completed service by service and provider by provider, to avoid inducing professionals to overlook services which

they believed necessary to patients' well-being. For each service, such as bathing, meal preparation, supervision of medications, or physical therapy, the professional was asked to indicate: first, whether the patient required the service; second, how long it would take to provide the service on average on each occasion; third, the total number of episodes per week (or month) the service would be needed; and fourth, who should provide the service and how often. A separate care plan was sought for each of two successive three-month periods following hospital discharge.¹ This would yield an estimate of the types, quantities, and providers of services thought necessary for the patient to live at home in a safe, adequate and dignified manner.

When first conceived, the study design was to have each professional prepare three separate care plans for each patient. The first was to be an optimal plan, containing all the services from which the patient might be expected to benefit. The second was to be a plan designed to approximate in its effectiveness the care the patient could be anticipated to receive in an institution of average quality which offered the level of service the patient was expected to require at discharge. The third was to be a minimal plan, containing the fewest possible services necessary to safety. The cost of preparing, editing,

¹To ask professionals to look forward six months seemed reasonable. Happily, it has been learned that this estimate coincides with that of Margaret W. Linn, et al., op. cit. No validation of the reasonableness of choosing this duration is yet available.

key-punching and computing all these data made it necessary ultimately to reduce to one the number of plans sought. It was decided to set as the standard for the hypothetical prescriptions that level of service which the professional thought would yield "safe, adequate, and dignified" home care.

It was realized in defining this level for home care that the ability directly to compare the costs of home and institutional care of equal effectiveness would be reduced. The decision was made in this way: since it was possible to obtain only one home care plan, the optimal plan was discarded as extravagant; the minimal plan did not seem to provide a decent level of care. This left home care of effectiveness equal to that of nursing home care. This plan, alone, did not seem adequate. It required professionals first to decide the effectiveness of institutional care and then to design an equivalent home care package. It was thought that this might be difficult to do. Further, the resulting care plan might bear no strong relation to patients' real service needs. It is believed that the goal "safe, adequate, and dignified" constitutes a standard at least as effective as care in the average nursing home. Further, the detailed and painstaking procedure required to complete the care planning form itself was devised to help prevent professionals from omitting needed services.

For these reasons, it was decided to set as the standard for home care the services which each professional thought necessary to enable the patient to live at home in a safe, adequate, and dignified manner.

The comparison of the costs of home and institutional care would be attacked indirectly, in the manner described in chapter VII.

In asking the professionals to write care plans, it was assumed that any patient could be safely cared for at home, given appropriate care. All conceivable goods or services could be hypothetically brought into the home. It was up to each professional to prescribe the types and quantities and providers of services necessary to care for the patient in a safe, adequate, and dignified manner. Drugs, appliances, supplies, and equipment were omitted from the care plan. It was assumed that these would vary directly with needed services, and a cost equal to 5% of the cost of services was included in calculating the total cost of home care.

As originally conceived, the project would employ nine consultant professionals. Each would prepare a care plan on each of 100 patients. Three of the professionals would be physicians of different specialties; three would be hospital discharge planners; and three would be home health agency care planners. The latter six would, it was hoped, be evenly split between nurses and social workers. Members of different professions, carrying out different roles, were sought because each was thought to have an important perspective on patients' needs. It was desired to know how well the three groups--physicians, nurses, and social workers--agreed with one another about patient needs. Two sorts of comparisons were sought: intra-profession (how well physicians agreed with one another, for example) and inter-profession (how well

physicians agreed with discharge planners, for example). In the subsequent analyses, role, rather than training, is the variable most frequently used to divide professionals from one another.

It has been desired throughout to obtain from each care planner his or her own, independent views of patient needs. While it might be argued that each sort of professional should be considered expert in his or her field,¹ the present study treats this argument not as given but to be investigated. For example, according to Berg, et al.:

The decision as to what health care is needed is generally regarded as the physician's responsibility, but he may not always be well informed regarding the availability of the needed services in different settings. In particular for the chronically ill or disabled patient who does not require institutional care, nurse observers can often judge the supervision of services required as well as or better than physicians.²

¹Kathleen Connelly, Philip K. Cohen, and Diana Chapman Walsh, "Periodic Medical Review: Assessing the Quality and Appropriateness of Care in Skilled-Nursing Facilities," New England Journal of Medicine, Vol. 296, No. 15 (14 April 1977), pp. 878-880. On the advantages of team planning generally, see Sidney Katz, Laura Halstead, and Mary Wierenga, "A Medical Perspective of Team Care," in Sylvia Sherwood (ed.), Long-term Care: A Handbook for Researchers, Planners, and Providers (New York: Spectrum, 1975); John E. Schuman and Harold N. Willard, "Role of the Acute Hospital Team in Planning Discharge of the Chronically Ill," Geriatrics, Vol. 31, No. 2 (February 1976), pp. 63-67.

²Robert L. Berg, Francis E. Browning, John G. Hill, and Walter Wenkert, "Assessing the Health Care Needs of the Aged," Health Services Research, Vol. 5, No. 1 (Spring 1970), pp. 36-59; they cite R. Walker and C. Frost, "Measurement of Social Restoration of the Mentally Ill by the General Adjustment and Planning Scale," Health Services Research, Vol. 4, No. 2 (Summer 1969), pp. 152ff.

It was decided in the course of the present study that, given the range of problems borne by patients in need of long-term care, it would be a useful exercise to attempt to learn whether different professionals indeed tended to be more consistent in their views of needs in the areas falling within their own fields of specialization--or whether all professionals tended to agree equally well across all needs.

In addition to the team approach to care planning, which follows from acceptance of the specialization argument, a Delphi approach to planning was considered and rejected.¹ Again, it was desired to learn the views of the individual professionals now practicing. It should be noted that some professions whose views of patient need are most important (such as physical or occupational therapists) were excluded from the sample simply in the interest of achieving a number of each group included sufficient to permit useful analysis of differences within professions and average across professions. When it became possible to expand the sample of professionals, it was decided to vary the information available for care planning rather than the number of

¹Rachel M. Rosser, "The Reliability and Application of Clinical Judgment in Evaluating the Use of Hospital Beds," Medical Care, Vol. 14, No. 1 (January 1976), pp. 39-48; see also the comment and reply in Medical Care, Vol. 15, No. 6 (June 1977), pp. 527-531. For an exciting use of a mechanized Delphi incorporating clinical judgment and empirical observations, see Richard M. Burton, William W. Damon, and David C. Wellinger, "Estimating the Impact of Health Services in a Community," Behavioral Science, Vol. 21 (1976), pp. 478-489.

professions.

Each of the nine original professionals was to rely only on the PACE form in prescribing home care. When the opportunity arose to double the sample of professionals, it was decided at the same time to test the effect of the type of information available to professionals on the prescribed types, quantities, and providers of services. Before writing their care plans, six of the additional prescribers would, at the Boston area hospitals only, review the PACE forms and then briefly (for five-ten minutes) visit each patient just prior to hospital discharge. Two of the six were physicians, two were hospital discharge planners, and two were home care planners. Because these professionals would visit only the patients at the Boston area hospitals, the nature of their care plans could be compared with those of the nine who never visited, to distinguish the effect of visiting from the effect of their individual characteristics as professionals. Dunn and Conrath found that reliability of professional views seemed independent of information levels.¹ It was desired here to see if reliability and validity in home care planning varied with information.

Three additional professionals who knew individual patients well were also asked to write care plans. These were each patient's own physician, discharge planner, and primary care or floor nurse. They were asked to rely on the PACE and their own detailed knowledge of the

¹Dunn and Conrath, op. cit.

patient. Each of these three professionals would be expected to write only a few care plans: physicians and floor nurses might prepare one or two; discharge planners would prepare one for each of their patients screened into the study. By contrast, each of the other fifteen professionals would write a plan for each patient. The fifteen are referred to as "consultants," "visitors" (six), or "non-visitors" (nine). The remaining three are called "hospital care planners."

Figure IV-A presents an overview of the care planning process. It indicates that some patients were visited, that others were not, and that recorded on the PACE form were data describing each individual.

Of the fifteen consultant professionals, nine relied exclusively on PACE data for all patients; six other consultants visited some patients but relied exclusively on PACE data for the others. The three hospital professionals used PACE data and their own personal knowledge in all cases. The data recorded in each plan were analyzed in total (hours, episodes, and costs of care) and in detail by type of service and by type of provider. These various subtotals will be explained in part three.

In the remainder of this part, chapter V describes the execution of the study and sets out modifications in method adopted in response to opportunities and obstacles which appeared in the course of data-gathering. Chapter VI then takes up the composition of the study sample and discusses its representativeness.

FIGURE IV-A
A SCHEME OF THE CARE PLANNING PROCESS

Patients (50)
(described by PACE variables)

visited (16) not visited (34)

Role	Information Available to Professionals				=	Total
	Consultants		+	Hospital		
	Non- Visitor	+ Visitor	Sub- Visitor	Workers		
	= Total					
Physician	3	2	5	1		6
Discharge Planner	3	2	5	1		6
Home Health	3	2	5			5
Floor Nurse				1		1
Total	9	6	15	3		18

Care Plans (900)

^aBy Services (41) and Service Subtotals (4); Providers (58) and Provider Subtotals (10).

^bBy hours; costs (\$); and episodes.

APPENDIX TO CHAPTER IV

THE FORTY-ONE SERVICES

Personal Care

Caregiving/Supervision--continuous
Periodic checking
Bathing
Dressing
Toilet
Transferring
Supervision of medication
Turning in bed
Grooming
Eating & drinking

Household

Shopping
Meal preparation
Telephone
Transportation
Socialization
Light housework
Heavy housework
Laundry
Management of personal affairs

Nursing

Bowel/Bladder training
Decubitus care
Wound care
Eye care
Bladder irrigation
Suctioning/chest PT
Inhalation/IPPB therapy
Other oxygen therapy
Range of motion exercises
Nutritional/Diet exercises
Medications administered
Monitoring of vital signs
Mental & neurological status
Foot care
Teaching--other
Nursing--other

Other Professional Services

Primary medical care
Medical specialist care
Dentist
Podiatrist
Physical therapy
Occupational therapy
Psychotherapy/Counseling

APPENDIX TO CHAPTER IV
CATEGORIES OF PROVIDERS

PAID PROVIDERS

MEDICAL

M.D.-Primary (G.P., F.P., Internist)

M.D.-Specialist

Dentist

Podiatrist

NURSING

Registered Nurse

Licensed Practical Nurse

Nurse Practitioner

Physician's Assistant

Psychiatric Nurse Clinician

PERSONAL CARE

Homemaker

Home Health Aide

Homemaker/Home Health Aide

Personal Care Attendant

Orderly

SUPPORT

Social Worker

Escort Service

Sitting Service

Daily Checking Service

Visiting Aide

Community Geriatric Coordinator

Community Mental Health Worker

Companion

Lawyer

THERAPY

Inhalation Respiratory Therapist

Physical Therapist

Physical Therapy Aide

Occupational Therapist

Occupational Therapy Aide

Recreational Therapist

Dietician

Dietary Aide

Speech Therapist

Laboratory Technician

MISCELLANEOUS

Home Delivery (groceries, etc.)

Meals-On-Wheels

Laundry/Diaper Service

Heavy Chore Service

Cleaning Agency

Ambulance

Medicab

Redi-Van/chair car

Hairdresser

Talking Books

UNPAID PROVIDERS

RESIDENT

Family

Friend

NON-RESIDENT

Family

Friend

Clergy

Friendly Visitor

Transportation service- e.g. Minibus for Senior Citizens

Building Superintendent

SKILLED PROVIDERS

M.D.-Primary (G.P., F.P., Internist)
M.D.-Specialist
Dentist
Podiatrist
Nurse Practitioner
Physician's Assistant
Psychiatric Nurse Clinician
Registered Nurse
Licensed Practical Nurse
Lab. Technician
Social Worker
Inhalation/Respiratory Therapist
Physical Therapist
Occupational Therapist
Recreational Therapist
Dietician
Speech Therapist
Clergy
Lawyer

UNSKILLED PROVIDERS

Homemaker	Redi-van/Chair car
Home Health Aide	Ambulance
Homemaker/Home Health Aide	Medicab
Personal Care Attendent	Meals-on-Wheels
Orderly	Laundry/Diaper Service
Escort Service	Heavy Chore Service
Sitting Service	Cleaning Agency
Daily Checking Service	Building Superintendent
Visiting Aide	Hairdresser
Friendly Visitor	Talking Books
Home Delivery Service	Community/Mental Health Worker
Community Geriatric Coordinator	Companion
Physical Therapy Aide	
Family- resident	
Family- non-resident	
Friend- resident	
Friend- non-resident	
Transportation Service- e.g. Minibus for Senior Citizens	

Chapter V

EXECUTION OF THE STUDY

Data gathering was planned to be conducted in six steps: designing forms, introducing the study in hospitals, orienting consultants, screening patients, completing forms, and managing information. Five of these proceeded as expected. The other, screening patients into the study, took much longer than expected. Consequently, certain aspects of the design had to be altered, even though these changes would affect somewhat the analyses planned. This chapter briefly sets out data gathering plans, discusses problems encountered and how they were overcome, and indicates how changes in design affected the methods and products of analyses.

A. Designing Forms

The PACE form required a certain amount of adaptation to enhance its utility to home care planning. A copy of the revised form appears in Appendix B. Additional space was provided to record medical diagnoses. A new section on major disabling conditions and their dates of onset was added. The patient's anticipated site of discharge was indicated, along with expected length-of-stay at that site. No changes were made in material on functional ability. A new section on instrumental activities of daily living was included. To learn patients' needs for assistance in mobility, inquiry into the presence of stairs and other barriers in the

home was made.

Information was requested on the composition of patients' households prior to hospitalization and the hours when family or friends were available in the home. This was followed by the assessment by the discharge planner of the ability and willingness of the family or other informal support to care for the patient in either their home or the patient's home. The PACE's sections on psychosocial functioning and impairment were retained with minor changes. Granger's criteria for evaluating active limb motion were added.¹

The section on medical status was expanded to leave room for many possible abnormal and normal test results and findings. Purpose of medications was sought. The nursing procedures section was enlarged to include space for recording what teaching had been done. For both medications and nursing procedures, those completing the forms were asked to indicate what was expected to be continued following discharge.

The general design of patient interview and professional care plan forms was described in the preceding chapter. These forms inquired about the same services, to permit comparison of requested episodes of care among patients, caregivers, and professionals. The patient and care-

¹ For this and other aspects of Granger's work, see Carl V. Granger, Marilyn Kaplan, Richard H. Fortinsky, and Donna A. Dryer, "Long-Term Care: Evaluation and Proposed Model for Delivery of Services to Chronically Ill People in the Metropolitan Providence Area", Providence: Metropolitan Nursing and Health Services Association, 31 March 1978.

giver interview was designed to be completed in 15-20 minutes. This seems to have been the case in practice. The professional care plan was intended to take 30-60 minutes to fill out, depending on familiarity with the form and the number of services the patient was thought to need. Because of coding and other requirements, the care planning form was somewhat time-consuming to complete for the first patient or two. Because these forms were completed well, it was decided to include the patients in the study. With practice, it seemed to go well. For hospital professionals, most of whom completed only one care plan, the design of the form probably did not enhance its acceptance. More important, it can be speculated that lack of familiarity with the form may have been a factor influencing these care planners' relatively high level of prescribed hours. Because the hospital professionals were not familiar with the forms, they may have prescribed duplicate care to ensure that patient's "received" needed services, not realizing that such care had already been called for. (One piece of evidence weakens the power of this explanation. It is that, while hospital discharge planners' mean prescribed hours for 50 patients fell slightly below that of hospital physicians, it exceeded that of floor nurses. Most discharge planners wrote several care plans. Most physicians or floor nurses wrote only one.) Patterns of prescribing have been reviewed to learn whether increased familiarity with the care planning form over time was associated with decreased hours, holding constant other variables. This information is present in Chapter VII, along with data in patient characteristics and prescribed care.

B. Introducing the Study

The task of introducing the study in the hospitals was accomplished in two phases. The first was to secure permission to conduct the project in the hospital; the second was to orient to hospital coordinator and other workers to data-gathering methods.

All of the four hospitals initially approached proved willing to participate. Discussions were held variously with members of hospitals' administration; medical staff; nursing, social work, and continuing care departments; and research and human subjects review committees.

Once permission was obtained, there followed the task of orienting the in-hospital coordinator to study procedures. The coordinator was the person responsible for discharge planning, usually the head of the social service department or the chief continuing care nurse. The hospital coordinator was responsible for supervising all aspects of in-hospital data collection: patient screening, obtaining informed consent, completing the PACE form, obtaining the three hospital professionals' care plans, mailing all completed forms to the study team at the Levinson Policy Institute, and recording the date, site, and level of care of discharge. At the Boston area facilities whose patients were visited, hospital coordinators also undertook to inform floor nurses when visits would take place, and to leave completed PACE and blank care planning forms at nursing stations for the use of visiting consultants.

Coordinating the flow of the data collection was a complex job. All forms had to be completed prior to a patient's discharge and, at the Boston area hospitals, in sufficient time to allow scheduling the six visits by consultants. (To protect patients, coordinators were asked the number of visits per day to be permitted.) After one or two patients had been screened into the study, it appeared to run smoothly at most hospitals.

C. Selecting and Orienting Consultants

While negotiations with hospitals were proceeding, consultants were recruited and oriented to the study. Their selection was purposive. In each category, it was desired to request the participation of well-trained professionals who were experienced in dealing with older patients requiring long-term care. Realizing that it would be difficult to perform multivariate analyses of the relation of professional variables, (such as age, experience, and attitude) to the magnitude or composition of home care plans, it was decided to seek the involvement of professionals who by reason of training, experience, and reputation seemed likely to represent good present practice in long-term care -- further that the number of full-time equivalent years of direct patient care of the members of the three groups, on average, would be similar. This criterion was met: physicians averaged 8.2 years of full-time equivalent practice; hospital discharge planners, 11.6 years; and home health planners, 8.7 years. Of the five consultant physicians, one is a geriatrician, one a physiatrist, one a psychiatrist and internist, and

two are internists specializing in cardiology and oncology, respectively. All work at teaching hospitals in Boston. Three of the discharge planners were registered nurses, one was a social worker, and one had degrees in both nursing and social work. Three of the home care planners were nurses; two were social workers. One worked in a hospital-based home care program, one in a neighborhood health center, one in a visiting nurse association, and two in home care corporations (the organizational vehicles for providing Title XX homemaker and chore services to the elderly in Massachusetts). All hospital discharge planners and home care planners are employed in the Boston Metropolitan area.

After consultants were selected, several orientation sessions were held to acquaint them with the study's goals and procedures. Directions for completing the care plan form were discussed; requests for clarification led to revisions in directions.

D. Screening Patients

Several difficulties were identified during the first two months of screening. At some hospitals, some physicians were reluctant to permit their patients' participation. Possible reasons were fear for patients' safety or reluctance themselves to complete forms. Other physicians were willing to allow their patients to be included in the study, but were not themselves prepared to complete care plans. To counter the first difficulty, opportunities were identified to present information about the study to physicians. To increase the rate at which patients were screened into the study, it was decided to drop the requirement that

physicians be willing to complete care plans. (As a result, hospital physicians care plans are available on only 52% of patients.)

A second difficulty pertained to the time required to coordinate the study in the hospital. In some institutions, coordinators proved too busy to discharge all tasks. Ways of dividing the work were found. Hospital administrators offered encouragement to help accomplish this.

The third, a more serious difficulty, concerned the slow rate at which patients were being screened and accepted into the study. At two of the hospitals, coordinators reported that fewer patients seemed to be being discharged to nursing homes than in recent years. This may have been attributable in part to a tightening of the Massachusetts long-term care bed supply relative to the population of likely candidates for care.

At all hospitals, the tighter bed supply may have resulted in a change in the distribution of characteristics of patients being discharged to nursing homes. Coordinators reported an increase in the average frailty, disability, and level of illness of patients being placed in institutions.

It might be expected that, in the face of a tighter bed supply, some nursing home administrators would attempt to accept patients who were easier to care for. This does not seem to have happened extensively-- at least not for patients referred for this study's sample hospitals to nursing homes. Rather, nursing homes have been persuaded to accept patients in greater need of care. Hospital coordinators reported that they were having to send home some patients who had in earlier years

been placed in nursing homes. Discharge planners seem to have been trying to ration available nursing home beds.

These changes in both the numbers and characteristics of patients referred from hospitals to nursing homes had three consequences. First, they probably reduced the number of patients who could potentially be screened into the study. Patients had to be cogent and sufficiently robust emotionally to cope with participation. Second, it probably meant a change in the composition of the study sample. Arguably, patients screened into the study were older, more frail, more disabled, and more ill than would have been the case had the study been conducted two years or even one year earlier. Third, it slowed the rate of intake into the study sample. This problem, and how it was dealt with, affected the size and composition of the sample, its representativeness, and the goals and analyses of the study itself.

In response to the slow rate at which patients were being screened into the study, two steps were taken. The number of hospitals included in the study was increased, and one of the requirements for inclusion in the study was dropped: Two hospitals, one a Boston area teaching hospital, agreed to participate in the study. This led to an increase in the study sample's rate of growth. Even more important was the decision to introduce a new class of patients. These patients might be too frail or ill to be interviewed or otherwise disturbed by the study. These "limited participants'" role in the study was, therefore, entirely passive; they were not disturbed: assessment data about them were recorded, their

principal caregiver was interviewed, and professional care plans were completed. Data which full participants supplied was obtained from the caregivers of limited participants. Of the final sample, 58% were full participants, most of whom were interviewed, and 42% were limited participants.

Addition of two hospitals and the inclusion of limited participants helped speed intake, but not enough to complete the planned sample size of 100 patients in time to permit processing and analysis of data. Therefore, the sample size had to be cut back to 50 patients.

At the same time, the sample became more representative of the entire population being discharged from Massachusetts hospitals to nursing homes. As planned, the sample would have stood for only those patients alert and emotionally robust enough to cope with full participation. Inclusion of limited participants after about six-eight patients had been screened into the study meant that more frail older persons would be represented as well.

Several other consequences followed. The smaller sample would represent a more diverse group. It was expected that full participants would be only about 50% of the reduced sample. So, instead of having data on 100 full participants, the study would obtain data on only about 25 full participants and 25 limited participants. This would permit analyses across a broader spectrum of patient characteristics. This would be an advantage. Relations between patient characteristics and service need across 50 patients could be calculated, but the smaller sample size

would reduce reliability of associations between a certain level of need for care and a certain kind of patient. It would be difficult to say much about the care needs of different classes of patients. The smaller sample size would constrain the use of multiple regression techniques of associating independent patient variables with dependent variables of average hours of prescribed home care, average cost of prescribed home care, or professional agreement about home care needs.

The representativeness of the sample was reduced somewhat in one way; the urgencies of recruiting patients meant that one hospital which met its original quota saw all those patients included in the study, double the proper proportion of the sample, which had been reduced 50%.

A further consequence of the drop in sample size and the additional limited participation was the diminution of the number of patients to be interviewed. Of 28 full participants, only 23 (82%) could actually be interviewed. This severely restricts the power of the comparison between patient and professional requests for home care services. Finally, the caregivers of only 20 of these 23 patients were themselves interviewed. In all, 36 (72%) of the caregivers were interviewed, but in only the 20 cases could patient-caregivers-professional comparisons be made. Nonetheless, these results are interesting for what they suggest.

The smaller sample size has also meant reduced power of discriminant analyses of the characteristics of patients for whom home care is cheaper versus the characteristics of patients for whom it is more expensive. The same difficulty limits factor analyses of professional

clusters of agreement about patient needs. Alternative methods of answering these questions have been found and will be presented in subsequent chapters.

As the study progressed, the importance of measuring professional agreement about patient needs became increasingly apparent. There were two reasons. Early results suggested an unexpectedly high level of disagreement, and the somewhat diminished ability to carry out certain other analyses highlighted the opportunity to study inter- and intra-profession agreement. A final mode of analysis here was to see how well professionals agree with themselves about patient needs. Each consultant was asked to re-do ten care plans on patients for whom he had already written prescriptions. The self-consistency of professional judgments over time will be measured as part of a continuation of this dissertation.

E. Completing Forms and Managing Information

PACE forms were completed while patients were in the hospital. Patients and caregivers were interviewed separately during this time. Before discharge of patients to be visited, hospital coordinators phoned study staff at the Levinson Policy Institute (LPI). The role of LPI in this project is set out in the acknowledgements section. Staff scheduled consultant visits. When a PACE form was completed, it was mailed to LPI, whence copies were distributed to all consultants who did not visit that particular patient.

Consultants mailed all care plans to LPI. Hospital coordinators

collected the three care plans completed by hospital professionals and mailed them, with the interviews, to LPI. In the entire process, only one form, a care plan, was lost and had to be re-done. At LPI, a double-entry log system was established to govern the flow of forms and to serve as a bookkeeping device to insure that all who completed forms were paid in a timely manner. It was also a device to learn which forms might be missing on a given patient, or which care plans might be outstanding from a given consultant. The diligence of the study staff in managing data meant that none of over 1500 forms was misplaced.

At LPI, PACE and screening forms were coded; interviews and care plans were edited and coded. An able staff of Brandeis undergraduates assisted LPI staff in these jobs. Key-punching was done by contract. Approximately 29,000 IBM cards of data were generated on the study sample of 50 patients. All data were edited and analyses run at the Harvard University Computer Center. The results of many of these analyses will be reported in part three.

Chapter VI now describes the characteristics of the study sample and indicates its representativeness.

Chapter VI

THE STUDY SAMPLE

A. Introduction

This chapter has two purposes. The first is to draw together a picture of the aspects of study design, execution, and long-term care system environment which seem to have affected the composition and representativeness of the study sample. The second is to describe the 50 patients who make up the sample and indicate in some detail how they variously resemble and differ from certain larger populations: a) residents of U.S. and Massachusetts nursing homes and b) those patients at participating hospitals who were screened out of the study.

Descriptive variables were not chosen because they were interesting in some abstract sense. Rather, patient characteristics were recorded on the PACE form in the hope that they would inform professionals' hypothetical home care plans. While describing the sample, the reasons these variables might influence care planning will be indicated.

B. Forces Affecting Sampling

It will be recalled from Chapter IV that 34.8% of U.S. nursing home residents in 1973-4 had been discharged from acute care hospitals directly to nursing homes. In the Northeast region of the country, this

figure was 41.0%.¹ In Massachusetts, however, as indicated in Table VI-A this proportion is both considerably higher and increasing. Thus, it is reasonable to assume that, because groups who reside in different settings before entering nursing homes have different characteristics, the study sample is more representative of persons newly admitted to Massachusetts' nursing homes than a sample similarly drawn in most other states would be of populations of persons newly admitted to nursing homes in those states. Finally, it should be noted that not all patients in the study sample were discharged to "nursing homes". Seven of the 50 were actually placed in rehabilitation/chronic disease hospitals. Massachusetts has an unusually large number of beds in such institutions; it is widely believed that many of them would by virtue of their services and their charges be classified as skilled nursing facilities in most other states. (Massachusetts has a relative deficit of SNF beds).² For these reasons, it was deemed appropriate to include in the study sample these seven patients.

Because the small sample studied in the course of this project was drawn under particular conditions described in Chapters IV and V, these should be set out to help the reader decide who is represented. Some analyses in part three, such as that concerning the proportion of the

¹ National Center for Health Statistics, Utilization of Nursing Homes, United States: National Nursing Home Survey, August 1973 - April 1974, "Vital and Health Statistics, Series 13, No. 28 (July 1977), T.5.

² Office of State Health Planning, Commonwealth of Massachusetts, "Report of the Long-Term Care Task Force," Boston: The Office, August 1977.

TABLE VI-A
SOURCES OF ADMISSION TO MASSACHUSETTS
NURSING HOMES AND REST HOMES, 1973 and 1975

Source of Admission	¹ 1 9 7 3		² 1 9 7 5	
	<u>Number</u>	<u>%</u>	<u>Number</u>	<u>%</u>
Acute Hospital	21,448	57.7%	23,859	67.6%
Mental Hospital	1,746	4.7	1,159	3.3
Other Nursing/Rest Home	3,686	9.9	3,383	9.6
Private Residence	6,768	18.2	5,856	16.6
Other Level of Same Home	2,616	7.0		
Other	<u>936</u>	<u>2.5</u>	<u>1,024</u>	<u>2.9</u>
Total All Sources	<u>37,200</u>	<u>100.0%</u>	<u>35,281</u>	<u>100.0%</u>

Sources

¹Massachusetts Department of Public Health, Health Data Annual, 1974, Boston: The Department, 30 October 1974, Table 67.

²Massachusetts Department of Public Health, Health Data Annual 1976, Boston: The Department, 12 May 1977, Table 42.

sample which could have been cared for at home at no increase in cost, probably are relatively sensitive to sample characteristics. But other analyses, such as that of inter-professional agreement, may be relatively insensitive to sample characteristics. In all analyses, however, trends may be identified and then extrapolated to groups which differ from that studied here.

Several aspects of the design and execution of the study, and of the long-term care environment during execution, probably affected the composition of the sample. Some of these influences were consequences of study method; others accompanied reactions to the slow rate at which patients were, initially, being screened into the sample; and still others followed from the tightened availability of nursing home beds in Massachusetts both generally and - as a consequence of Massachusetts Medicaid reimbursement policies - particularly for Medicaid-funded patients.

Two forces worked toward a relatively healthy, alert, and robust sample, and four countervailing forces worked toward a relatively ill, confused, and frail sample. In the first direction, the initial requirements that all patients must be medically, intellectually, and emotionally able to give informed consent and be interviewed excluded patients who would tend to require more help to remain safely at home. Human subjects protection obligations and other guarantees of safety built into the study's screening process seem also to have had this effect.

Several forces, however, worked to offset these. The most important was the introduction of "Limited Participation". Here, the desire to interview patients was sacrificed in the interests of securing a sample and, to a lesser extent, representativeness. In the final sample, full and limited participants were indeed very different in all important respects. Across all eighteen professionals, a mean of 45% more hours of care was recommended for the average limited participant than for the average full participant.

Several other forces acted to include relatively ill, frail, and disabled patients in the sample. Because as a condition of participation, a family member or close friend who knew the patient at home had to be available to be interviewed; some patients in relatively good condition had to be excluded from the study. Patients who lived with someone or who otherwise had help available at home, were able to live at home in the face of greater disability than those who lacked such help.

Because of the considerable and growing difficulty of obtaining nursing home beds in Massachusetts during the time when patients were being screened into the study, more patients who in past years would probably have been sent from hospitals to nursing homes were sent home instead. (See Table VI-B) This may also reflect the growing availability of home care. These were those best able to manage at home. Statements by study hospital coordinators testify to this practice.

Table VI-B

PATIENT DISCHARGES FOR LONG-TERM CARE FROM

SAMPLE HOSPITALS, 1975 - 1977

<u>Year</u>	<u>Discharge to LTC Facilities*</u>	<u>% Change From Previous Year</u>	<u>Discharges to Home Care</u>	<u>% Change From Previous Year</u>
1975	1995		575	
1976	2296	+ 15.1%	806	+ 40.2%
1977	1938	- 15.6%	1050	+ 30.3%

Note

*Chronic care and rehabilitation hospitals, SNFs, ICFs, and rest homes

Source

Unpublished annual hospital statistical reports.

Vladeck has reported a similar pattern in New York State.¹

It might be expected that, given tight nursing home bed supply, some nursing homes might seek to "cream" or "skim" patients by taking those requiring relatively little care. This does not seem to have been a common practice, in the experience of discharge planners at hospitals participating in the present study.

As the nursing home population becomes sicker and older, however, and as Medicaid payment levels seem to lag behind cost increases, many nursing homes in Massachusetts have been limiting the proportion of their beds available to Medicaid patients. Consequently, such patients remain atypically long in hospitals, and are therefore likelier to be included in the study sample.

This comes about because a considerable amount of time was required to complete study forms: consent, assessment, and interview, and - at Boston area hospitals - to arrange for consultant visits to patients. Patients discharged to nursing homes before these steps could be completed, tended to be in relatively good condition and to have incomes and assets above the very lowest, in that they did not require Medicaid support at time of nursing home admission.

¹ Bruce C. Vladeck, "Some Issues in the Economics and Financing of Long-term Care" (paper prepared for the Institute on Continuity of Long-term Care, Arden House, New York, December 18-20, 1977). Copyright the Twentieth Century Fund, Inc. Reprinted by permission. See also "Nursing Home Bed Shortage (in Western Massachusetts)", New York Times, 13 June 1978; and "Shortage of Space in Nursing Homes Plagues Elderly", Washington Post, 16 June 1978; Jean Dietz, "Useless Hospitalizations cited in Report on Nursing Home Beds", Boston Globe, 3 May, 1979.

How, as a product of these different pressures, did the study sample differ from (and how did it resemble) patients newly admitted to, or resident in Massachusetts or United States nursing homes? The next section presents this information.

C. The Sample: Characteristics and Comparisons

Fifty patients were screened into the study sample from six different Massachusetts' hospitals over the fifteen months from April 1977 to June 1978. This section will describe these patients in detail to permit comparisons with other samples. It will also describe how patients screened into the study differed from those screened out.

Age and Sex - As Table VI-C indicates, the sex distribution of the study sample is fairly close to Massachusetts and U.S. patterns. The sample has two or three more men than would have been required to conform to the general proportions. As measured by median age, both the men and women of the sample are slightly younger than their state or national counterparts. Greater age is associated with greater functional problems. These problems increase especially after age 75.¹ Functional ability, as discussed shortly, seems to be the best predictor of need for care.

¹ See the discussion in Thomas T.H. Wan, William G. Weissert, and Barbara B. Livieratos, "Determinants of Outcomes of Care in Two Geriatric Service Modalities: An experimental Study," a paper presented at the 31st Annual Scientific Meeting of the Gerontological Society, Dallas, 16-20 November.

Table VI-C

STUDY SAMPLE vs. MASSACHUSETTS, AND U.S, NURSING
HOME POPULATIONS; SEX AND AGE COMPARISONS

	<u>Male</u>	<u>Female</u>	<u>Total</u>
<u>% By Sex</u>			
Sample	24.0%	76.0%	100,0%
Mass ¹	27.8%	72.2%	100,0%
U.S. ²	29.6%	70.4%	100,0%
 <u>Median Age By Sex</u>			
Sample	75.5	81.0	79,5
Mass ¹	76.7	81.8	80,7
U.S. ³	78.2	83.1	81,0

Sources

¹ Massachusetts Department of Public Health, Health Data Annual, 1976, op. cit., T. 45. Median age of residents, not admissions.

² National Center for Health Statistics, Vital and Health Statistic, Series 13, No. 28, op. cit., T.D.

³ Ibid., T.3. Age of residents adjusted to reflect age at admission.

Marital Status - Sixteen of the patients in the sample (32%) have a living spouse versus only 12.4% of U.S. nursing home residents. The meaning of this information is not clear. It may signify that home care for the members of the sample would cost less than for the average member of the U.S. nursing home population, other things equal, because of greater availability of help. But other things probably are not equal: married patients are likely to be sicker or more disabled because if they lacked a spouse, they would probably not have been able to live outside an institution for as many years as they did. This point will be discussed in Chapter VIII.

Functional Ability - Much of this speculation about correlates of need for care would be unnecessary were data on the functional ability of larger populations available. Functional ability is the capacity to perform such ordinary activities of daily living as bathing, dressing, walking, transferring, eating, toileting and the like. It seems clearly to be thought of as the best predictor of the magnitude of need for long-term care.¹ Regretably, no national data on the functional ability

¹Kenneth M. McCaffree, Sharon Winn, and Carl A. Bennett, "Final Report of Cost Data Reporting System for Nursing Home Care," Seattle: Battelle Human Affairs Research Centers, 1 October 1976, Carl V. Granger, et al op cit.; Sidney Katz, Amasa B. Ford, Roland W. Moskowitz, Beverly A. J Jackson, and Marjorie W. Jaffe, "The Index of ADL: A Standardized Measure of Biological and Psychosocial Function," Journal of the American Medical Association, Vol. 185 (21 September 1963), pp. 914-919.

of the nursing home population is as yet available in a form permitting comparison with the study sample. Such data were collected during the "1976 Survey of Institutionalized Persons."¹ Comparisons should be possible within one year.

The remainder of this section will be devoted to distinguishing the study sample of 50 patients from those 296 patients screened out. It is hoped that this information will fill some of the gaps in our knowledge of the representativeness of the sample left by the present unavailability of national data. As appropriate, the justification for including the different variables will be indicated.

The differences between patients screened in and out of the study were compared using soci-demographic, medical-functional, and discharge-related variables. In general, the two groups were fairly similar.

Greater age, other things equal, is associated with greater need for home care. As recorded in Table VI-D, the sample screened into the study is 0.7 years (0.9%) older than those screened out.

The study sample is disproportionately female. Other things equal, this is associated with reduced availability of spouse to provide care. Further, women tend to be thought of by care planners as more willing to discharge ordinary household maintenance tasks. This would reduce part of the perceived need for help from others.

¹ U.S. Bureau of the Census, Current Population Reports, Special Studies, Series P-23, No. 69 (June 1978)

TABLE VI-D

COMPARISONS: PATIENTS SCREENED IN AND OUT OF THE STUDY

<u>PATIENT VARIABLE</u>	<u>SCREENED IN</u>	<u>SCREENED OUT</u>
Median Age	79.9	29.2
% Female	76 %	56%
% Married	32 %	34%
Resides:		
Alone	36 %	36%
With spouse	28 %	34%
With other relatives	36 %	26%
With non-relatives	0 %	4%
Mean Number of:		
Medical Diagnoses	4.1	3.5
Disabling Conditions	2.6	2.1
Hospital Admissions	0.9	0.8
LTC admissions	0.2	0.1
Anticipated Discharge Site:		
Rehabilitation Hospital	2 %	6%
Chronic Disease Hospital	6 %	13%
Level I SNF (Medicare)	24 %	29%
Level II SNF (Medicaid)	42 %	32%
Level III ICF	26 %	20%
Level IV Rest Home	0 %	1%
To Indefinite Placement	68 %	50%

Despite the sex composition of the sample, its members are just as likely as those screened out to be married and to reside with at least one other person. The screening process does not seem to have affected this aspect of the sample's attributes as had been feared. About a third of each group is married; about a third lives with other family; and about a third live alone. Great availability of family members indicates that many tasks could be discharged by unpaid providers. Hours of home care recommended by professionals would probably not be affected very much, but the unpaid proportion of total hours would be lowered, as would the cost of hypothetical home care. Further, patients who live with others will be shown to be older and more disabled than others. This seems to be because patients with given problems who live with others tend to be able to live at home longer than similar patients who reside alone. Thus, the latter have a lower disability or frailty threshold for institutionalization.

In the medical-functional areas, the study sample seems to have been in slightly worse condition than those screened out. Those screened in had, on average, a slightly higher number of medical diagnoses, disabling conditions, hospital admissions, and long-term care admissions. While medical diagnoses itself has not been systematically related to need for long-term care services, the number of different diagnoses was counted as a possible measure of medical instability or frailty. The number of disabling conditions was counted for the same reason. These data, together with information on admissions to hospitals and long-term care facilities provide a meaningful comparison of how medically unstable

is the study sample and the group screened out.

Regarding anticipated site of discharge, patients screened into the study were substantially likelier than those screened out to be headed to level II SNF care and somewhat likelier to go to Level III ICF care. Those screened in were less likely to be expected to be placed in rehabilitation or chronic disease hospitals or level I SNF nursing homes. The concentration of patients screened out in the higher levels of discharge probably includes both patients in relatively good shape who left the acute care hospital for short-term rehabilitation too quickly for forms to be completed on them and patients too ill to be screened in. This is supported by the relatively low proportion of patients screened out who were expected to have indefinite placements.

This general picture of the two groups emerges: those screened in are somewhat older and disproportionately female. They appear to suffer from more acute medical diagnoses and chronic conditions, and they are expected to be more likely to remain indefinitely in long-term care facilities. Their concentration in the level II SNF group strongly suggests that many are potentially Medicaid-funded patients for whom nursing home beds are difficult to locate. Because these patients therefore tend to remain in the hospital for a relatively long time, it was easier to complete necessary forms on them. In sum, the various forces discussed earlier in this chapter seem to have acted to yield a sample fairly representative of the group discharged from study hospitals. Acutely ill patients, the very sick, seem to have been excluded. Patients

hospitalized for a short stay, headed for relatively uncomplicated recuperation from a single ailment, seem usually to have been missed as well.

Still more detailed information was obtained on patients screened into the study. Unfortunately time and cost limits made it impossible to record comparable data on patients screened out. Three major areas will be discussed now: functional ability, instrumental activities, and psychosocial status.

Three measures were made of functional ability or independence in activities of daily living (ADL). The Barthel index was used to measure independence in walking, climbing stairs, wheeling (if patient could not walk), transferring to chair and bed, transferring to tub or shower, bathing, toileting, bladder function, bowel function, dressing, grooming, eating and feeding, and mobility outside room and house. The degree of dependence in these activities suggests the need for many types of supportive services. A score of zero indicates total dependence on other persons in these activities and a score of 100 indicates full independence.¹

¹For information on the Barthel scale, see Florence I. Mahoney and Dorothea W. Barthel, "Functional Evaluation: The Barthel Index," Maryland State Medical Journal, Vol. 14, No. 2 (February 1965), pp. 61-65; Carl V. Granger, Gary L. Albrecht, and Byron B. Hamilton, "Outcome of Comprehensive Medical Evaluation: Measurement with the Barthel Index and the PULSES Profile," Providence: Brown University School of Medicine, 1978 (mimeo). This study's version of the Barthel index is Granger's modification.

Table VI-E indicates the pre-hospital and anticipated distributions of Barthel scores. A clear drop in functional ability in the course of the present illness is indicated. For members of the study sample, important declines in functional ability are associated with the decision to institutionalize. On average, such factors as change in family willingness to help sustain a patient at home do not seem to have operated alone.

Pearson product-moment correlations have indicated that higher pre-hospital Barthel scores are associated with bigger drops in scores ($R^2 = .32$; significant at $<.001$) and higher anticipated Barthel scores are associated with smaller drops ($R^2 = .15$; significant at $.01$). These relations are to have been expected.

A measure related to ADL is that of patients' independence at eight instrumental activities of daily living (IADL): shopping, housework, meal preparation, laundry, taking medication, transportation, managing money, and using the telephone. Patients were asked whether, prior to this hospitalization, they did or were able to do these IADL tasks without help. Eight patients could do none of these independently; 25 could do one-four tasks; and seventeen could do 5-8 tasks. These data suggest further the frailty of the members of the sample. They appear more dependent on the IADL than on the ADL activities. In general, pre-hospital Barthel and IADL scores correlated closely ($R^2 = .54$; significant at $<.001$).

TABLE VI-E
FUNCTIONAL ABILITY OF THE STUDY SAMPLE

	<u>Mean</u>	<u>Median</u>
Pre-hospital Barthel score	77.1	82.5
Barthel anticipated at discharge	49.8	45.8
Barthel change	-27.3	-36.7

	<u>0-74</u>	<u>Number</u> <u>75-94</u>	<u>95-100</u>
Pre-hospital Barthel score	17	16	17

	<u>0-40</u>	<u>Number</u> <u>41-60</u>	<u>61-100</u>
Barthel anticipated at discharge	17	19	15

Discharge planners were also asked to assess patients' psychosocial characteristics. These included such items as whether the patient talked with other people, smiled or laughed, was lethargic, or was abusive to self or others. Twenty-two patients were scored positively on fewer than half of the seventeen characteristics.

Of the 50 patients, 24 were originally sought from Boston area hospitals and 26 from elsewhere in Massachusetts; 25 were to be from teaching hospitals and 25 from community hospitals. Table VI-F indicates how closely these overall targets were struck. At a finer level of detail, however, certain disparities appear. Boston area teaching hospitals and non-Boston community hospitals were unable, for a number of valid reasons, to contribute their share of the study sample in sufficient time. Boston area community hospitals and non-Boston teaching hospitals picked up the slack. Thus, while the sample does not simultaneously represent type and location of hospital, it does represent both variables viewed overall.

The participation and visit statuses of patients are somewhat less well-balanced. Most of the patients (29 of 50) are full participants, but only sixteen of 50 were visited (See Table VI-G). The low number of visits is owing to the initial difficulty of securing patients at Boston area hospitals. A community hospital subsequently added proved too inconvenient for visiting. Despite this disproportion, sufficient patients were visited to suggest whether this brief visit affected planning.

TABLE VI-F
Actual Versus Planned Sources of Patients

<u>Type of Hospital</u>	<u>Actual</u>	<u>Planned</u>
Boston area	23	24
teaching	7	14
community	16	10
Non-Boston area	27	26
teaching	21	11
community	6	15
Total	50	50
teaching	28	25
community	22	25

TABLE VI-G

The Sample: Participation by Visit Status

Participation	<u>Visit Status</u>		<u>Total</u>
	<u>Full</u>	<u>Limited</u>	
Visited	10	6	16
Not visted	18	16	34
Total	28	22	50

P A R T T H R E E

FINDINGS AND WHAT THEY SUGGEST

CHAPTER VII

COMPARING THE COSTS OF HOME AND INSTITUTIONAL CARE

This chapter is divided into six sections. In section A, the actual cost of institutional care is indicated, along with how it was calculated and it relates to patient characteristics. Section B does the same for home care costs and section C for comparisons between the two.

Section D takes up the relation of professional, family and patient views to home care cost; section E goes into greater detail on how professionals see costs. In section F, data are summarized and their implications are considered.

A. The Costs of Institutional Care

The cost of institutional care for the members of the study sample was calculated by a straightforward method. The actual charges for care in patients' site of discharge was acquired. If, during the six months following hospital discharge, the patients resided in two or more institutions, the weighted average of these was computed.¹ Excluding

¹ To allow for patients' personal allowance, drugs, medical-therapeutic professionals, and other goods and services not included in the nursing home daily rate charged to Medicare or Medicaid, an additional 15% was added. (This was not done where the institutional rate was all-inclusive.) Similarly, on the home care side of the cost comparison, prescribed service costs were inflated by 5% to cover drugs, supplies, and appliances. Both of these proportions are best guesses, based on available data and off-the-record estimates by knowledgeable persons of average costs. They may be in error, but the possible consequences of even fairly large

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administratively necessary days (time spent in hospital by a patient ready for discharge because no nursing home bed was available), the average cost of institutional care for the 45 patients for whom data could be obtained is \$373 per week. When administratively necessary days (AND's) are included, institutional cost rises to \$410 per week. Administratively necessary days are excluded from most cost comparisons because they reflect the cost of -- hopefully -- transient and conceptually easy-to-eliminate inefficiencies in the present system. Taken at the hospitals' actual base per diem rates, they represent a fixed cost equal to 9.9% of actual nursing home costs. Over larger stages, this proportion would drop. For interested readers, comparisons between home care costs and institutional costs both with and without the extra cost of administratively necessary days are occasionally provided.

Patient characteristics and nursing home cost. Multiple regression analysis was performed relating sixteen variables characterizing patients on the actual cost of their institutional care. Table VII-A lists these variables and indicates their correlation with nursing home cost excluding administratively necessary days. Variables are defined in some detail in Appendix C. Of the sixteen variables, ten had a positive relation to institutional cost and six had a negative relation. Only one relationship was statistically significant: the patients' anticipated discharge site -- the level of long-term care which the hospital discharge planner thought the patient would receive after leaving the hospital --

errors for the analyses in this chapter do not seem to be serious.

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TABLE VII - A

Patient Characteristics and Nursing Home Cost

patient variable ¹	correlation with N.H. cost ²
age	-.130
number of persons patient resided with	.053
marital status (yes/no)	-.126
anticipated site of LTC discharge	-.684***
indefinite LTC placement (yes/no)	-.206
number of medical diagnoses	.242
number of disabling conditions	.054
number of hospital discharges in past year	.025
number LTC admissions in past two years	-.231
number of medications, in hospital	.111
% of nursing services used, in hospital	.152
psychosocial score	-.072
anticipated Barthel score at hospital discharge	.055
change in Barthel score: pre-admission to discharge	.198
pre-hospital/ADL score	.155
family willing to maintain patient at home (yes/no)	.015

¹ these variables are defined in detail in Appendix C

² omits administratively necessary days

***significant at .001

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bore a strong negative relation to actual institutional care costs. This was expected. As this independent variable was coded, the negative relation indicates that patients expected to be placed in facilities providing more care (rehabilitation hospitals, skilled nursing facilities) did indeed cost more to care for than patients placed in intermediate care facilities. This relation was significant at the .001 level. What is very surprising is that no other variable bore a statistically significant relation (at the 5% level) to actual nursing home cost.

Table VII-B now reports the results of regression analysis of the relation of the sixteen variables to actual nursing home cost. Four variables -- anticipated discharge site, marital status, number of disabling conditions, and number of medical diagnoses -- together "explain" about 57% of the variation in nursing home cost. Only the first plays an important role. Of the other three, being married and having more disabling conditions and diagnoses were all positively associated with nursing home costs. Being married is associated, in this sample, with being in need of more home care also (as will be seen in the next chapter) probably because presence of a spouse permits patients to remain at home longer, with given disability, than had they not been married.

These variables all contrast sharply with those explaining average levels of hypothetical home care cost. This clearly indicates that the costs of institutional care and home care relate in very different ways to patient characteristics. The costs of home care vary more systematically with patient qualities which reasonably should be associated with cost. Institutional care costs have only a haphazard relation to patient variables.

TABLE VII - B

Regression Results: Patient Characteristics and Nursing Home Cost

<u>patient variable</u> ¹	<u>significance</u> ²	<u>unique variance</u> ³
anticipated discharge site	<.001	.437
marital status	.012	.079
number of disabling conditions	.040	.051
number of medical diagnoses	.237	.016

$R^2 = .573 (<.001)$

¹ stepping in stopped when last variable not significant at .07

² t-test

³ proportion of variation in dependent variable explained by this independent variable

This indicates that the cost of institutional care may in individual cases be largely a product of such factors as the location or age of the nursing home, rather than the care it provides. (Newer facilities in metropolitan areas tend to cost more.) Further, patients might be placed in facilities unrelated to their needs, or the facilities may not be responding to the needs.

Alternatively, it might be argued that patients are being placed in a reasonable way, but the variables employed in this study do not appropriately represent care needs or their costs. A companion to this argument is that patients' nursing home cost, taken here as average charge by level, does not reflect the cost of care for individuals. It is likely that a mixture of these explanations is at play. This discussion's importance will become clearer in the next section.

B. The Costs of Home Care

A large number of home care hours were prescribed for the patients in the study sample. For the 50 patients, mean prescribed home care across eighteen professionals was 125.4 hours weekly. The weekly cost of home care would therefore seem very high.

However, of these hours, about two-thirds were paid and over 90% were unskilled. Table VII-C presents these breakdowns in prescribed hours. Because only some of the hours were paid (the remainder of the prescribed hours were to be provided by informal supports, generally relatives or friends residing with the patient) and because almost all hours of care were to be delivered by unskilled providers, the weekly cost of prescribed home care is less than the total prescribed hours might suggest.

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Table VII-C

Total Mean Prescribed Hours: Paid versus Unpaid
and Skilled versus Unskilled

<u>Payment Status</u>	<u>Hours/week</u>	<u>%</u>
paid	84.3	67.2%
unpaid	41.1	32.8%
Total	125.4	100.0%

<u>Skill Status</u>	<u>Hours/week</u>	<u>%</u>
skilled	7.3	5.8%
unskilled	118.1	91.2%
Total	125.4	100.0%

Note

Almost all skilled providers are paid, but most of the paid providers are unskilled. Lists of the titles of paid, unpaid, skilled, and unskilled providers recommended by prescribing consultants are appended to Chapter IV.

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The cost of home care was calculated first by taking the mean, across 50 patients, of the mean of the eighteen professionals' care plans for each patient. The cost of these prescribed home care services is \$514 per week. Since an average of 84.3 paid hours of care are prescribed weekly, the average hourly charge for home care is \$6.10. (Appendix A of this chapter lists the hourly rates used to calculate the cost of prescribed home care.) This relatively low hourly charge reflects the predominance of unskilled services in the package of paid care.

This mean service cost does not fully reflect the expense of maintaining a patient at home. Non-service costs can be important. As Bruce Vladeck has noted:

Cost comparisons between institutional and non-institutional services have foundered on the difficulty of comparing the housing, nutritional, and housekeeping services received in an institution with those a non-institutionalized person receives elsewhere.¹

While this problem is not particularly serious in the present study, because of the high ratio between service cost and non-service cost (housekeeping requirements, for example, are included in the hypothetical home care plans), it is still necessary to include in the total cost of home care spending on housing and other goods. Based on the U.S. Department of Labor's lower budget for a retired couple for the Boston standard metropolitan statistical area, this cost was estimated to be \$50

¹ Bruce C. Vladeck, "Some Issues in the Economics and Financing of of Long-term Care" (paper prepared for the Institute on Continuity of Long-term Care, Arden House, New York, December 18-20, 1977), p.9. Copyright the Twentieth Century Fund, Inc., Reprinted by permission.

per week for a patient whose family was willing to maintain her/him at home, and \$76 per week for a patient who would live alone.¹ The average for all 50 patients is \$60 per week.

Including non-service requirements, the mean total cost of home care is \$574 per week. Two other methods of calculating total costs of home care have been used. One has been to take the mean across 50 patients of the median of the eighteen professionals' plans for each patient. The other has been to take the mean across 50 patients of the 33rd percentile of home care costs for each patient.² To each of the three is added the non-service costs for individual patients. These results are compared in Table VII-D. The mean of the medians, \$453 per week, is 88% of the mean of the means. The mean of the 33rd percentiles is only 65% of the means.

¹ U.S. Department of Labor, "Three Budgets for a Retired Couple, Autumn 1977," USDL News, 78-698, 13 August 1978. Acute medical care costs were omitted from the cost comparison on both of the home care and nursing home side. A factor of 55% was applied to the food budget and a factor of 50% to all other categories, for patients whose families were willing to maintain them at home. For patients living alone, a factor of 11% was applied to housing costs. All costs were inflated by 6% to reach an estimated 1 July 1978 level. The home care-nursing home care cost comparisons are not very sensitive to these assumptions in estimating procedures because the great bulk of the home care costs are due to prescribed services. These proportions were chosen because they seem to reasonably reflect one person's share of the retired couple's budget. Readers may adjust these as desired, but, because of non-service costs' relatively small share (12-18%) of total home care costs, these assumptions will not greatly affect cost comparisons.

² This standard was chosen arbitrarily. It was desired to learn the cost of home care based on the care plan of the sixth least costly prescriber for each of the 50 patients.

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TABLE VII - D

Total Home Care Costs Using Different Measures

<u>Measure of Service Cost</u>	<u>Mean Service Cost</u>	<u>Mean Non- Service Cost</u>	<u>Total Cost</u>
Mean of 50 means	\$514	\$ 60	\$ 574
Mean of 50 medians	\$453	\$ 60	\$ 513
Mean of 50 33rd percentiles	\$335	\$ 60	\$ 395

Patient variables and home care costs. The relation of sixteen independent variables to different measure of home care cost has been examined by multiple regression analysis. The results of one such examination are now presented. Table VII-E indicates the correlation between each of the sixteen variables and the median total cost of home care. (Median total cost, for each patient, is the median of the eighteen professional views of service cost, plus non-service cost for that patient.)

Half of the variables are positively related to hypothetical home care cost and half are negatively related. Five of the variables are significantly (at the .05 level or better) related to median total home care cost. The number of persons the patient resided with prior to hospitalization, better psychosocial status, and better anticipated Barthel score (functional ability) are negatively related to home care cost. The percentage of nursing services used in hospital and the size of decline in Barthel score are positively associated with home care cost. Each of these relations appears entirely reasonable. It should be noted further that anticipated site of institutional discharge has only a weak relation to home care cost: a more expensive institutional placement is associated with more expensive home care.

The results of multiple regression analysis on median total home care cost indicate a pattern quite different from that reported in the previous section, where actual institutional cost was the dependent variable. In the present case, four variables were fitted into the equation, three of which were significant at the .05 level or better. Regression results appear in Table VII-F. Together, the four characteristics "explain" about 44% of the

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TABLE VII - E

Patient Characteristics and Median Total Home Care Cost

<u>patient variable</u> ¹	<u>correlation with home care cost</u>
Age	.197
number of persons patient resided with	-.316*
marital status (yes/no)	.089
anticipated discharge site	-.204
indefinite placement (yes/no)	.164
number of medical diagnoses	.178
number of disabling conditions	.184
number of hospital discharges (past year)	-.025
number of LTC admissions (past year)	.045
number of medications in hospital	-.079
% of nursing services used in hospital	.291*
psychosocial score	.315*
anticipated Barthel score at discharge	-.459**
Barthel change from pre-admission	.359*
pre-hospital /ADL	-.040
family willing to maintain at home (yes/no)	.074

¹ Variables are described in appendix C of this study.

* significant at .05

** significant at .01

TABLE VII - F

Regression Results: Patient Characteristics and Home Care Cost¹

<u>patient variable²</u>	<u>significance³</u>	<u>unique variance⁴</u>
Barthel score anticipated at discharge	<.001	.225
number of persons patient resides with	.003	.138
age	.019	.078
anticipated discharge site	.097	.037

R² = .442 (<.001)

¹ median total home care cost

² stepping stopped when last variable not significant at .07

³ t-test

⁴ proportion of variation in dependent variable explained by this independent variable

variation in home care cost. Anticipated Barthel score is the most important of the independent variables followed by the number of persons the patient resides with, age, and anticipated discharge site. This list contrasts with the variables -- anticipated discharge site, marital status, number of disabling conditions, and number of medical diagnoses -- which explained 57% of the variation in actual institutional costs.

For the reasons set out in the preceding section, it is not possible to decide whether the relation of patient variables to cost is more sensible in the home care case or the nursing home case. Certainly, some of the variables relevant to the cost of home care, such as the number of persons the patient lived with at home, have only an indirect bearing on how much institutional care should cost. The variable functional ability should have a stronger relation to the actual cost of institutional care. It certainly has been taken into account by home care planners. Its weak impact on institutional costs may follow from this sequence: 1) the cost of institutional care is closely tied to reimbursed level (SNF, ICF, and the like); 2) overall need for help, suggested by functional ability has little to do with level of placement, which is mandated by regulation to be made largely in light of medical considerations.

In the area of home care costs, another regression was run using the same sixteen patient variables. Here, the dependent variable was each patient's coefficient of variation in prescribed costs across eighteen professional care planners. The purpose of this analysis was to learn the

relation of patient variables to professional agreement about home care service cost.¹ It is interesting to note that the average CoV is 55.5%, indicating that for the average patient, the standard deviation equals 55.5% of the mean. This suggests a fairly high level of disagreement among professionals about the average cost of care. Table VII-G sets out the relation of patient variables to CoV in service costs and Table VII-H contains the results of the regression itself.

The patients about whose home care costs the professionals agree best are patients whose functional ability dropped most over the course of their current illness, who needed many nursing services, who were older, and who had suffered more acute episodes in recent months. Thus more change in functional ability and medical status, and greater age, are associated with more agreement among professionals. It should also be noted that patients whose anticipated functional ability at discharge was better were harder to agree about as well.

¹ Coefficient of variation (CoV¹ is the relative standard deviation. This is the standard deviation in cost, divided by the mean of cost for that patient. It thus controls agreement for the base of costs, serving thereby as a standard for comparison across patients.

TABLE VII - G

Patient Characteristics and CoV¹ in Home Care Service Costs

<u>patient variable</u> ²	<u>correlation with CoV service cost</u>
age	-.224
number of persons patient resided with	.013
marital status (yes/no)	.045
anticipated discharge site	.149
indefinite placement (yes/no)	-.023
number of medical diagnoses	.222
number of disabling conditions	-.091
number of hospital discharges (past year)	-.110
number of LTC admissions (past two years)	.032
number of medications in hospital	.051
% of nursing services used in hospital	-.361*
psychosocial score	.085
anticipated Barthel score at discharge	.352*
Barthel change from pre-admission	-.428**
pre-hospital /ADL	-.035
family willing to maintain at home (yes/no)	-.157

¹ coefficient of variation = $\bar{X} \div S.D.$

² variables are described in appendix C

* significant at .05

** significant at .01

TABLE VII - H

Regression Results: Patient Characteristics and CoV¹ Home Care

<u>patient variable</u> ²	<u>significance</u> ³	<u>unique variance</u> ⁴
Barthel change	.005	.128
% of nursing services used	.006	.125
age	.037	.068
number known hospital discharges	.112	.038

$R^2 = .377 (< .001)$

¹ CoV = $\bar{X} \pm S.D.$

² stepping stopped when last variable not significant at .07

³ t-test

⁴ proportion of variation in dependent variable explained by this independent variable

C. Cost Comparisons

The average cost of institutional care, excluding administratively necessary days, was \$373 per week. For total home care cost, the mean of the individual means was \$574 per week. The mean of the medians, \$513; and the mean of the 33rd percentiles, \$395. (These are the costs of professionals' home care plans. Costs of patients' and families' plans are taken up in section D.) Table VII-I presents the numbers of patients for whom home care was more and less expensive under each of these standards.

While insitutional care is always cheaper for the average of all patients for home data are available, there is always a sub-set of people for whom home care is cheaper. As would be expected, the size of this group rises as the standard for calculating home care costs changes from the mean to the median to the 33rd percentile of care planners. Its size is greater when institutional costs include administratively necessary days.

It is noteworthy that even in this very ill and disabled sample of patients who are being referred to institutions, there is a substantial number for whom home care is less expensive.

In Table VII-J, the savings that would accrue from placing each patient in the cheaper setting are set out. (Institutional costs are given both including and excluding administratively necessary days, thereby indicating their unimportance.) A substantial saving in total long-term costs follows, under each of the six comparisons, after patients for whom home care is cheaper are in fact diverted. These savings range from 11.3% to 25.6%, depending on the standard of comparison. These savings represent the decreased cost of care for the individual patients directed

Table VII-I

Patients for Whom Home Care is Less Expensive
(A.N.D.'s Excluded¹)

Standard for calculating home care cost

	<u>Mean</u>		<u>Median</u>		<u>33rd Percentile</u>				
	<u>\bar{X} home care cost</u>	<u>\bar{X} nursing home cost</u>	<u>\bar{X} home care cost</u>	<u>\bar{X} nursing home cost</u>	<u>\bar{X} home care cost</u>	<u>\bar{X} nursing home cost</u>			
	<u>n</u>		<u>n</u>		<u>n</u>				
Patients for whom home care is <u>less</u> expensive	8	\$448	\$763	9	\$408	\$727	14	\$309	\$604
Patients for whom home care is <u>more</u> expensive	37	\$622	\$289	36	\$562	\$284	31	\$461	\$268
Total	45	\$591	\$373	45	\$531	\$373	45	\$413	\$373

¹ Administratively necessary days (A.N.D.s) are excluded from the cost of institutional care.

Table VII-J

Total Weekly Costs in Various Settings (\$)

<u>Standard of cost</u>	<u>All patients in</u>			<u>Savings</u> <u>Accompanying</u> <u>Diversion</u> <u>(2)-(3)</u>	<u>% saved</u> <u>over (2)</u>
	<u>(1)</u> <u>home</u> <u>care</u>	<u>(2)</u> <u>inst.</u> <u>care</u>	<u>(3)</u> <u>less</u> <u>exp. care</u> ¹		
Exclude A.N.D.'s					
\bar{X} home care costs	26,595	16,785	14,277	2508	14.9%
median home care costs	23,895	16,785	14,896	1889	11.3%
33rd percentile	18,585	16,785	12,634	4151	24.7%
Include A.N.D.'s					
\bar{X} home care costs	26,595	18,450	15,665	2785	15.1%
median home care costs	23,895	18,450	15,111	3339	18.1%
33rd percentile	18,585	18,450	13,721	4729	25.6%

¹less expensive care

to home care. They do not represent net system savings. The latter would depend on how the total costs of home and institutional care were affected by changes in the numbers and characteristics of patients receiving care in the two sites.

The impact on the long-term care system at large of the diversion of individual patients must be considered. If patients are diverted to home care and the nursing home beds they would have occupied are filled by others, who would not be eligible for home care, then total long-term care costs would rise by the costs of home care for those diverted \pm the difference in the cost of nursing home care for the two groups. If the beds which would have been occupied by diverted patients are closed, a net savings is likely. This would depend on whether the drop in total nursing home cost is or is not offset by the rise in total home care cost.

Institutional care is cheaper for the majority of patients in the study sample, regardless of the standard used to calculate home or institutional costs. By each standard, however, some patients are identified for whom home care is less expensive. Even greater numbers of patients, if the savings on the patients diverted to home care were used to subsidize care for those for whom home care was marginally more expensive.

Using a standard of diverting to home care the nine patients (Table VII-I) whose median prescribed cost fell below institutional cost excluding administratively necessary days, \$1889 would be saved weekly (Table VII-J). If this sum were applied to subsidizing home care for patients whose institutional care was marginally cheaper, an additional fifteen patients could have been diverted. Thus, 24 of 45 patients (53%)

could have been cared for at home with no increase in cost.

What are the characteristics of the patients for whom hypothetical home care was thought cheaper versus the characteristics of those for whom it was thought more expensive? The standard of comparison used to categorize patients is the 33rd percentile of total home care costs versus institutional costs which excluded administratively necessary days. There were fourteen patients for whom home care was cheaper and 31 for whom nursing home care was cheaper. The home care group was somewhat less likely to have resided alone prior to this hospitalization; its members were less likely to be married; but the family was somewhat likelier to be willing to maintain the patient at home. The Barthel score anticipated at discharge was ten points (12%) higher for the home care group. This group was taking more medications in-hospital but it received fewer nursing services. The home care patients were slightly more likely to be full participants. Perhaps the most important distinction is that fully nine (62%) of the fourteen home care patients were being referred to rehabilitation or chronic disease hospitals or Medicare SNFs while only seven (23%) of the nursing home patients were being referred to these more intensive and costly facilities. Table VII-K displays in detail the characteristics of the two groups. Home care seems to have fared relatively well in the cases of patients whose institutional care is quite expensive. As Thomas R. Willemain has noted, it is not so much that home care is cheaper for these patients; it is that their institutional care is more expensive.¹

¹ Personal Communication, Thomas R. Willemain, February 1979.

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Table VII-K

Characteristics of Patients for Whom Home Care is Cheaper
Versus Those for Whom It Is More Expensive

<u>Variable</u>	<u>Home Care Cheaper</u>	<u>Nursing Home Care Cheaper</u>
number of patients	14	31
age (\bar{X})	80.0 years	78.8 years
% female	71.4%	74.2%
% residing with others	71.4%	58.1%
% married	21.4%	41.9%
% family willing to maintain at home	85.7%	71.0%
anticipated Barthel score (\bar{X})	54.5	44.6
Barthel change (\bar{X})	-30.6	-30.2
% IADL positive	44.0%	38.5%
no. of diagnoses (\bar{X})	4.1	3.8
no. of hospital discharges (\bar{X})	0.7	0.9
no. of current medications (\bar{X})	6.6	5.1
% of current nursing services (\bar{X})	29.0%	34.0%
% indefinite institutional placement	71.4%	67.7%
% rehab., chronic, Medicare SNF placement	64.3%	23.3%
% Medicaid SNF placement	14.3%	43.3%
% Medicaid ICF placement	21.4%	33.3%
% full participants	54.1%	51.6%

This pattern is quite different from that argued¹ or found² in other studies. The usual pattern is that home care is likelier to be less expensive than institutional care for the less ill or disabled. This may well be true among the general population of older citizens who need help, but, at least in the sample studied here, the reverse is likelier to hold. This suggests that real opportunities may exist in caring at home for persons with serious functional or medical problems. For them, institutional care may have become so expensive that home care is cheaper.

Figure VII-A graphs these possible relations. In the range between points A and B, home care is more expensive for the average patient. If the range of disability of the members of the study sample extends between points X and Y, some of the above cost findings would be explained.

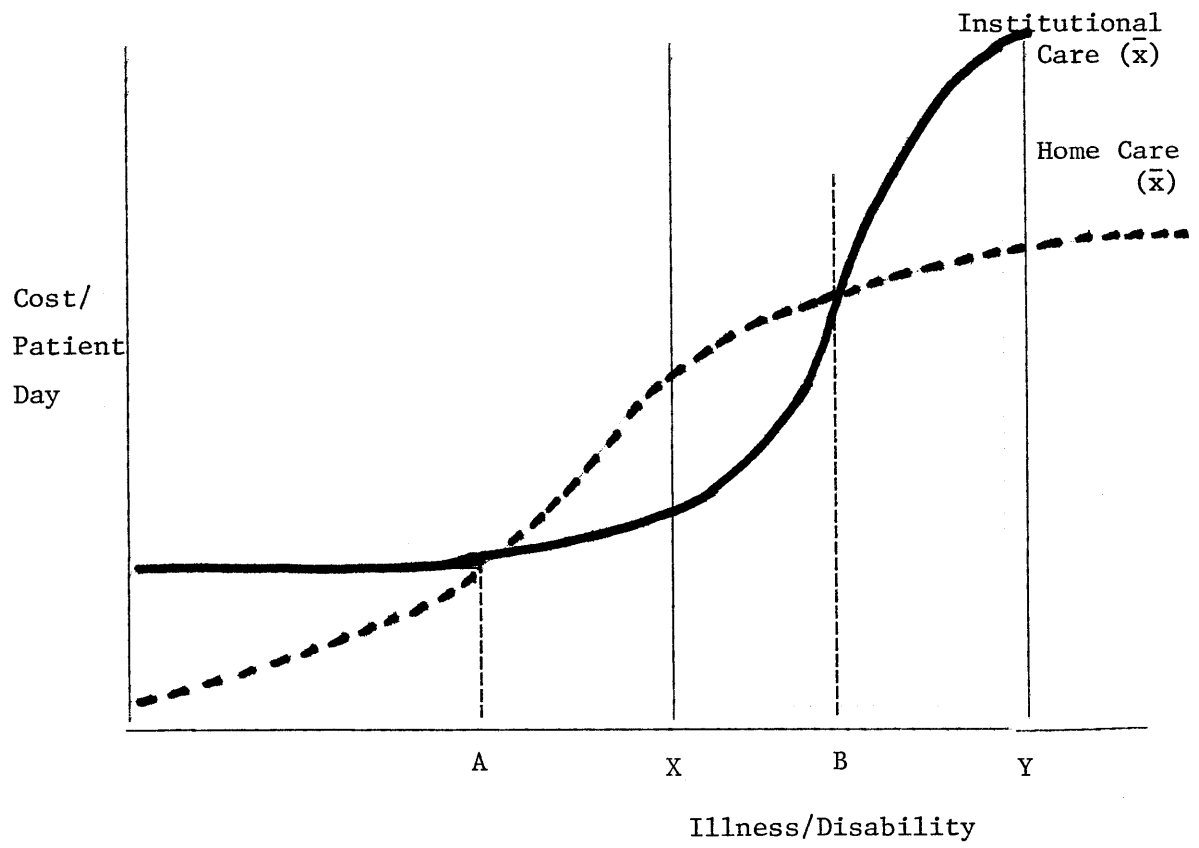
The relation of patient characteristics to the relative costs of home and institutional care has been analyzed by multiple regression in addition to the technique just discussed. Home care costs and institutional costs were formed into two dependent variables. One was the difference between the two; the other was their ratio. Results under the two analyses are generally similar so, for the sake of coherence, only regressions on median total home care cost minus institutional cost (excluding administratively necessary days) will be discussed. A higher value for this dependent

¹ Jay Greenberg, "The Costs of In-home Services," in Nancy N. Anderson, A Planning Study of Services to Non-institutionalized Older Persons in Minnesota, Minneapolis: Governor's Citizens Council on Aging, 1974, Part II.

² Comptroller General of the United States, "Report to Congress on Home Health--The Need for a National Policy to Better Provide for the Elderly," Washington: General Accounting Office, HRD-78-19, 30 December 1977. A

FIGURE VII-A

ONE VIEW OF HOME AND INSTITUTIONAL CARE COSTS



variable means that home care is more expensive; a lower value means that institutional care is more expensive.

How do the different patient variables influence the direction of the cost comparison? This question is answered by the data in Table VII-L, which presents the correlation coefficients between each of the patient characteristics and the difference between home and institutional care costs. A positive relation means that a higher value for the independent variable is associated with a probable increase in the relative cost of home care. Anticipation that the patient will be discharged to a more intense level of care is strongly associated with home care being cheaper. Conversely, a higher Barthel score anticipated at discharge is fairly strongly associated with home care being cheaper. Both of these relations hold when other variables are not controlled. Table VII-M displays the regression results themselves. They indicate that more intense levels of anticipated institutional placement, higher anticipated Barthel score, and greater numbers of residents in the patient's household are all associated with greater likelihood that home care will cost less than institutional care. Conversely, the greater the number of disabling conditions the patient suffers from, the higher the likelihood that home care will cost more than institutional care. The last relation is not strong, but it does offer support for the conventional view that people who need more help are cheaper to care for in institutions. The host of factors confounding appropriate

possible limitation on the applicability of this approach lies in its use of average institutional cost across all disability levels.

TABLE VII-L
 PATIENT CHARACTERISTICS AND THE COMPARATIVE COSTS
 OF HOME AND INSTITUTIONAL CARE

<u>Patient Variable</u> ¹	<u>Correlation with H.C. Cost minus N.H. Cost</u> ²
Age	.151
Number of Persons Patient Resides with	-.272
Marital Status (yes/no)	.125
Anticipated Discharge Site	.398**
Indefinite LTC Placement Expected (yes/no)	.266
Number of Medical Diagnoses	-.290
Number of Disabling Conditions	.215
Number Known Hospital Discharges (past year)	-.041
Number Known LTC Admissions (past 2 years)	.166
Number of Medications in Hospital	-.150
% Nursing Services Used in Hospital	.097
Psychosocial Status	-.156
Anticipated Barthel Score at Discharge	-.332*
Change From Pre-admission Barthel	.049
Pre-hospital IADL	-.120
Family Willing to Maintain at Home (yes/no)	.085

¹Variables are described in Appendix C.

²Home care costs rise relative to institutional costs as value for dependent variable rises; a negative correlation means that as value of independent variable rises, it is probable that cost of home care falls relative to cost of institutional care.

* Significant at .05

** Significant at .01

TABLE VII-M

REGRESSION RESULTS: PATIENT CHARACTERISTICS AND THE
COMPARATIVE COSTS OF HOME AND INSTITUTIONAL CARE

<u>PATIENT VARIABLE</u> ¹	<u>SIGNIFICANCE</u> ²	<u>UNIQUE VARIANCE</u> ³
Anticipated Discharge Site	.001	.236
Anticipated Barthel Score	.002	.156
# of Persons Patient Resides with	.013	.098
# of Disabling Conditions	.087	.044

R² = .465 (.001)

¹Stepping-in stopped when last variable entered not significant at .07.

²T-Test

³Proportion of variation in dependent variable explained by variation in this independent variable.

placement or actual cost of institutional care, which were discussed earlier in this chapter, may dim the conventional view's perspicacity in regard to the study sample.

In general, these regression results support the earlier analysis of the characteristics of patients for whom home care is likely to be less expensive. In this study sample of patients about to enter Massachusetts long-term care facilities, it appears that real opportunities for saving might be found by diverting to home care selected patients bound for relatively intensive levels of institutional care. The study sample is far too small to permit even the suggestion that policies should be re-made to permit greater diversion of such patients. But these findings do suggest the desirability of looking more closely at the possibilities for home care for selected patients in this group.

D. Professionals', Patients', and Families' Views of Cost.

All analyses of cost to this point have concerned only professionals' views of cost of hypothetical home care. Means, medians, and 33rd percentiles of professionals' views have been examined.

This has followed largely from the composition of the available data. The cost of professionals' prescribed plans could be accurately estimated because, as noted in Chapter IV, each home care plan called for a service-by-service statement of the episodes, hours, and providers of care. To protect patients and family members from the stress of a lengthy interview, they were asked only the service-by-service episodes of help required, and whether these episodes would need to be delivered by paid or unpaid providers.

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Thus, a rough measure of the comparative costs of professionals', patients', and families' requests for help may be gained by considering episodes of paid services sought.

There are only 20 patients for whom both patient and family interviews could be completed. For these patients, the median cost of professionals' home care plans was less expensive than institutional care in five of the eighteen cases (28%) in which institutional cost data were available. The median number of paid episodes prescribed by professionals for the 20 patients was 88 episodes of care weekly. Patients sought only 75 paid episodes; family members, 72. Patients sought less help than professionals in eight cases (40%); family members sought less than professionals in 13 cases (65%). As will be seen in Chapter IX, this seems to have been due more to greater reliance on unpaid providers by patients and families than to any meaningful reduction in total episodes thought necessary.

On this basis, it seems reasonable to conclude (barring differences in average durations of episodes for the three groups) that patients' and families' care requests would probably cost a bit less to meet than would the care plans of the median professional. If the mean of professional views were employed, patient and family requests would look cheaper still.

E. Breakdown of Home Care Costs

The total cost of home care has been divided by characteristics of prescribing professions, services prescribed, and providers recommended. In the two discussions that follow, costs of different professionals' views of hypothetical home care need are cross-cut first by services and then by

providers.

Professional prescribers are the five physicians, hospital discharge planners, and home health agency care planners (who together comprise the fifteen consultants), and the three hospital care planners (the patient's physician, discharge planner, and floor nurse). Service sub-totals are personal care, housekeeping, nursing, and medical-therapeutic ("other"). The 41 individual services, sorted into the four sub-totals appear in a list appended to Chapter IV.

As Table VII-N indicates, the three hospital care planners prescribed more expensive care than the fifteen consultants. By analysis of variance, this \$105 per week difference is significant at .005. It is not clear which of these views of need is more appropriate or valid; this question will be taken up in subsequent chapters.

Among the consultants, a range of \$145 was found between the mean weekly costs of physicians' and hospital discharge planners' views. Home health planners fell almost exactly in between. These differences were significant at .001.

A most striking pattern which emerges across the various means of the groups of professionals is the similarity in the proportion of total cost allotted to each of the four categories of service (see Table VII-0).

By calculating the average coefficient of variation across all patients within each professional group, it was found that hospital consultants agreed best about costs, followed by consultant physicians, discharge planners, and home health planners. For no group, however, was agreement about cost very good. The average coefficient of variation across all care

TABLE VII-N
 PROFESSIONAL VIEWS: WEEKLY COST OF CARE DISTRIBUTED
 ACROSS SERVICE SUB-TOTALS

Service Sub-total (\$/week)¹

<u>Professional Care Planner</u>	<u>Personal Care</u>	<u>House- keeping</u>	<u>Nursing</u>	<u>Other</u>	<u>Total</u>
Physicians	\$395	\$81	\$39	\$30	\$545
Discharge Planners	264	76	40	20	400
Home Health	293	107	49	26	475
Consultant Sub-Total	331	90	44	26	491
Hospital Sub-Total	401	104	59	32	596
Total	\$343	\$92	\$47	\$27	\$509

¹ Mean (\bar{X}) for each group

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TABLE VII-0
 PROFESSIONAL VIEWS: PERCENTAGE OF WEEKLY COST DISTRIBUTION
 ACROSS SERVICE SUB-TOTALS

	<u>% OF COST TO</u>				
<u>Professional Care Planner</u>	<u>Personal Care</u>	<u>Housekeeping</u>	<u>Nursing</u>	<u>Other</u>	<u>Total</u>
Physicians	72%	15%	7%	6%	100%
Discharge Planners	66%	19%	10%	5%	100%
Home Health	62%	23%	10%	5%	100%
Consultant Sub-Total	67%	18%	9%	5%	99%
Hospital Sub-Total	67%	17%	10%	5%	99%
Total	67%	18%	9%	5%	99%

planners was 40.9%.

Costs can be broken down into a large number of provider sub-totals. For this analysis, only a distinction between the costs of skilled and unskilled providers will be drawn (see Appendix to Chapter IV for lists of providers by sub-total).

Among the consultants, physicians recommend the most skilled help, followed by discharge planners and home health planners. Differences among consultants are significant at .04. Consultants generally recommend substantially less costly skilled care than do hospital professionals; this difference is significant at .015 and far exceeds the disagreement between consultant and hospital professionals regarding unskilled services. These data are reported in Table VII-P.

The relatively high cost of unpaid providers, 82% of the total across all professionals' care plans, suggests real opportunities for reducing the costs of in-home care. Skilled providers tend to be busy in the course of their visits. By caring for more than one patient in a given location, the only saving would be reduced travel time (an important home care overhead cost). Unskilled providers are busy in much of what they do, but much other unskilled care is devoted to delivering continuous supervision.

This single service required an average of \$293 per week, across all prescribers, patients, and providers. Almost all providers were unskilled. This sum was 70% of the cost of all unskilled care and 47% of the total cost of care. The costs of home care per person would be markedly reduced by a doubling-up of patients. Further, in other areas of personal care, and in housekeeping as well, there exist opportunities for economies of scale.

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These suggestions may run beyond the scope of home care for individuals into shared housing, foster care, and domiciliary arrangements. These all carry difficulties in quality assurance and, in general, they fall beyond the scope of this study. But the clear and predictable opportunities for savings in these areas indicate the need for continuing investigation into the alternatives mentioned. Up to the present, shared housing and foster care seem to have been suggested largely for frail older persons without serious medical difficulties. They may also be suitable sites of care for older citizens who, like many members of the study sample, have problems requiring supervision by skilled professionals.

TABLE VII--P

PROFESSIONAL VIEWS: COSTS OF SKILLED AND UNSKILLED PROVIDERS

<u>PROFESSIONAL</u>	<u>\$/WEEK</u>		<u>TOTAL</u>
	<u>SKILLED PROVIDERS</u> ¹	<u>UNSKILLED PROVIDERS</u> ²	
Physician	\$100 (18%)	\$445 (82%)	\$545
Discharge Planner	67 (17%)	334 (83%)	401
Home Health	62 (13%)	414 (87%)	476
Consultants	79 (16%)	412 (84%)	491
Hospital	153 (26%)	442 (74%)	595
Total	\$ 91 (18%)	\$417 (82%)	\$508

¹Difference among consultants significant at .04; between consultants and professionals at .015.

²Difference among consultants significant at .001; between consultants and professionals at .235.

F. Summary and Implications

This chapter has looked at several aspects of the comparative costs of home and institutional care. First, very different groups of patient characteristics explained actual institutional costs and hypothetical home care costs. This would be appropriate if different aspects of patients actually affected real costs of care in the two settings. Alternatively, if professionals' views of home care need are accurate, the relation of patient variables to institutional costs could well reflect distortions which accompany regulating financial and practical aspects of nursing home placement and payment. There is little relation between hypothetical home care costs and real institutional costs: $R^2 = .02$. Further, median home care hours, which would perhaps better reflect the real burden of providing home care, correlate with institutional costs at only .05.

Several important patient variables were identified which predict whether home care or institutional care would tend to be more (or less) expensive. More intense level of institutional placement, higher Barthel score (functional ability) anticipated at discharge, and greater number of persons residing with the patient at home each predict increased likelihood that home care will cost less than institutional care.

Care in both settings is expensive. By diverting to home care those patients for whom it is markedly cheaper, substantial savings may be won. When these savings are applied to subsidizing the home care of patients for whom it is marginally more expensive, a total of about half of the sample could be cared for at home with no increase in overall spending on these patients.

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Patient and family views about episodes were compared with the median of professional views. Patients and family members generally requested a bit less paid help than professionals thought necessary. This indicates at least that the cost of permitting to patients or family members control over service allocation would probably be no greater than the cost of professional control.

Differences in hours recommended by professionals for the various services and provider groups are clearly statistically significant in most cases. The predominance of unskilled hours in all care plans suggests opportunities could be realized through shared housing, faster care, or other arrangements. In this way, the large share of home care cost which is owing to the need to have a caregiver in place, to prevent or contain harm to patients, is spread over many patients. Clearly, however, moves in this direction must be made with the dangers in mind that the growth of small and unsatisfactory semi-institutions might thereby be nurtured.

The impact on long-term care system cost of diversion to home care of patients for whom home care is no more expensive is unclear. Since it depends on the size and savings accrued from diversion of individuals, on how these savings are spent, on the characteristics of patients diverted and of those who replace them in nursing home (if any), and on the types of controls placed on entry into the expanded home care benefit structure. These important issues fall beyond the scope of the present study.

This chapter contains virtually all of the material that will appear on comparative costs. The discussion from this point will rely on recommended hours of home care as principal units of measurement. Chapter VIII will report on professional-patient-family agreement about care needs and on the relation of patient characteristics to prescribed care; Chapter IX considers the different aspects of agreement among professionals themselves.

APPENDIX TO CHAPTER VII

Provider Charges

<u>Provider Category</u>	<u>Hourly Rate</u> ²
<u>Medical</u>	
M.D.-primary ¹ (internist, G.P., F.P.)	\$55.00
M.D.-specialist ¹	60.00
Dentist ¹	40.00
Podiatrist ¹	24.00
<u>Nursing</u>	
Registered	12.47
Licensed practical nurse	10.05
<u>Personal Care</u>	
Homemaker	4.85
Home health aide	5.17
Personal care attendant	5.74
<u>Support</u>	
Social worker	9.62
Escort service	4.25
Visiting aide	4.00
<u>Therapy</u>	
Physical Therapist	14.00
Physical therapy aide	7.50
Occupational therapist	14.00
Dietician	20.00
<u>Miscellaneous Services</u>	
Meals-on-Wheels ³	1.67 ³
Heavy chore service	8.00
Cleaning service	7.00
Medicab ³	37.50 ³

¹Where applicable a visit or episode rate, equal to 1/2 the hourly rate, was used in calculating costs.

²Based on Medicare, Medicaid, Title XX, and other home care charges in effect during period for which institutional costs were calculated.

³This service was delivered on an episode basis only.

CHAPTER VIII

PROFESSIONAL, PATIENT, AND FAMILY VIEWS OF HOME CARE NEEDS; THEIR RELATION TO PATIENT CHARACTERISTICS

In three sections, this chapter reports: a) the extent of agreement among professionals, patients, and their families about home care needs; b) the relation of patient characteristics to perceived home care needs; and c) the effect of these same characteristics on inter-professional agreement about needs.

A. Do Professionals, Patients, and Family Members Agree About Needed Hours of Home Care?

The brief answer to this question is that they seem to agree fairly well on average but somewhat less well in individual cases. A more detailed answer now follows.

Whenever possible, the patient and the family member (or other caregiver) who knew the patient best were interviewed (separately) to learn how much help they thought was required to permit the patient to live at home in a safe, adequate, and dignified manner. Each was asked, service by service, how many episodes of help would be necessary. A total of 23 (79% of the full participants, who could be interviewed) patients and 36 family members were interviewed.

Overall, the two groups agreed with one another well in most respects. This was especially true of the 20 cases where both patient and family members were interviewed. As seen in Table VIII-A, patients requested a mean number of 118 discrete episodes (such as being bathed or receiving

physical therapy) of service weekly. Family members thought that 130 episodes were necessary. Most of the professional groups, and the professionals on average, recommended slightly more episodes in total than the patients requested, and about as much as the families requested. Professional groups agreed well among one another.

In the area of paid services, however, as indicated in Table VIII-B, both patients and family members sought considerably less paid help than professionals prescribed. Further, regardless of their views of the number of total episodes needed, patients and families--particularly the latter--felt that unpaid providers could carry an appreciably greater share of total episodes than did professionals. Patients believed that unpaid providers could deliver an average of 43 episodes weekly (36% of the total). For family members and professionals, these figures were 58 (45%) and 38 (29%), respectively. Thus, compared to both patients and families, professionals under-estimated both the quantity and proportion of episodes which unpaid providers could deliver.

It is particularly noteworthy that family members were highest in their estimates of availability, ability, and willingness of the informal support system to help sustain patients at home. It might be argued that families are overstating how much help they and other informal supports would provide because they felt guilty at the prospect of their relative being institutionalized. In response, others might assert that family members are best informed about how much the informal supports would be willing to do. Predictions would have to be compared with

Table VIII-A

PROFESSIONAL-PATIENT-FAMILY VIEWS OF TOTAL NEED¹

<u>Need as Viewed by</u>	<u>Total Weekly Episodes Needed in</u>				<u>Total</u>
	<u>Personal Care</u>	<u>House- keeping</u>	<u>Nursing</u>	<u>Other</u>	
Physicians	80	34	22	4	140
Discharge Planners	75	38	27	2	142
Home Health Planners	60	29	18	3	110
All consultants	72	34	22	3	131
Hospital professionals	67	30	23	3	123
All Professionals	71	34	22	3	130
Patients	60	32	23	3	118
Families	70	29	27	4	130

¹_N = 20 patients

Table VIII-B

PROFESSIONAL-PATIENT-FAMILY VIEWS OF PAID EPISODES NEEDED¹

<u>Need as viewed by</u>	<u>Paid Weekly Episodes need in</u>				<u>Total</u>
	<u>Personal Care</u>	<u>House- keeping</u>	<u>Nursing</u>	<u>Other</u>	
Physicians	63	21	19	4	107
Discharge Planners	54	21	19	2	96
Home Health Planners	46	20	15	2	83
All consultants	54	21	18	3	96
Hospital Professionals	40	18	14	3	75
All Professionals	52	20	17	3	92
Patients	43	16	13	3	75
Families	36	15	17	4	72

¹N = 20 patients

behavior to learn whose views of family effort are correct, but the above data, on a small sub-sample, suggest that if professionals were to negotiate with family members about the relative contribution of the latter to home care plan fulfilled by paid and unpaid providers, family members would be forthcoming.

The preceding discussion of perceived need rests on the assumption that the average episode prescribed by professionals is of a duration similar to that requested by patients or their families. Implications of these findings for costs of care sought by the three groups may be suggested if a parallel assumption is made: that the average cost per episode of care by paid providers would be similar across the three groups.

The relatively low imputed value of unpaid help prescribed by professionals themselves can be estimated without such assumptions. Across fifty patients, a mean of 40.7 hours per week of unpaid help was prescribed by professionals. This figure represents the mean across patients of the mean of eighteen individual professionals' prescriptions for unpaid hours for each patient. For this help to be delivered in the absence of family and other unpaid help, paid providers would be required. Perhaps, the most appropriate paid provider to substitute for unpaid help is the generalist homemaker-home health aide. In this study, as noted in the Appendix Chapter VII, the hourly cost of a homemaker-home health aide's care is estimated at \$5.17. Thus, the average cost of replacing unpaid help with that of a homemaker-home health aide is estimated to

be \$210 per week. Table VIII-C summarizes these data and presents quintile values for the cost of substituting paid providers. It can be seen that for many patients, even the relatively low professional estimates of hours of unpaid help represent a considerable contribution to home care.

To this point, the examination of the extent of agreement among professionals, patients, and family members about needed home care episodes has compared only the averages of each group's recommendations. When the number of episodes recommended for individual patients is examined using Pearson product-moment correlation analysis, agreement fades badly in many cases. In general, the patient-family diad showed best agreement. Patient-professional and family-professional agreement about total episodes of care needed was only fair; about paid or unpaid episodes, it was worse still. (See Table VIII-D.) These data indicate that disagreements about individual patients across patient-family-professional lines can be obscured when averages alone are considered. For program of budgetary purposes, congruence among the three groups is excellent; when planning care for individuals, conflicts may well be anticipated.

B. Patient Characteristics and Different Views of Need

It was argued in earlier chapters that Barthel score anticipated at discharge, a reliable and valid measure of independence in functional ability (in activities of daily living), is probably the best single

TABLE VIII-C
THE IMPUTED VALUE OF UNPAID HELP PRESCRIBED
BY PROFESSIONALS

A.	<u>Value Unpaid Help</u>	<u>Mean of Means</u>	<u>Mean of Medians</u>
	Hours/week	40.7	35.3
	Value/week	\$210	\$182
B.	<u>Distribution of Mean Hours and Value</u>	<u>Hours/Week</u>	<u>Value/Week</u>
	Patient with highest prescribed hours	85.7	\$443
	10th	72.4	374
	20th	57.0	295
	30th	30.7	159
	40th	8.6	44
	Patient with lowest prescribed hours	1.5	8

TABLE VIII-D

PATIENT - FAMILY - PROFESSIONAL AGREEMENT

ABOUT NEEDED EPISODES OF HOME CARE

PEARSON PRODUCT MOMENT CORRELATION

	<u>r</u>	<u>r-squared</u>	<u>p¹</u>
<u>A. TOTAL EPISODES</u>			
Patient - Family	.67	.45	.002
Patient - Professional ²	.50	.25	.030
Family - Professional ²	.57	.32	.010

<u>B. PAID EPISODES</u>			
Patient - Family	.70	.48	<.001
Patient - Professional ²	.26	.07	.266
Family - Professional ²	.35	.12	.141

<u>C. UNPAID EPISODES</u>			
Patient - Family	.74	.55	<.001
Patient - Professional	.43	.19	.061
Family - Professional	.25	.06	.283

¹Two - tail test

²Mean of 18 professional care planners
n = 20

In several cases, patients or family members deferred to professional judgment for various technical sources. Professional views of these deferrals have been included in the appropriate patient or family totals.

predictor of need for home care services. Barthel score is not only important in itself. In the present study, it also correlates well with other variables which can reasonably be expected to affect need for home care services. For the sample of 50 patients, anticipated Barthel at discharge relates significantly to psychosocial status ($R^2 = .17$; significant at .01) and independence in instrumental activities of daily living ($R^2 = .09$; significant at .05). While these Pearson product-moment correlations are not impressive, they do lend some support to an agreement that anticipated Barthel score is a fairly good predictor of the overall need for home care.

Pearson correlations were performed for patients' anticipated Barthel scores with the number of episodes of home care requested by patients, family members, and the mean of professionals. Each group sought reasonable numbers of episodes of home care; requested episodes bore a clearly negative relation to functional ability. (See Table VIII-E.) Each group considered that patients with greater functional ability indeed needed fewer episodes of home care. According to each of the three groups, the relation was roughly linear. Professionals appeared to adhere closest to this pattern, although the use of an "average" professional care plan makes comparability of R^2 values difficult.

It is not possible to say, on the basis of this analysis, that any one of the three groups of prescribers can be trusted to write care plans which are clearly most equitable. All three can distinguish patients who seem to need more care from those who need less;

TABLE VIII-E

WHAT IS THE RELATION OF THE NUMBER OF EPISODES OF HOME CARE REQUESTED BY PATIENTS, THEIR FAMILIES AND PROFESSIONALS TO PATIENTS' ANTICIPATED BARTHEL SCORES?

Anticipated Barthel Score at discharge with number of home care episodes requested by:	<u>Pearson Product - Moment Correlation</u>		
	<u>r</u>	<u>r - squared</u>	<u>p¹</u>
Patient	-.62	.39	.005
Family	-.57	.32	.010
Professionals ²	-.76	.58	<.001

¹One-tail test

²Mean of 18 professionals

professionals are best able to do this. The nature of the relation of anticipated Barthel score to needed episodes of care has not, however, been established well enough to say with assurance that professionals are more likely to have been right. It is, for example, possible that professionals are on average over-rigid in their use of the anticipated Barthel score standard.

Because interviews with both patients and family members could be obtained in only 20 cases, the above analysis of equity of care planning by members of the three groups is certainly limited in its generalizability. For the same reason of sample size, only the relation of professionals' prescribed hours of home care to patient variables will now be examined in detail. The purposes of this examination are first, to learn how predictable are professionals' views in light of patient characteristics and second to compare this predictability across different areas of home care services and providers.

Patient variables and professionally prescribed hours of home care. Sixteen different patient characteristics, the same as those employed in chapter VII, were selected as independent variables for multiple regression analyses. (The importance of these variables is described in Appendix C to this study.) Dependent variables considered first were hours of care prescribed by the average of the eighteen professionals in eight service areas, five different sub-totals of services, and total hours. A series of five tables, VIII-F to VIII-J, appended to this

chapter, reports the results of these regression analyses. These results are now discussed.

Several findings are salient. First, given the small sample size, it is interesting to note that from three to six independent variables bore statistically significant relations to each dependent variable. Second, these variables "explained" a high proportion of the variation in the dependent variables, as shown by the R^2 results. The high R^2 s thus indicate that just a few independent variables are useful in predicting hours of home care prescribed by the mean of professionals. This means that professional views are, on average, relatively predictable--a finding of no small importance. Professionals' plans may or may not be effective, but they do at least seem reasonable. Further, the integrity or reasonableness of average professional views is reinforced by the selective predictive utility of different variables for different services and service sub-totals. That this selectivity seems reasonable will be shown by the nature of association between classes of variables. Documentation for these findings follows.

The dependent variables selected for analysis are the four service sub-totals, one-three of the individual services making up each sub-total, total prescribed hours, and total minus continuous supervision hours. The last item was included because about 51% of all hours prescribed by professionals were on average allotted to the one service, continuous supervision. The eight individual services analyzed were selected as interesting illustrations of the care planning process and

because it was thought that they were important and fairly representative services.

For personal care services (Table VIII-F), the proportion of variation in prescribed hours explained by just a few independent variables (R^2) is quite high. While this explanation does not go so far as to indicate that care plans are valid, it does indicate that the "average professional" used this information about patients in a consistent manner. Patients with lower functional ability were thought clearly to need more help; younger patients, less help; and so on. It is, however, surprising that the family's willingness to maintain the patient at home should be negatively associated with prescribed total hours. A negative relation of family willingness with paid hours on total cost would be expected; with total hours, not.

Professionals were not able to use data about patients to prescribe needed hours of household help in so consistent a manner. The R^2 's in this group are measurably lower. In each case, however, prescribed hours of care appear most sensible. This is particularly true for transportation (Table VIII-G), which at first glance seem to suffer from reversal of coefficients' signs: high Barthel and psychosocial status, for example, are associated with greater prescribed help with transportation. The most reasonable interpretation here is that some patients were thought safe to transport more frequently because they were in better condition.

The pattern of professional prescribing in the nursing field also indicates that appropriate variables informed decisions. Witness the importance of nursing services used in hospital to total prescribed hours of nursing care, and the importance of Barthel change to the need to monitor vital signs (Table VIII-H).

In the medical-therapeutic area, patients whose institutional placement was expected to be indefinite (probably because they had suffered too much harm or lacked informal support permitting them to go home) were thought by professionals to need markedly less care overall and less physical therapy in particular (Table VIII-I). It cannot be said whether this represents reasonable resource allocation or a tendency to invest too little effort in actively caring for patients not expected to improve.

The prescribed total need for home care, and for the total less continuous supervision, is explained very well by only a few patient characteristics: anticipated Barthel score, age, and psychosocial status. This high R^2 suggests that "cookbook" formulas might be useful in establishing guidelines for budgeted home care hours for patients with given characteristics. Only a few such characteristics might have to be recorded and incorporated into possible care planning or utilization review equations. Of course, this should not be done until the average of the professionals' views, or some other standard of home care need, is actually validated.

Regression results on mean prescribed hours have, to this point, concerned only individual services or service sub-totals. Regressions were run as well on the provider sub-totals. Multiple correlations and their significance are the only results on providers which will be discussed. These are presented in Table VIII-K, at the end of this chapter. Worth noting are these points: patient characteristics generally have better power in explaining differences in average prescribed hours for the unskilled providers or for the unpaid providers (particularly residents of the patient's household), than for the skilled providers or the paid providers. Thus, for example, in light of families' declared willingness to provide more episodes of care than professionals prescribed--both absolutely and proportionately--it is of interest to note the high R^2 relations patient variables to mean hours of unpaid help prescribed by professionals. Professionals may be underestimating family ability or willingness to provide help, but they are doing so in a most reasonable manner, given the information made available to them.

C. What Are the Characteristics of Patients About Whom Professionals Agree?

Across the 50 patients of the study sample, an average of 124.8 hours of home care weekly was prescribed by the mean of the eighteen professional care planners. One measure of agreement among professionals about an individual patient's needs is the standard deviation across the

eighteen professionals' hours of care prescribed for that patient. The standard deviation ranged from 11.9 to 67.1 hours weekly. The mean standard deviation across patients was 48.8 hours weekly.

But is the standard deviation a good yardstick for measuring how well professionals agree about one patient versus another? A general trend has been observed (empirically), in many areas, that standard deviations tend to increase with the mean. In these instances, variability may be compared by using the relative standard deviation or "coefficient of variation," the standard deviation's proportion of the mean.

In the present study, it has been decided to use the standard deviation to examine the characteristics of patients about whom professional agreement is best and to use the coefficient of variation for inter-service and inter-provider comparisons. This is because, across patients, the standard deviation does not increase with the mean. Rather, the relation between the two is slightly negative: $r_s = -0.129$ (Spearman rank-order correlation). Thus, to use the coefficient of variation as the inter-patient yardstick would inappropriately over-control the standard deviation in prescribed hours per patient.

Patient characteristics have been found to explain between 13.5% and 41.2% of the differences in standard deviations in professionally prescribed hours for each patient. In personal care, lower age, lower

pre-hospital IADL independence, and greater family willingness to maintain the patient at home characterized patients about whom professional agreement was better. (See Table VIII-L.) Among the household services, professional agreement was better for patients whose Barthel scores had fallen relatively little and for patients whose psychosocial status was judged relatively poor. Poor psychosocial status, low anticipated Barthel score, and use of many nursing services in hospital were associated with better professional agreement about hours of nursing care needed. Agreement about medical-therapeutic services (Table VIII-M) was better for patients whose institutionalization was expected to last indefinitely, whose anticipated Barthel score was expected to be high, and whose psychosocial status was relatively poor.

For the important service called continuous supervision, agreement was good for patients who were younger, had lower pre-hospital IADL scores, and used more nursing services in hospital. The category, all hours of care other than continuous supervision, presents a different picture: higher Barthel score meant better agreement, as did discharge to a more intensive level of care.

Agreement about total home care hours was predicted principally by greater family willingness to maintain patients at home and lower patient age (Table VIII-N).

Why professional agreement is better about patients with certain characteristics, and why presence of particular characteristics en-

hances agreement in some areas but not others cannot be answered by the foregoing exploratory discussion. But there is a wide range in the standard deviation in prescribed hours across individual patients. Better information about the factors enhancing agreement about particular service needs of particular patients might help yield improved understanding of how professionals plan care. This sort of detailed look at the building blocks of the home care plans might help professionals make manifest their own views of service need and expected effectiveness. The importance of this incremental approach to care planning will be more apparent after the material in the following chapter has been presented.

Earlier in this section, the intention was stated to employ the coefficient of variation to compare agreement among professionals about need for specific services, service sub-totals, and provider sub-totals. Appendix E to this dissertation presents these descriptive data. Selected patterns are now briefly identified.

Among the service sub-totals themselves, the lowest coefficient of variation is found for household services, followed by personal care, nursing, and medical-therapeutic (in that order). Average coefficients of variation across 50 patients are lower for sub-totals than for individual services. This probably reflects a cancelling-out of the individual differences.

Among the personal care services, bathing's coefficient of variation was lowest; that for periodic checking was highest. Among household

services, best agreement was about shopping; the worst, about assistance with telephoning. For nursing: best was monitoring of vital signs; worst, decubitus care. For medical-therapeutic services, best was primary medical care; worst, dentists' services.

The pattern which emerges here is that professionals generally agreed best about hours of care required to discharge more necessary and pressing functions. This might have been expected; its presence is nonetheless a reassuring sign pointing toward the reasonableness of professional decision making. It should also be noted, however, that while agreement is better about the more necessary and pressing services, it seems none too good overall. Across 50 patients, a mean coefficient of variation equal to 41.7% of prescribed hours suggests wide confidence intervals. The extent and nature of inter-professional agreement about patients' care needs is the subject of chapter IX.

D. Summary of Findings: Their Implications

In the first section of this chapter, evidence was offered to indicate that, on average, agreement was good among professionals, patients, and family members about needed episodes of home care. This agreement was not very good in individual cases, but differences tended to average out. That averaging out occurs is important because it suggests that the preferences of the three groups could be accommodated within a single program budget. Agreement about planning care for individual patients--how to carve up the budget--is by no

means as good (as the Pearson product-moment correlations indicated).

Of particular interest was the finding that family members' estimates of the number of episodes unpaid providers would deliver was the highest of the three groups--both absolutely and as a proportion of total episodes. Because the number of hours of unpaid help could be calculated only from professional care plans, these were used to estimate the imputed values of unpaid help. These values for most patients were significant, pointing to the potential importance of family effort on behalf of a group even so ill and disabled as the study sample.

The second section of the chapter took up the relation of patient characteristics to prescribed care. Members of all three groups--professionals, patients, and family members--sought episodes of care whose numbers varied inversely with anticipated Barthel score. This negative relation points to the reasonableness of all three groups of care planners.

A more detailed look at the relation of professional prescriptions to patient characteristics was made possible by the larger sample size available for this analysis. Multiple regressions were performed on the mean number of hours prescribed per patient (across eighteen professionals) for a group of different services and service and provider sub-totals. Mean professionally prescribed hours could be approximated with fair accuracy (R^2 typically $> 60\%$ were found) using only a relatively small number of patient characteristics. The particular characteristics

varied in sensible relation to the dependent variable, in most cases, further testifying to the overall reasonableness of the average professional's prescription. This reasonableness may be taken as an indication of equity in care planning, in that patients who, by their characteristics seem to need more care, have more care prescribed for them. A similar pattern was identified earlier, in which episodes of care sought by patients, family members, and professionals all bore equitable relations to anticipated Barthel score. This evidence on equity is by no means strong or conclusive. It does, however, point in an encouraging direction.

Finally, the third section of this chapter explored the relation of patient characteristics to professional agreement: who were the patients (and for which areas of home care) about whom (which) professional agreement was relatively good? No firm conclusions emerged from this exploratory analysis, but more careful work in this area might help to build a firmer foundation of professional agreement about patients' home care needs. The same can be said about the extent of professional agreement about particular services and providers. Here, consistency seemed better about the more necessary or pressing services, but it was not very impressive in most areas.

The extent of professional agreement about all aspects of the hypothetical home care needs of the elderly is taken up in the next chapter.

TABLE VIII-F

REGRESSION RESULTS: PERSONAL CARE: MEAN PRESCRIBED HOURS AND PATIENT VARIABLES

Patient Variable	S.T. Personal Care			Bathing			Eating-Drinking		
	Std. Coeff. ¹	Sig. ²	Unique Var. ³	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Antic. Barthel	-.657	<.001	.346	-.855	<.001	.686	-.547	<.001	.232
Resides with				.134	.051	.017			
Main. at home				-.123	.074	.014	-.177	.115	.025
Age	.349	<.001	.106						
Psychosocial	-.239	.013	.046				-.245	.037	.045
# disabl. cond.							.280	.011	.069
R ²		.707			.821			.582	
Significance		<.001			<.001			<.001	

¹Standardized coefficient.²F-test.³Proportion of dependent variable explained by this variable alone.

TABLE VIII-G

REGRESSION RESULTS: HOUSEHOLD SERVICES: MEAN PRESCRIBED HOURS AND PATIENT VARIABLES

Patient Variable	S.T. Household			Transportation			Light Housekeeping		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Antic. Barthel	-.267	.062	.056	.392	.004	.123			
Antic. disch. site				.374	.004	.122			
Age				-.279	.027	.068			
Psychosocial	-.238	.095	.045	.215	.096	.037	-.302	.015	.076
Marital stat.							.411	.002	.144
IADL	-.256	.061	.057				-.396	.004	.112
# diagnoses							-.267	.026	.062
Indef. place?							-.247	.049	.048
R ²		.325			.450			.523	
Significance		<.001			<.001			<.001	

TABLE VIII-H

REGRESSION RESULTS: NURSING SERVICES: MEAN PRESCRIBED HOURS AND PATIENT VARIABLES

Patient Variable	S.T. Nursing			Monitoring Vital Signs		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Barthel change				.516	.001	.188
# disabl. cond.				.275	.032	.070
IADL				-.268	.066	.051
Antic. disch. site				-.228	.073	.048
Antic. Barthel	-.372	.002	.099			
% nurs. serv.	.382	<.001	.128			
Psychosocial	-.367	<.001	.108			
Reside with	.168	.076	.027			
R^2		.653		.388		
Significance		<.001		<.001		

TABLE VIII-I

REGRESSION RESULTS: MEDICAL-THERAPEUTIC SERVICES: MEAN PRESCRIBED
HOURS AND PATIENT VARIABLES

Patient Variable	S.T. Med.-Ther.			Primary Med.			Physical Therapy		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Indef. place?	-.568	<.001	.269	.240	.080	.057	-.609	<.001	.356
Antic. Barthel	-.330	.012	.077				-.489	<.001	.229
Marital stat.	.260	.041	.049						
# disabl. cond.				.345	.018	.108	-.184	.082	.033
# current meds.				.285	.046	.075			
R ²		.527			.225			.546	
Significance		<.001			.011			<.001	

TABLE VIII-J

REGRESSION RESULTS: TOTALS: MEAN PRESCRIBED HOURS AND PATIENT VARIABLES

Patient Variable	Total			Continuous Supervision			Total Minus Cont. Super.		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Antic. Barthel	-.670	<.001	.359	-.524	<.001	.220	-.596	<.001	.209
Age	.317	<.001	.088	.396	<.001	.137	.175	.023	.025
Psychosocial	-.276	.003	.061	-.244	.038	.048	-.287	<.001	.065
Antic. disch. site	-.142	.086	.018						
% nurs. serv.							.224	.004	.042
R ²		.754			.553			.813	
Significance		<.001			<.001			<.001	

TABLE VIII-K

REGRESSION RESULTS: PROVIDER SUB-TOTALS (MEAN HOURS)

Category of Providers ¹	R ²	Significance
Medical	.190	.009
Nursing	.383	<.001
Care	.530	<.001
Support	.412	<.001
Therapy	.477	<.001
Miscellaneous	.395	<.001
Paid	.475	<.001
Unpaid	.640	<.001
resident	.674	<.001
non-resident	.368	<.001
Skilled	.421	<.001
Unskilled	.711	<.001
Total	.754	<.001

¹See appendix to chapter IV for categorization.

TABLE VIII-L

REGRESSION RESULTS: PATIENT CHARACTERISTICS AND PROFESSIONAL AGREEMENT: SUB-TOTALS

Patient Variable	Personal Care			Housekeeping			Nursing		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Age	.340	.014	.116						
Main. at home	-.251	.066	.062						
IADL	-.194	.153	.037						
Psychosocial				-.302	.034	.091	-.346	.010	.098
Barthel change				-.235	.097	.055			
Antic. Barthel							-.319	.022	.076
% nurs. serv.							.224	.074	.045
R ²		.235			.143			.412	
Significance		.008			.032			.001	

TABLE VIII-M

REGRESSION RESULTS: PATIENT CHARACTERISTICS AND PROFESSIONAL AGREEMENT: SUB-TOTALS

Patient Variable	Medical-Therapeutic			Continuous Supervision			Total Minus Cont. Super.		
	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.	Std. Coeff.	Sig.	Unique Var.
Indef. place.	-.424	.003	.167						
Antic. Barthel	-.308	.035	.078				.295	.042	.084
Psychosocial	-.199	.175	.031						
Age				.262	.062	.065			
IADL				-.334	.019	.106			
% nurs. serv.				-.234	.102	.049			
Antic. disch. site							.172	.228	.029
R ²		.276			.229			.135	
Significance		.003			.010			.039	

TABLE VIII-N

REGRESSION RESULTS: PATIENT CHARACTERISTICS AND
PROFESSIONAL AGREEMENT: TOTAL

Patient Variable	Std. Coeff.	Total Sig.	Unique Var.
Maintain at home	-.283	.052	.071
Age	.276	.044	.076
# known LTC admissions	.180	.210	.029
R^2		.225	
Significance		.011	

CHAPTER IX

AGREEMENT AMONG PROFESSIONALS: PATTERNS OF CONSISTENCY AND VARIATION

A. Introduction

This chapter will examine the extent of agreement among professionals about the home care needs of the elderly. If professionals agree well, such reliability points to the possibility that prescribed services would be effective. And, given the difficulty of measuring effectiveness of long-term care services, this pointer would be most welcome. If professionals do not generally agree well, it would be desirable to explore when they do agree and, if possible, why. This would indicate opportunities for improving reliability in the future. Multiple clusters of views, if they were found to exist, would point to opportunities for clinical trials or natural experiments to attempt to learn who is right. Finally, low levels of professional agreement, could help open the door to greater patient and family influence over the design of home care plans.

There are four potential sources of disagreement among professionals about the hypothetical home care needs of the elderly patients who comprise the sample of the present study:

1. The phrase "safe, adequate, and dignified" may be interpreted to mean service at different levels in different areas of home care. Goals may vary; household services may matter more to one professional; continuous supervision and medical monitoring may matter more to another.
2. Given agreement about goals, professionals may synthesize the discrete objective data on the PACE form into varying pictures of patients' overall condition.

3. Given agreement about goals and current status, professionals may disagree about prognosis--the path the patient might take absent care.

4. Even given agreement about the foregoing, professionals could still disagree about the types, quantities, and providers of home care required to move the patient from current status along a desired trajectory toward particular goals. In view of these opportunities for disagreement, the reader will not be surprised to learn that the following sections report much variety in professional prescriptions. What is surprising is the many types of agreement about home care needs and the depth of these agreements.

Failure to define the word "agreement" is not the source of this apparent paradox, although different meanings will indeed emerge below. There really is no a priori way to identify when agreement fades to disagreement. Rather, it must be decided in specific instances whether the extent of agreement which may be expected is sufficient for the purpose at hand. Even weak agreement is enough to support parimutual wagering on horse races; somewhat better agreement on rules of ordinary behavior is adequate to govern Boston-area auto drivers (except at rotaries); but only excellent agreement among engineers will persuade public authority bond underwriters that a bridge will support investors' financial risks.

Section B of this chapter will present progressively disaggregated views of the extent of professional agreement about the hypothetical

home care needs of the members of the study sample. In the course of disaggregation, various groups' views of different needs will be presented and contrasted. The relation of professional variables--role, training, information, and experience--to types and quantities and providers of care prescribed (and to agreement about them) will be analyzed. Such questions as, Do professionals recommend more care or agree better about care in their own disciplines? will be addressed. Better agreement in a professional's field of expertise might reassuringly point to validity. (It might, alternatively, point to blind worship of in-bred error, but this is less likely.) Another question addressed is whether intra-profession agreement exceeds inter-profession agreement. Techniques of analysis of variance and factor analysis are employed to begin to re-aggregate the data into understandable patterns.

The need to build such patterns is considerable. For example, any attempt to understand how well individual professionals agree about which providers should deliver what proportions of individual service to individual patients would require examination of an $18 \times 58 \times 41 \times 50 \times 3$ (= 6,420,600-celled) matrix.

Section C continues the task of re-aggregation and analysis. The techniques of Cronbach's Alpha and Kendall's W are used, in conjunction with certain regression results introduced in chapter VIII, to seek patterns of professional agreement about patients' home care needs. Areas of relatively good and bad agreement are identified, along with possible explanations for the various patterns. The chapter closes with a brief summary of findings and discussion of their meanings.

B. Patterns of Professional Care Planning

This section will begin by presenting progressively disaggregated views of professionals' home care plans. It will consider different groups and groupings of professionals' prescriptions about total need, need for various categories of service and care providers, and need for individual services. At the same time as the content of the care plan is being sliced finer and finer, the study sample is being disaggregated as well.

By means of disaggregation, the relation of professional variables to care plans' content, and to agreement about that content will be measured. Analysis of variance and factor analysis will aid in this measurement, which at the same time beginning the task of re-aggregating professional care plans into analyzable levels of generalization.

Service groupings. Table IX-A-1, which appears at the end of this chapter, presents the number of hours per week prescribed by different care planners grouped by role for the mean of the 50 patients who make up the study sample. It will be seen that the means of the three groups of consultant physicians are very similar in total and fairly similar for the various sub-totals. Agreement between the mean of the fifteen consultants and the mean of the hospital professionals is not as good, either in total or for the various sub-totals.

Also noteworthy in Table XI-A-1 is the distribution of the proportion of total hours assigned by the means of the three consultants

to different sub-totals. Physicians are highest on personal care and medical-therapeutic hours; home health care planners are highest on household and nursing hours. Hospital discharge planners fall in between on most sub-totals and are lowest on total hours. Hospital professionals recommended more hours of care than consultants in all categories.

Table IX-A-2 contains the results of one-way analysis of variance (means comparison, repeated measures) tests of the extent of agreement among consultants, and between consultants and hospital care planners. The prescriber variable is significant for most service groupings for both comparisons. Disagreement about needed household services and about total hours minus continuous supervision was particularly strong.

A somewhat different picture emerges when agreement by type of training is examined. (This concerns only consultants, so hospital consultants are excluded to avoid repetition.) Disagreement among consultants by training is considerably greater when specific categories of services are examined, but agreement about total hours of home care needed is just as good as when consultants were grouped by role. It should be noted that both nurses and physicians tended to recommend more care in their own areas of specialization (see Table IX-B).

Professional agreements about specific care needs of patients for specific services have been analyzed. Seven services were selected

from among the 41 for a closer look at inter-professional agreement. Considering first the role of the professionals, no one group of consultants consistently prescribed more hours of care across the services. Rather, ranking of consultant group varied from service to service. In all cases, however, the hospital consultants continued to recommend more care than did consultants. The explanatory power of the prescriber variable among consultants was generally greater for specific services than it was in the case of service sub-totals. (See Table IX-C-2.) Between the means of consultants and hospital planners, however, it was lower, indicating better agreement between the two groups of consultants about these specific services than about the sub-totals.

When consultants are re-grouped by their training, a more dramatic set of differences emerges (Table IX-D). For several of the specific services, the explanatory power of the variable of professional training is very great indeed. This is particularly true for the services in which none of a fairly wide range of views might be expected to harm patients: housework, transportation, or bathing. Agreement about specific care needs for services such as monitoring of vital signs and primary medical care remains relatively good. In general, agreement seems better for services requiring skilled providers.

The descriptive review of agreement about means of patients' needs now concludes with a brief examination of the consistency of professional

views of which groups of providers are needed. Inspection of the data in Table IX-E-1 indicate that there is little disagreement among professionals grouped by role, and only a bit more disagreement between consultants and hospital care planners. Although most differences among and between the means are statistically significant, the explanatory power of the prescriber variable is weak in most cases (see Table IX-E-2). A similar pattern holds for consultants grouped by training (Table IX-F). For all skilled providers, grouped together, agreement is not as good as for unskilled providers. This difference, however, is minor in all cases.

Summary to this point. What has been established thus far? It has been shown that agreement regarding total hours of needed care among and between professional groups about the needs of the members of the study sample as a whole is fairly good. When total hours of need are split into service and provider sub-totals and into specific services, however, inter-group agreement falls. Agreement is particularly poor among consultants when they are grouped by training. This indicates that training is a more important influence on the prescriptions of study consultants than is role. Another clear pattern is that hospital professionals generally prescribe more care, by all measures, than do consultants. This point will be recalled shortly, as part of the discussion of the effects of information.

Prescribed care and professional experience. The relation between consultant professionals' years of practice in direct patient care and the number of hours of home care service they recommend has been measured by Pearson product - moment correlation. A slight negative relation has been found ($R = -.35$; $R^2 = .12$; significance = .199), indicating that prescribed hours generally decline as professional experience increases. This relation is so slight that it could have been found by chance about one time in five. It does, however, point to the possibility that experience encourages or permits professionals to be less cautious or conservative. With greater experience, they may learn or believe that patients may remain safely at home with a bit less care than they had thought necessary earlier in their careers. The seven less experienced professionals recommended an average of 131 hours weekly; the eight more experienced, 115 hours. This was a difference of 14% or one hour in seven.

Variations in intra-group disagreement. Which groups of professionals, defined in what ways, show the strongest consistency in their views of patients' needs? Using group coefficient of variation as the standard for comparison, consistency among hospital professionals is seen to be superior to that among the consultant professionals collectively (Table IX - G). This distinction is so strong that the question should be posed whether a difference between the size of the hospital professional group (three) and the consultant group (fifteen) affected this compari-

son. Inspection of Table IX - G does not, however, point to a general relation between group size and coefficient of variation. Nor is there any logical reason to suspect such a relation.

A possible influence here may be one of method. In the hospitals, the three consultants may have had opportunities to discuss the content of their care plans, perhaps while assisting one another in understanding how to complete the form. This is not considered likely. What remains then is to suspect that the better information about patients gained by hospital care planners in the course of their personal associations enhanced the consistency of these professionals' prescriptions.

Whether consultants are grouped by role or by training, only small differences among intra-group coefficients of variation in total hours are found. The most noteworthy distinctions appear when consultants are grouped by training. Social workers' coefficients of variations are lowest across almost all service categories. Social workers distinguished themselves best in the nursing services sub-total. It could reasonably have been expected that nurses would have agreed best in their own field, but they may have held differing though well-grounded views of need (based on different experience) while social workers adhered to a common pattern perhaps based on elements in past training.

Agreement and information. It will be recalled that the three hospital care planners relied on PACE data plus their own detailed personal information about all patients. At the other extreme, nine of the fif-

teen consultants had access only to PACE data in all cases. For the six "visiting" consultants, this pattern was deliberately altered. These six briefly visited patients at the Boston area hospitals and wrote care plans based on this information and the PACE data. For the remaining patients in the study, from the hospitals outside Boston, these six "visiting" consultants relied only on PACE data. Thus, by three-way analysis of variance, it has been possible to control for the effects on care planning of both information available to prescribers and characteristics of patients.

Across all fifty patients, as Table IX-H-1 makes fairly clear, an average of 125.4 hours of care was prescribed weekly by the mean of the eighteen care planners. The mean across patients for the three hospital consultants was above 141 hours; for the six "visitors," 129.8 hours; and for the nine PACE - only "non-visitor" consultants, 117.1 hours. A pattern seems to have emerged, that more information about patients is associated with higher prescribed hours. Is this in fact the case?

Hospital professionals clearly prescribed more hours of care. It might be speculated that this was due to relatively poor familiarity with the care planning form, or perhaps due to inexperience with care planning in general, and the inter-personal trade-offs that are often involved. Consequently, it might be thought, hospital professionals tried to write even hypothetical plans that would seek to obtain for patients all possible resources. These speculations are probably only that. Reduced familiarity with the care planning form may have

led to some duplications, as professionals inexperienced with the form sought to ensure that needed services were delivered. But one group of hospital professionals are well experienced in care planning and in weighing the needs of one patient against another's; they thereby test this hypothesis. These are the hospital discharge planners, whose mean prescribed hours (147.6) was slightly above the average for hospital professionals. Moreover, these care planners were fairly well acquainted with the care planning form, having the job of explaining its use to other hospital professionals. A final point in support of hospital care planners' view of need comes from their relatively low intra-group coefficients of variation across the different categories of service, as noted above.

Does the positive relation between information and prescribed hours of home care extend into the consultant category, as appears to be the case? Probably not. It seems rather that the higher hours prescribed by "visitors" is a consequence of the characteristics of the professionals as individuals, rather than of the better information available to them (on some patients).

How is this known? First, the reader can see, by inspecting Table IX-H-1, that the "visitors" prescribed more care for both groups of patients -- the thirty four not visited and the sixteen visited. (More care, that is, than the nine "non-visitors" prescribed for the two groups of patients.) Second, as indicated in Table IX-H-2, part B, the interaction between patient status (visited or not) and prescriber status

(visitor or not) has absolutely no measurable influence on prescribed hours of home care. Rather, visiting status of prescribers, particularly in interaction with prescribers' professional role, has fairly considerable impact on prescribed hours and is statistically significant beyond .001. The explanatory power of visitor status alone was only 1.9%; but visitor status interacting with professional role explained 6.6% of the total sum of squares in this three-way analysis of variance. It seems that, the more discretely care planning by various professionals is examined, the greater the disagreement among professionals. Complete disaggregation of a representative care plan is discussed following a brief summary of this discussion of the effects of information on professionals' prescribed hours of care.

Professionals with the best information about patients tended to prescribe the greatest amounts of care. But the brief visit made by some consultants to some patients does not seem to have affected the magnitude of the care plans at all. Visits may have led to more sensitive allocations of hours of care within the total, but this cannot be measured. Hospital prescribers recommended more hours of care in almost every service or provider category (see Table IX-A-1, -C-1, and -E-1). This raises the suspicion that the greater number of hours may be more than the product of better information. It may also follow from a relatively indiscriminate outlook -- that older people need more home care of all types. Such a suspicion indicates a need for a closer examination of hospital planners' views, before it is decided that these may be par-

ticularly valid.

Complete disaggregation. In this section, increasingly discrete looks have been taken at care planning: by professional role, training, information; by service and provider sub-totals and by individual service. When to these is added distinctions among patients, the extent of agreement among professionals appears by inspection to break down entirely. Refer to Appendix D of this thesis for a photocopy of a complete care plan on one patient, selected at random. The four sheets form one care plan with services down the left hand margin (with appropriate sub-totals and total) and individual prescriber labels across the top (with various group means). There appears to be little agreement, either within a profession or across professional boundaries, about any aspect of the care plan. In the course of attempting to analyze these data, it was realized that appearances could be deceiving, that the mass of data about patients, prescribers, services, and providers could obscure patterns of agreement and disagreement of some importance to better understanding patient needs or to building firmer future foundations for care planning. Similarly, it was feared that important differences could be masked by inspection of grouped data alone: distinctive patterns of variation could be hidden by averaging. This has undoubtedly been the case to some extent for the grouped data discussed earlier in this section. To re-aggregate discrete pieces of information about individual patients, to seek patterns of agreement and difference

among professionals, several statistical tests have been employed. These are factor analysis, Cronbach's alpha, and Kendall's W. The present section concludes by indicating how factor analysis seems to produce certain meaningful patterns of inter-professional agreement. Section C then presents and discusses the results produced by the two other tests.

Throughout, it is of interest to see how seemingly formless data, those which appear in the individual care plans, actually constitute very definite and consistent patterns. While these patterns are not quite of a nature which inspires the confidence in reliability of professional views which has been posited as a pointer toward validity, they do indicate that professional care planning is a deliberate, thoughtful, and internally consistent process. These results are encouraging; they will now be presented.

Aggregation through factor analysis. Factor analysis was performed on the hours of care recommended by different groups of professionals to learn from another vantage point whether inter-profession agreement (by role or training) was stronger than intra-profession agreement. Clusters of consultant care planners were formed in interesting patterns.

Using varimax rotation and .5000 as the cut-off for assignment of consultants to groups, four factors were formed on total prescribed hours, and from three to six factors on the various service sub-totals. Factors were included only if their Eigenvalues exceeded 1.0. By this

cut-off standard only a few consultants were left outside all groups; this happened in only two of the sub-totals. In a few cases, individual consultants were loaded on to more than one factor.

Inspection of the members of factors formed by these procedures indicates no consistent pattern of agreement within boundaries of professional role (Table IX-I). Physicians, discharge planners, and home health planners cluster together fairly tightly, but across roles. Professional roles are thus not associated with agreement about needed home care -- either in total or in most of the four service sub-totals. (An exception is the nursing sub-totals: discharge planners and home health planners sorted themselves into two groups in this case.)

In sum then, the extent of agreement across lines of professional training is better than agreement within these lines. Patterns of agreement, while fairly strong in each instance, seem idiosyncratic and fluid from service to service. Certain professionals agree with certain others about a given service, such as personal care, but form new patterns of agreement for household, nursing, and medical therapeutic services. Few linkages last. These observations hold whether professional affiliations are considered by role or by training: nurses or social workers do not seem to group any more tightly than did discharge planners or home health care planners.

Factor analysis indicates that the seemingly inchoate mix of prescribed hours -- as it appears after successive disaggregation to the level of individual care planners, services, and patients -- in fact

yields definite but shifting associations. These patterns are formed separately for each service sub-total, much as major European powers of the eighteenth century or Balkan states of the early twentieth formed new alliances for each war. Section C now pursues the question of inter-professional agreement further.

C. The Reliability of Professional Views

In this section, two measures of inter-rater reliability, Cronbach's alpha and Kendall's W, are briefly described. Questions about their meaning and their relation to each other are posed. Useful results of certain analyses are presented; their implications are then discussed.

Perhaps the best description of Kendall's W, also known as Kendall's "coefficient of concordance" is that by Siegel.¹ This technique can be thought of as the extension of Spearman's rank-order correlation -- how well two people agree about the ordering of any set of data -- to how well more than two people agree about that ordering. In the present study, Spearman's correlation could have been used to measure agreement between any two professionals about the ranking of patients by hours of home care needed.

Cronbach's alpha, on the other hand, can best be conceived of as the cardinal equivalent of the ordinal Kendall's W. Alpha is to W, then,

¹Sidney Siegel, Nonparametric Statistics for the Behavioral Sciences, New York: McGraw-Hill, 1956. pp. 229-238.

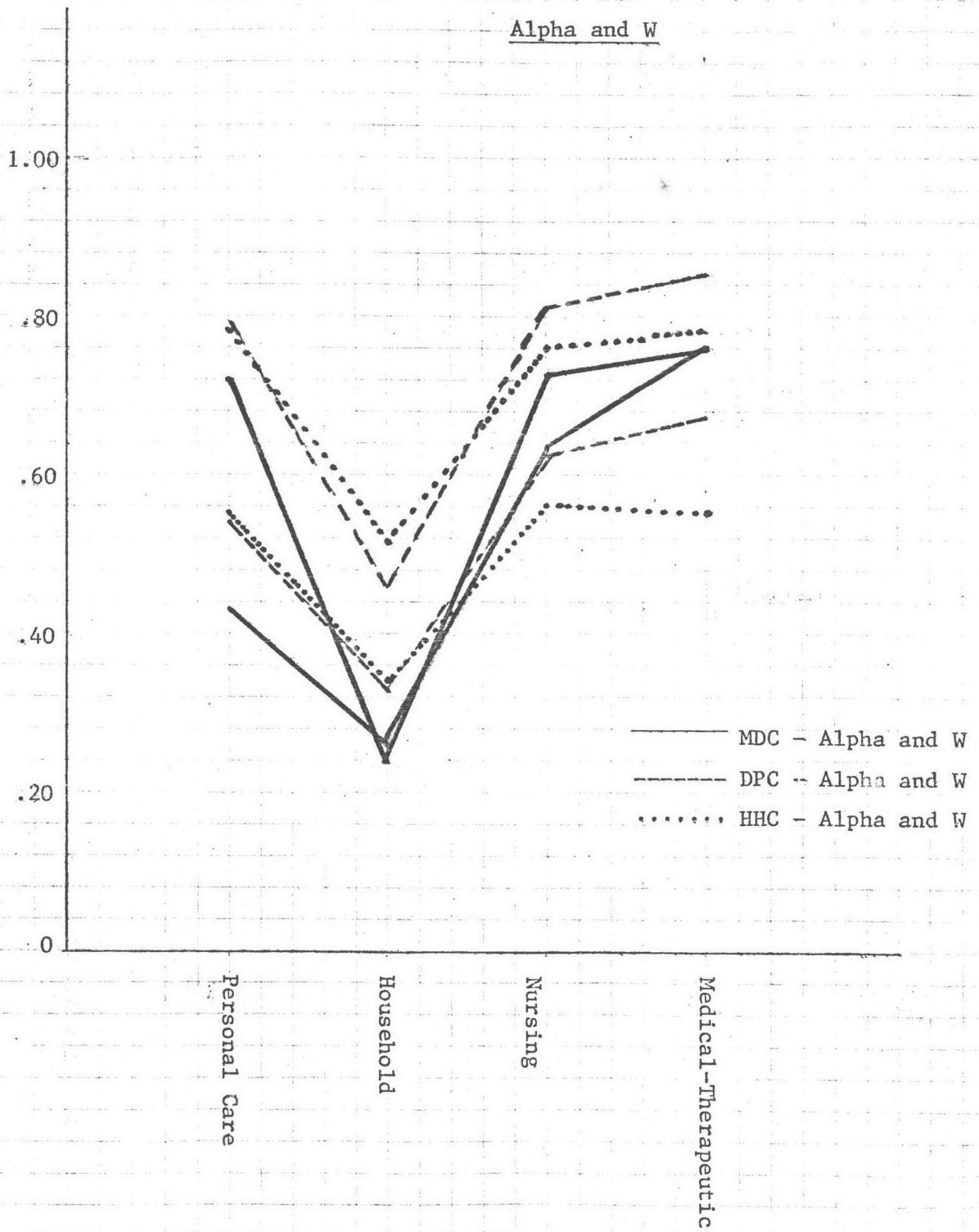
as the Pearson product-moment correlation is to Spearman's rank-order correlation.¹

In the present study alpha and W have been applied to the same sets of data. This was done because the first test of reliability which was performed, alpha, yields suspiciously high scores. Suggested agreement among individual professionals about individual patients seemed too high: the results did not "feel" right in view of the observed patterns of disagreement about patients. One pointer toward sensible results, however, was the relatively low alpha calculated for prescribed hours of care in the sub-total household services. This confirmed the high inter-profession disagreement in household services uncovered by analysis of variance (see Tables IX-A-1, IX-A-2, and IX-B). A strong direct relation was found in general between alpha and the explanatory power of the prescriber variable in one-way analysis of variance across the various service sub-totals.

Kendall's W tests on these data tended to confirm the alpha scores. Relatively high alphas were associated with relatively high W's (and low with low); $R^2 = .85$; significance = .001. Figure IX-A graphs this relation. The parallel movements of the two sets of data, alpha and W, are clear.

¹For descriptions of Cronbach's alpha, see Lee J. Cronbach, "Test 'Reliability': Its Meaning and Determination," Psychometrika, Vol. 12, No. 1 (March, 1947), pp. 1-16; William W. Rozeboom, Foundations of the Theory of Prediction, Homewood, Ill.: Dorsey, 1966, pp. 410-415, 445-447.

FIGURE IX - A



Interpretation of the meaning of the alpha and W results, however, is not clear. The alphas are very high: they point to extraordinary consistency among professionals (see Table IX-J). The W's are only fairly high, suggesting a somewhat weaker pattern of agreement. This question is being actively explored.

A further question concerns the clearly higher alpha's for consultants as a group than for the individual sets of physicians, discharge planners, and home health planners. Is this an artifact of the larger number of individuals grouped together? It probably is, in part. Both alphas are best compared for equal numbers of judges. Another likely explanation is that suggested by the results of the factor analysis just presented: inter-profession groupings tend to be stronger than intra-profession groupings. Care planners agree best through shifting alliances across professions. Thus, the alphas on the fifteen consultants may well reflect the higher agreement across professional lines than within them. W scores across the fifteen consultants are lower than for the individual groups. This requires further investigation. Consultant alpha and W scores are nonetheless fairly closely correlated.

For present purposes, happily, both sets of scores have similar practical consequences for interpreting the reliability of professional views of the home care needs of the elderly.

What both alpha and W analyses tell us is that the care plans of individual professionals about individual patients for specific service subtotal and total hours signify good agreement about which patients need more

care and which patients need less -- by each individual professional's yardstick. Some professionals seem to believe that individual patients and patients on average need relatively large numbers of hours of home care in order to live at home in a safe, adequate, and dignified manner. Other professionals feel that less care would be tolerable. Thus, professionals are consistent with themselves: one who usually recommends a relatively high number of hours of care seldom prescribes a low number (relative to other professionals). This is the first meaning of the alpha and W analyses.

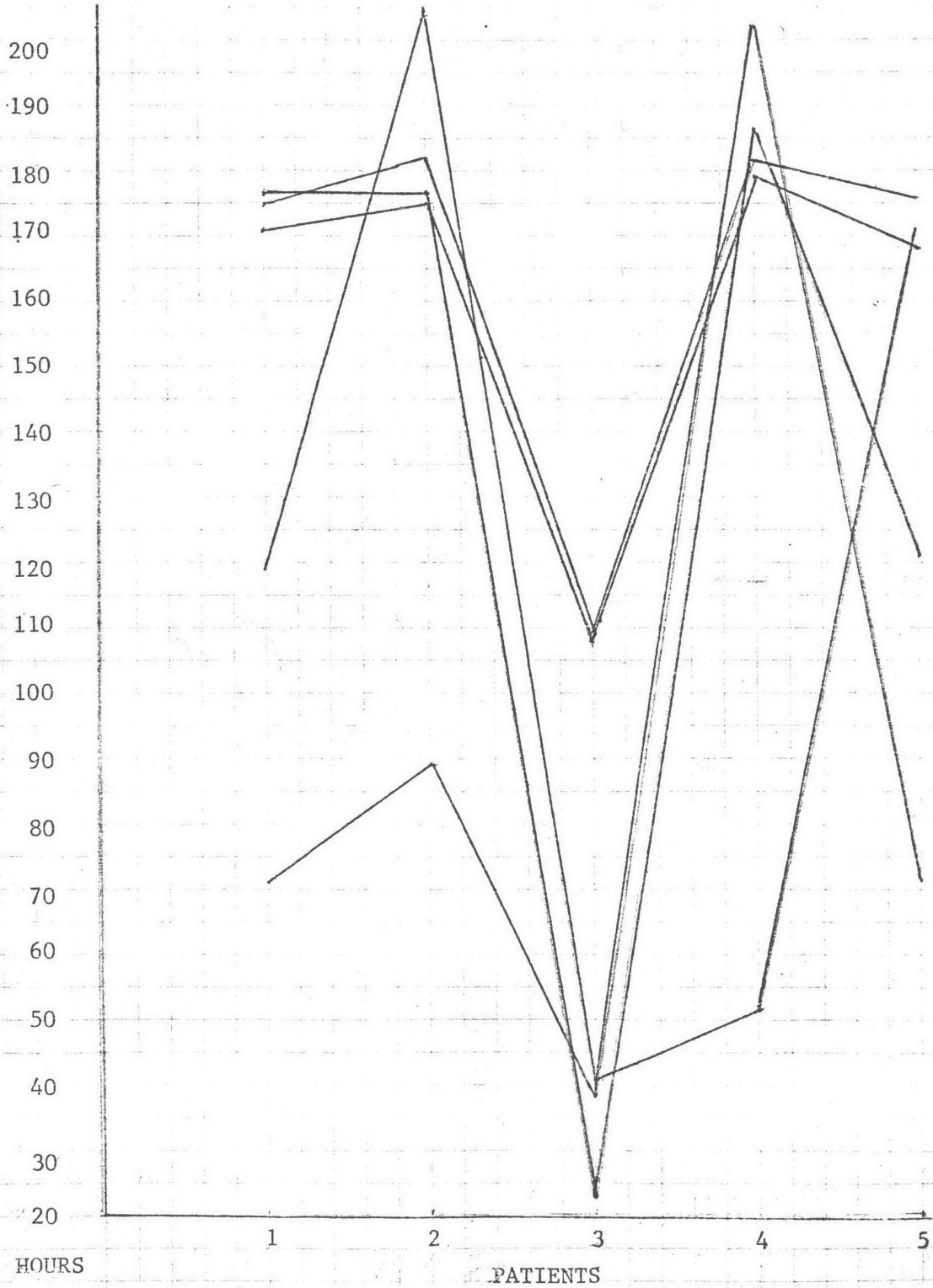
The second meaning follows from the first: professionals agree, by their own personal yardstick, about which patients need more help and which need less. If a patient were thought by one care planner to need more hours of service than other patients, a second care planner also would tend to recommend more care for this patient than he or she would recommend for other patients.

Thus, professionals tend to agree well about which patients need more care and which need less -- but, they disagree about how many hours of care are sufficient to sustain individual patients at home. Figure IX-B graphs this pattern by presenting five professionals' views of five patients' home care needs.

The meaning of this analysis for understanding the reliability of care planning by professionals in the present study is important. Individual professionals do not plan care arbitrarily. They are quite consistent with their own views of patient need. This argument is reinforced and extended by the very reasonable relation between average hours of care prescribed

FIGURE IX - B

Five Physicians' Views of Five Patients' Needs



across all eighteen professionals and patient characteristics (as was shown in Chapter VIII). If the average view of need relates reasonably to patient characteristics, and professionals are individually consistent, it then follows that professionals as individuals probably do well at relating prescribed hours to patient need. This proposition could be tested by using individual care planners' prescribed hours as regressions' dependent variables.

What remains to be decided in the midst of this consistency and reasonableness is why do professionals disagree, and whose views of patients' needs are valid. These tasks largely fall beyond the scope of the present study.¹ It must also be decided for present purposes whether the extent of professional agreement identified in this chapter (on a sample of eighteen care planners and 50 patients) is sufficient to argue in favor of increased or diminished professional control over home care planning. Section D will shortly assess the overall extent and meaning of professional reliability and Chapter X will consider this identified reliability when it discusses control over in-home services. This section will close by briefly considering why professionals might disagree in so consistent a pattern. What forces might influence them?

One general factor may be professional experience. Professionals with more years in practice tend to recommend somewhat fewer hours of care. Another such factor may be choice of goals. Some professionals may value

1

A new investigation, arising from this thesis, aims to help answer this question. See Alan Sager, "Decision-making for Home Care," Interim Report to the U.S. Administration on Aging, 23 March 1979.

patient safety and recommend generous home care plans even at the risk of engendering avoidable dependence. Other professionals are perhaps willing to be less cautious in assuring patient safety, in order to encourage or permit greater self-reliance.¹

Further, professionals may differ in other aspects of home care goals. Some emphasize rehabilitation more than others. Average hours of physical therapy across all patients ranges from 0.25 hours weekly to 2.70. This indicates different attitudes toward rehabilitation and perhaps toward prognosis as well. Finally, as noted earlier in this chapter, professionals may well differ in their views of the efficacy of services generally, or about the meaning of objective data describing patients.

It should be noted that a separate analysis is being performed of intra-professional consistency. This is how well each of the fifteen consultants agrees with him- or herself. Ten patients not visited by any of the consultants were selected. Five of these were patients on whom inter-professional agreement was good; five on whom it was poor. This will permit analysis of the relation of inter-professional to intra-professional agreement, suggesting whether some patients are simply harder to plan for. More important is that the repeat care plans will make possible a last measure of consistency: how well care planners agree with themselves. This analysis cannot be included in this thesis because it is not yet completed.

1

This perspective on care planning is shared by Andrew S. Dibner, personal communication, 12 February 1979.

Section D now concludes this chapter with an overview of available findings on professional reliability.

D. The Nature, Extent and Meaning of Professional Reliability

When professional views of home care needed by patients are first examined, agreement seems good. Progressively more disaggregated looks reveal increasing disagreement. Re-aggregation via summary measures, however, yields a moderately encouraging picture of professional agreement.

There is good agreement among consultants, whether grouped by training or by role, about total hours of home care needed by the members of the study sample. As the care plans are split into categories of service subtotal and then into individual services, consistency among the means of the professional groups steadily falls. Agreement about non-technical household services was clearly weakest. Overall agreement was slightly better for unskilled providers and for unpaid providers.

Inter-profession disagreement is only moderate. Professional role (physician-discharge planner-home health planner) generally has little relation to prescribed hours. Professional training has a somewhat stronger relation: physicians and nurses, for example, prescribe more hours of home care in their areas of specialization. More special knowledge of field seems to be associated with more prescribed hours.

Further, more knowledge about patients is associated with higher prescribed hours across almost all services: hospital professionals prescribed considerably (20%) more care than did consultants. The brief visit made by some professionals to some patients did not affect prescribed hours at all,

so what therefore seems important is extended personal acquaintance with the patient. Do higher prescribed hours more validly reflect patient need or are they the consequence of a personal attachment to the patient -- as higher nursing hours prescribed by nurses might be a consequence of attachment to the field of nursing? The relative usefulness of special knowledge and objectivity is at issue; it demands empirical investigation in this instance. Indirect support for the utility of greater information about patients is found in the stronger intra-group consistency in prescribed hours generated by hospital care planners.

Knowledge acts in yet another way: more experienced consultants tended to prescribe slightly fewer hours of home care. The sample size of consultants (fifteen) and of all professionals (eighteen) precludes simultaneous testing of the effects of professional role, training, information about patient, and general experience on prescribed hours. The types and directions of influences identified in this chapter will assuredly be studied in years to come.

When prescribed home care hours are considered not by groups of prescribers, patients, and services--but rather by individual prescribers' views of individual patients' needs for individual services or individual providers, inter-professional agreement appears terrible. Inspection of these data reveals little commonality of recommended service hours. The discreteness of this information, however, hides strong and interesting patterns of association.

Factor analysis, treating as units of analysis the hours prescribed by individual consultants for individual patients in distinct service

categories, uncovers fairly strong inter-professional similarities. These cross lines of role, training, and experience. Professionals join together in agreement about hours of care required for individual service sub-totals, and then break apart to agree with other professionals about other service sub-totals. Thus, professionals do not randomly prescribe home care. Several common views of need can be identified for each service; the validity of these common views can be tested.

Consistency of professional views was demonstrated further by use of Cronbach's alpha and Kendall's W. While some discrepancies were found between these two measures of inter-judge reliability, both point to important patterns of care planning. Individual care planners agree about which patients need more care and which need less, by each care planner's yardstick. They are consistent both with themselves and relative to other professionals. Some professionals consistently recommend much in-home service; others, less service. Each professional's views seem sensitive to patient characteristics. Professionals are thus well able to rank patients by needed hours of home care. What professionals disagree about, however, is how much care a particular patient requires. Professional reliability appears excellent, as far as it goes, but stops short of perfect consistency.

In light of these findings and in the context of the present study, what must be asked is, how much control or influence over the allocation of in-home services should professionals receive? Is this agreement sufficient to retain in professional hands the allocation of in-home services? For some, no amount of agreement could be enough, for others, no amount

could be too little. This question will be the principal focus of chapter X in which findings reported throughout part three will be assembled to answer the question: Whose views of home care need seem most valid? Beyond considerations of effectiveness, chapter X will examine the public costs of controls of home care allocation by various parties, present models for decision-making, and summarize other findings from this study.

TABLE IX-A-1
 PRESCRIBED HOURS¹ BY PROFESSIONAL ROLE AND SERVICE SUB-TOTAL

Service S.T.	Professional Role ² : Weekly Hours Prescribed By					
	\bar{X} MDC	\bar{X} DPC	\bar{X} HHC	\bar{X} C	\bar{X} H	\bar{X} A11
Personal care s.t.	93.2	81.5	77.5	87.3	96.4	85.6
Household s.t.	24.7	28.1	33.1	29.0	36.4	29.7
Nursing s.t.	6.0	7.6	7.7	7.4	9.7	7.4
Medical-therapeutic s.t.	2.5	1.5	2.1	2.1	2.4	2.1
Continuous supervision	74.5	56.4	55.8	64.8	69.8	63.1
Total minus cont. super.	51.9	62.3	64.6	57.0	75.1	61.7
Total	126.4	118.7	120.4	121.8	144.9	124.8

¹N = 50 patients.

²MDC = physician consultants; DPC = discharge planner consultants; HHC = home health consultant; C = mean of all consultants; H = hospital consultants.

TABLE IX-A-2

PRESCRIBED HOURS BY PROFESSIONAL ROLE AND SERVICE SUB-TOTAL:
SIGNIFICANCE AND EXPLANATORY POWER OF PRESCRIBER EFFECT

Service S.T.	Among Consultant Groups		Between Consultants & Hospital Professionals	
	Signifi- cance ¹	Explanatory Power ²	Signifi- cance ¹	Explanatory Power ²
Personal care s.t.	<.001	3.4%	.055	1.47%
Household s.t.	<.001	34.7	.001	13.58
Nursing s.t.	.002	2.4	.017	3.04
Medical-therapeutic s.t.	<.001	7.6	.272	0.66
Continuous supervision	<.001	8.3	.296	0.62
Total minus cont. super.	<.001	9.8	.001	8.92
Total	.015	0.7%	.001	4.71%

¹Of prescriber effects in one-way analysis of variance.

²% of total sum.

TABLE IX-B
 PRESCRIBED HOURS¹ BY PROFESSIONAL TRAINING
 AND SERVICE SUB-TOTAL

Service S.T.	Weekly Hours Prescribed By ²			Significance and Explanatory Power of Prescriber Effect	
	MD	RN	SW	Sig.	Ex. Power
Personal care s.t.	93.2	80.3	92.5	.003	2.2%
Household s.t.	24.7	34.6	22.7	<.001	51.7
Nursing s.t.	6.0	9.3	5.0	<.001	13.4
Medical-therapeutic s.t.	2.5	2.2	1.2	<.001	14.2
Continuous supervision	74.5	53.9	74.8	<.001	7.5
Total minus cont. super.	52.0	72.5	46.9	<.001	32.0
Total	126.4	125.4	121.8	.392	0.2%

¹N = 50 patients.

²MD = consultant physician; RN = consultant nurse; SW = consultant social worker.

TABLE IX-C-1
PRESCRIBED HOURS¹ BY PROFESSIONAL ROLE AND SPECIFIC SERVICE

Service	Professional Role: Weekly Hours Prescribed By:					
	\bar{X}_{MDC}	\bar{X}_{DPC}	\bar{X}_{HHC}	\bar{X}_C	\bar{X}_H	\bar{X}_{A11}
Bathing	2.1	2.7	3.3	2.7	3.6	2.8
Eating/drinking	2.3	2.6	2.2	2.3	2.8	2.4
Transportation	2.1	1.9	0.6	1.5	2.1	1.6
Light housework	3.5	4.6	6.9	5.0	5.8	5.1
Monitoring vital signs	0.6	0.6	0.9	0.7	0.7	0.7
Primary medical care	0.08	0.07	0.07	0.08	0.12	0.08
Physical therapy	1.8	0.8	1.4	1.3	1.6	1.4

¹N = 50.

TABLE IX-C-2

PRESCRIBED HOURS BY PROFESSIONAL ROLE AND SPECIFIC SERVICE:
SIGNIFICANCE AND EXPLANATORY POWER OF PRESCRIBER EFFECT

Service	Among Consultant Groups		Between Consultants & Hospital Professionals	
	Signifi- cance	Explanatory Power	Signifi- cance	Explanatory Power
Bathing	<.001	23.6%	.003	8.6%
Eating/drinking	.317	0.2	.276	0.3
Transportation	<.001	31.5	.013	5.9
Light housework	<.001	54.0	.110	2.6
Monitoring vital signs	<.001	6.5	>.500	0.1
Primary medical care	.024	3.2	<.001	12.1
Physical therapy	<.001	10.4%	.260	0.7%

TABLE IX-D

PRESCRIBED HOURS BY PROFESSIONAL TRAINING AND SPECIFIC SERVICE

Service	Weekly Hours Prescribed By			Significance and Explanatory Power of Prescriber Effect	
	MD	RN	SW	Sig.	Ex. Power
Bathing	2.1	3.7	1.7	<.001	52.6%
Eating/drinking	2.3	2.7	1.9	.034	0.7
Transportation	2.1	1.1	0.8	<.001	33.9
Light housework	3.5	7.5	2.5	<.001	73.3
Monitoring vital signs	0.6	0.7	0.8	.082	2.1
Primary medical care	0.8	0.6	0.8	<.001	6.2
Physical therapy	1.8	1.4	0.7	<.001	13.2%

TABLE IX-E-1

PRESCRIBED HOURS BY PROFESSIONAL ROLE AND SELECTED PROVIDER
SUB-TOTALS PROFESSIONAL ROLE: WEEKLY HOURS PRESCRIBED BY

Provider S.T.	XMDC	XDPC	XHHC	XC ¹	XH ¹	XA11 ²
Paid	92.2	71.2	83.2	85.2	97.5	84.2
Unpaid	34.3	47.4	37.2	40.5	47.4	40.7
Skilled	8.0	5.7	5.0	6.4	12.8	7.1
Unskilled	118.4	113.0	115.3	119.3	132.1	117.8
Total	126.4	118.7	120.4	125.7	144.9	124.8

¹_N = 48.

²_N = 50.

TABLE IX-E-2

PRESCRIBED HOURS BY PROFESSIONAL ROLE AND SELECTED PROVIDER
SUB-TOTALS: SIGNIFICANCE AND EXPLANATORY POWER OF
PROVIDER EFFECT

Provider S.T.	Among Consultant Groups		Between Consultants & Hospital Professionals	
	Signifi- cance	Explanatory Power	Signifi- cance	Explanatory Power
Paid	<.001	5.5%	.018	2.3%
Unpaid	<.001	3.6	.045	1.1
Skilled	.127	1.7	.020	3.6
Unskilled	.193	0.3%	.017	2.6
Total	.015	0.7%	.001	4.7%

TABLE IX-F
PRESCRIBED HOURS BY PROFESSIONAL TRAINING AND SELECTED
PROVIDER SUB-TOTALS

Provider S.T.	Weekly Hours Prescribed By			Significance and Explanatory Power of Prescriber Effects	
	MD	RN	SW	Sig.	Ex. Power
Paid	92.2	81.1	78.3	.001	2.4%
Unpaid	34.3	45.3	43.5	.002	2.2
Skilled	8.0	4.9	4.3	.038	2.9
Unskilled	118.4	121.5	117.5	>.500	0.2
Total	126.4	126.4	121.8	.392	0.2%

TABLE IX-G
CoV¹ in Prescribed Hours: Selected Prescriber Groups:
Service Sub-totals

<u>Prescriber Group</u>	<u>Area of Service</u>				<u>TOTAL</u>
	<u>Personal Care</u>	<u>Household</u>	<u>Nursing</u>	<u>Medical Therapeutic</u>	
Physicians	56.2	27.1	77.1	76.9	36.7
Discharge Planners	59.7	24.8	67.4	69.1	39.0
Home Health	71.7	40.0	79.3	83.1	41.0
Physicians	56.2	27.1	77.1	76.9	36.7
Nurses	57.5	31.8	67.0	80.9	34.0
Social Workers	49.3	29.0	53.5	71.3	31.0
Consultants	65.7	37.1	82.8	95.7	40.3
Hospital	34.3	28.5	48.8	46.7	23.7
All	67.6	41.3	87.5	100.3	41.7

¹Coefficient of variation = $S.D. \div \bar{X}$

Table IX-H-1

Total Prescribed Hours by Patient Visit Status
and Information Available to Professionals

	<u>Non-visitors (9)¹</u>				<u>Professionals</u> <u>Visitors (6)¹</u>				<u>Consult-¹</u> <u>ants (15)</u>	<u>Hospi-²</u> <u>tal (3)</u>	<u>Total (18)</u>
	<u>MDC</u> <u>(3)</u>	<u>DPC</u> <u>(3)</u>	<u>HHC</u> <u>(3)</u>	<u>\bar{X}</u> <u>(9)</u>	<u>MDC</u> <u>(2)</u>	<u>DPC</u> <u>(2)</u>	<u>HHC</u> <u>(2)</u>	<u>\bar{X}</u> <u>(6)</u>			
<u>Patients</u>											
Non-visit (34)	123.3	132.2	112.5	122.7	151.1	106.6	146.1	134.6	127.5	148.2	130.9
Visit (16)	103.3	122.7	102.8	109.6	137.6	104.7	130.8	124.4	115.5	127.1	117.5
Total (50)	117.2	129.3	109.5	117.1	146.9	106.0	141.4	129.8	123.8	141.4	125.4

¹_n = 49

²_n = 50

Table IX-H-2

Total Prescribed Hours by Information
Available to Professionals and Visit Status
of Patients: Significance and Explanatory Power

Variable	Significance (F-test)	Percent of Total Sum of Squares Explained
A. Eighteen care planners:		
<u>Non-visiting, Visiting, Hospital(9-6-3)</u>		
Visited-Non-visited Status (patients)	.155	3.3%
Non-Visiting, Visiting, Hospital Prof.	<.001	3.9%
Patient Status X Professionals	>.500	0.1%
B. Fifteen consultants only:		
<u>Non-visiting, Visiting X MDC, DPC, HHC (3/2-3/2-3/2)</u>		
Visited-Non-visited Status (patients)	.322	1.4%
Profession (MDC, DPC, HHC)	<.001	1.1%
Patient Status X Profession	.165	0.2%
Visiting(6)-Non-visiting(9) Consultants	<.001	1.9%
Patient Status X Visiting Status of Consult.	>.500	0.0%
Profession X Visiting Status of Consultants	<.001	6.6%
Patient Status X Prof. X Visiting Status	>.500	0.1%

TABLE IX - I

Consultant Groupings Formed Through Factor Analysis:
Service Sub-totals

<u>Service Category</u>	<u>Factor and Members</u> ¹						<u>Loners</u>
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	
Personal Care	MD-2	MD-1	MD-4	MD-3			MD-5
	DP-4	DP-1	DP-3	DP-2			HH-5
	HH-1	HH-3	DP-5	HH-4			
Household	DP-5	MD-1	HH-1	MD-4	MD-3	MD-2	
	HH-2	MD-5	HH-3	DP-3	DP-4		
	HH-5	DP-2	HH-4				
Nursing	MD-2	MD-1	MD-4				
	MD-3	MD-3	MD-5				
	DP-1						
	DP-2		DP-2				
	DP-3	DP-3					
	DP-4						
	DP-5						
	HH-2	HH-1					
	HH-3	HH-3					
		HH-4					
	HH-5	HH-5					
Medical-Therapeutic	MD-1	MD-3	MD-2	MD-2			HH-1
	MD-5	DP-3	DP-2	MD-4			
	DP-2	DP-4	HH-5	HH-4			
	DP-5	HH-3					
	HH-2						

Consultant Groupings Formed Through Factor Analysis:
Total Hours of Care

	<u>Factor and Members</u>			
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
Total hours	MD-4	MD-1	MD-2	MD-3
	MD-5	MD-5	DP-4	DP-2
	DP-3	DP-1	HH-1	
	DP-5		HH-2	
	HH-5		HH-4	
		HH-3	HH-3	

¹MD=Physician; DP= Discharge Planner; HH=Home Health Care Planner

TABLE IX-J

Professional Consistency: Alpha and W Compared

<u>Service sub-total</u>	<u>Alpha</u>	<u>W</u>
<u>Personal sub-total</u>		
MDC	.72	.43
DPC	.79	.54
HHC	.79	.55
Hospital	.51	
Consultants	.90	.38
<u>Household sub-total</u>		
MDC	.24	.25
DPC	.46	.33
HHC	.51	.33
Hospital	.35	
Consultants	.59	.15
<u>Nursing sub-total</u>		
MDC	.73	.63
DPC	.81	.62
HHC	.76	.60
Hospital	.36	
Consultants	.91	.56
<u>Medical-Therapeutic sub total</u>		
MDC	.76	.58
DPC	.85	.67
HHC	.78	.58
Hospital	.73	
Consultants	.91	.52
<u>Total</u>		
MDC	.75	.50
DPC	.84	.57
HHC	.83	.56
Hospital	.53	
Consultants	.93	.45

CHAPTER X

Summary of Findings: What They Mean

Critics of public long-term care policy in the United States have complained of its heavy emphasis on institutional care for the elderly. Many who would like to see the elderly permitted choice among a variety of alternative sites of care, including their own homes, are fearful of the cost of more generous public funding of these alternatives.

The comparative costs of home and institutional care have been difficult to measure experimentally because of problems in controlling for the initial characteristics of the two samples, in measuring outcomes, and, consequently, in learning what services are indeed effective. Given our present knowledge of how well various types, quantities, and providers of long-term care services enhance well-being, costs and effects of long-term care in various settings have not usually been measured well.

This study was designed to improve our knowledge. It begins with a sample of patients in fact about to enter nursing homes, obtains many hypothetical estimates of the costs of an in-home alternative of equal or greater effectiveness, and then compares these costs with those of institutional care actually provided.

If the greater availability of public funds for home care in the future will depend in large part on the costs of care at home and in institutions, then the cost of home care itself, in the present research design, depends on the hypothetical care plans written. Given our weak ability to measure

effectiveness of long-term care services, how is it to be decided which view of hypothetical home care need is valid -- in that it calls for appropriate services?

In this scheme, home care costs clearly depend on the types, quantities, and providers chosen by the care plans' designers. But the question of who should control the allocation of in-home services is an important issue in itself. Arguments may be advanced on behalf of competing claims of various professionals, patients, and their families. These claims may be judged by comparing the likely effectiveness and costs of services sought by the three groups. Some of the analyses presented in earlier chapters suggest the relative effectiveness and cost of the three groups' home care plans.

The hypothetical nature of the present study permits members of the three groups of claimants to prepare home care plans independently. One measure of the validity of the different views is how well they relate to patients' characteristics: is more care prescribed for patients who might "reasonably" be thought to need more care? A second measure which points toward validity, for professional control over home care planning and, therefore, for relying on costs of professionals' home care plans as the standard of comparison with the costs of institutional care.

This study's principal interest has been in deciding who should be permitted to influence or control the allocation of in-home services. On this foundation, the costs of home and institutional care can be compared. Four specific goals have been articulated:

I. To learn how well patients, their families, and various health and social service professionals agree about the types, quantities, and providers needed to sustain patients at home in a safe, adequate, and dignified manner.

II. To assess whose views of home care need seem more valid, should the three groups of hypothetical care planners disagree.

III. To compare the costs of home and institutional care for a group of patients who are in fact about to enter nursing homes.

IV. To mine the results and by-products of data gathered to reach the preceding goals, in order to learn how to better plan home care for individual patients. This means first, learning more about which patients seem to need which services, and second, devising a sensible model for cooperative care planning -- involving patients, families, and professionals -- should this seem appropriate.

The costs of home and institutional care were reported in chapter VII. Several useful points emerged from various analyses of the data:

1. Care in both settings is expensive, for the patients studied. By diverting to home care those patients for whom it is (hypothetically) cheaper, substantial savings may be gained. For the members of the study sample, such savings were likeliest to be achieved by diverting patients bound for relatively intensive and costly levels of institutional care: rehabilitation hospitals, chronic disease hospitals, and Medicare-funded skilled nursing home care. This pattern seems to be quite different from that usually expected: that the less ill or disabled patients can be

cared for at home at less expense. In the present study, the pattern of savings found may partly reflect rigidities and/or vagaries of institutional placement and reimbursement.

2. Very different groups of patient characteristics explained actual institutional costs and hypothetical home care costs. Not surprisingly, therefore, there is almost no predictable relation between hypothetical home care costs and real nursing home costs. Prescribed hours of home care, which might represent the real burden of home care better than does cost (because unpaid family contribution is included only in hours of care), correlate with institutional costs only marginally better. The real world forces and decisions which determine the cost of institutional care work in very different ways from the decisions about home care costs made by study professionals.

3. Several important patient characteristics were identified that predict which long-term care setting would be less expensive. More intense level of institutional placement, higher patient functional ability, and greater number of persons residing with the patient at home each predict increased likelihood that home care will be less expensive than institutional care. Thus, other things being equal, less disabled patients do tend to be less expensive to care for at home. This is particularly true when these patients are in fact being discharged to a relatively intensive level of care.

4. By employing savings, won by diverting to home care those patients for whom it is markedly cheaper, to subsidize the home care costs of patients for whom it is marginally more expensive, it is estimated that a

total of about half of the sample could be cared for at home at no increase in overall spending on the sample patients collectively. This is not to say that system costs would necessarily be unaffected: if, for example, nursing home beds emptied by diversion are not filled by other patients, overhead must be spread over a smaller denominator, yielding some increase in the average cost per patient-day for those who remain in institutions. If those diverted require less intense care than the average nursing home patient, as may well be the case, then average variable costs of institutional care will rise following diversion. But, on the other hand, diversion will reduce the need to build new nursing home beds in the face of the rising demand for all forms of long-term care which is certain to materialize in coming years and decades. If the beds emptied by those patients diverted to home care are soon filled by persons needing institutional care, very real systems savings may accrue from diversion, as some new construction is delayed or obviated.

5. Family members and patients typically requested less paid help than the median of professionals (using episodes of care as the unit of measurement). This suggests that the cost of permitting patients and/or their families to influence or control home care planning would probably be no greater than the cost of professional control.

6. Unskilled care generates the great bulk of costs of prescribed services. A great part of this is owing to one service, continuous supervision. If these costs could be spread over more than one patient, home care would appear more attractive financially. Vehicles such as adult foster care or shared housing have been proposed to do this. The dangers of creating

small and unsatisfactory quasi-institutions must be avoided, however; one of the chief purposes of establishing today's nursing homes, under medical control, was to banish the identified evils of just such arrangements.

Paid helpers or organized, neighborhood-based unpaid services could spread such service needs as shopping and cooking for several older persons who lived apart. If older citizens lived with their families or with others in similar circumstances, costs of shelter (including heat, maintenance, cleaning, and the like) could be shared.

If older persons in need of care remain in their own communities, it is easier to organize unpaid helpers than would be the case if these persons entered institutions. When older people remain in their own homes or neighborhoods, potential helpers -- relatives and friends -- can both perceive needs for care and, in many cases, conveniently provide help.

Potentially powerful schemes for summoning forth greater contributions of unpaid help are being developed. These include housing shared by persons initially aged perhaps 45 - 65, in which the able care for the disabled, as needed, and are in turn cared for by younger entrants as they, themselves, age. Another organizing device would involve the use of tokens to reward those who provide "unpaid" help. These tokens could be saved for pay for home care as their holders came to need it.

By providing home care more efficiently or by substituting unpaid for paid providers, the future budget costs per person of home care may be markedly reduced.

Goal I, to learn the extent of agreement among patients, families, and professionals about needed home care services, was reached in chapter VIII:

7. Patients, family members, and professionals agreed fairly well on average but somewhat less well in individual cases. The averaging out is important in itself because it suggests (and even "suggest" may be too strong a verb in view of the small size of the sub-sample which could be analyzed) that the preferences of the three groups of care planners could be accommodated within a single budget sum. The sum might, with allowances for particular individual circumstances, be set in relation to variables proven to predict service needs. Only the proof is needed.

8. Agreement about the care needs of individual patients was not as good as the overall average might indicate. Patients and family members agreed better between themselves than either group did with professionals. Thus, patients and family members might tend to unite against professionals' analyses of needed home care because the three groups disagree in important respects about the scope and composition of individual home care plans. Control over the content of these plans is therefore of considerable significance.

9. Surprisingly, family members' estimates of episodes of unpaid help available to patients were the highest of the three types of care planners -- both absolutely and as a proportion of total episodes. This is important in itself, as it indicates that families do not seem, by their plans, to be shirking whatever responsibilities they might be thought to have in caring for their older members. This is important also because it suggests

that one potential source of conflict among patients, families and professionals -- how much the family should do -- might not in practice present a great difficulty. Family plans pre-supposed certain levels of paid support, but these were below those prescribed by professionals. Therefore, families' predictions of their contributions might well be realistic. Of course, it is possible that family members, facing the prospect of their relative's institutionalization, may have been exaggerating their own willingness to provide home care.

Goal II, to assess the validity of various views of home care needs, was pursued in chapters VIII and IX. Chapter VIII took up the relation of patient characteristics to episodes of care sought by patients, families, and professionals.

10. All three of the groups sought episodes of care in inverse relation to patients' anticipated functional ability. This relation appears on its face to be reasonable and equitable. All three groups thus seem able to distinguish in general ways between patients needing more home care and those needing less.

Because professional care plans were available in greater detail and for a larger sample than patient or family recommendations, the relation of patient characteristics to professionally prescribed home care hours could be examined with some rigor:

11. By means of multiple regression, it was found that fairly high proportions of the difference in mean hours prescribed for individual patients (across eighteen professionals) in most areas of service, could

be explained by only a few patient characteristics. The particular characteristics which proved useful seemed to relate reasonably to the particular dependent variable in question. This finding lends further support to the view that professionals, on average, plan care in a sensible manner.

The possible validity of professional views was explored further by examining patterns of agreement, among professionals themselves, about patients' home care needs, both individually and collectively. The relations of several variables to patterns of inter-professional reliability and to specific hours of care recommended by different professionals were analyzed. Data on care recommendations are presented first:

12. When professional views of home care needed by patients are first examined, agreement seems good. Consultants, whether grouped by training or by role, agree fairly well about the home care hours required on average by patients.

13. Professional role has little relation to total prescribed hours. Professional training has only a slightly stronger relation. There is some tendency for professionals to prescribe more hours of care in their own field. Physicians and nurses, for example, tend to prescribe more hours of care in their special areas -- medical and nursing services respectively -- than other professionals prescribe in those areas. Special training in a given field may indicate that the higher hours prescribed here by physicians and nurses represent more valid views of patients' need. Alternatively, professionals may be inappropriately emphasizing the importance of their own fields. While the former explanation

is the more reasonable, this question demands careful investigation. Multi-disciplinary team planning for long-term care, as usually practiced today, usually grants authority or special influence to each member in his or her own field. The appropriateness of doing so should be confirmed. If inappropriate, this study's results would indicate that present patterns of influence in team care planning may yield inflated home care prescriptions.

14. While more knowledge in a specialty is mildly associated with greater prescribed home care hours, more familiarity and contact with patients themselves is fairly strongly associated with more prescribed care: Hours prescribed by hospital professionals were 20% greater than those prescribed by consultants. The brief visits made by some consultants to some patients do not seem to have influenced the outcome of care planning.

In this case, as in that of special training, the validity of care plans based on increased familiarity must be confirmed. Do higher prescribed hours more validly reflect patient need or are they a consequence of personal attachment to a patient or to a field of care? Alternatively, might the difference in prescribed hours only reflect the personal or systematic forces governing selection of the consultants?

15. Knowledge acts in yet another way: More experienced consultants tended to prescribe slightly fewer hours of care across all patients than did the less experienced consultants. In sum, then, familiarity with patients or knowledge about a field of learning are directly related to prescribed care; general professional knowledge (correlated with experience) is inversely related. The effects of these forces should be studied

simultaneously by means of a larger sample of professionals combined with a narrower scope for care planning and, to contain cost, possibly with a smaller sample of patients than those in the present study.

Beyond the associations of certain variables with different levels of prescribed home care hours lies the association of some of the same variables, and others as well, with the extent of agreement among professionals about the home care needs of the elderly. The variables in question are: patient characteristics, information available to care planners, type of service or provider, degree of aggregation of the care plan, and professional role and training:

16. While no firm conclusions have emerged about which sorts of patients the professionals agree about best, greater age and family willingness to maintain the patient at home, and better psychosocial status were associated with enhanced agreement. Patients about whom professionals agree well are better candidates for the exercise of professional influence, other things equal. Unfortunately, other things are not equal in this case, because the patients professionals agree about relatively weakly tend also to be the patients whose psychosocial status is relatively poor. Hence, the void which might be created by interprofessional disagreement is opened for the patients who would typically have greater difficulty in filling it. This relation, however, is not a very strong one.

17. More familiarity and contact with patients tends to be associated with greater inter-professional agreement. Hospital professionals' coefficients of variation, averaged across patients, were lower than consultants.

This was true as well for average standard deviations, uncontrolled for differences in mean prescribed hours.

18. Professional agreement varied by type of service and provider.

Professionals agreed best about the more technical nursing and medical-therapeutic services, somewhat less well about personal care, and least well about household services. Thus, there is a fortunate matching of relative professional weakness and relative patient-family strength: the latter can be expected to have more informed (and stronger) opinions about need for personal care and household services than for nursing or medical-therapeutic care. Household services in particular appear to be a prime arena for some sort of cooperative planning among patients, families, and professionals. Some degree of patient and family influence seems called for, in light of their special knowledge and of professionals' relatively weak agreement, but some professional involvement or institution of ceilings on hours in some relation to objective patient/family/housing characteristics might be desirable as well, in view of the potential attractiveness of many household services (cleaning, cooking, and the like) to many patients and families.

19. Apparent professional consistency is highest at the most general levels; consistency falls steadily as the components of the care planning process are disaggregated. Among the consultants grouped by role, for example, agreement about total hours of care needed across patients is excellent; about care needed in service or provider sub-totals, somewhat worse; and about care in specific services, worse still. When the needs of individual patients -- for individual services -- prescribed by

individual consultants -- are examined, very little evidence of consistency is present. This suggests that professional judgments could help set overall patient hours of care, in relation to objective characteristics, and that patients and/or families might be permitted to allocate that care among specific services and providers. The very discreteness of the disaggregated data, however, hides strong and interesting underlying patterns of association.

20. Professional role and training seem to have little cohesive influence on inter-professional consistency. Factor analyses uncovered clear patterns of association, but these generally crossed lines of professional role and training. In each category of service, separate clusters of professional agreement can be identified. Few professionals, however, were strongly bonded to others across services. Care planners A, B, C, and D might agree about personal care; A, E, and F about household help; B, E, and G about nursing; and so on. Thus, professionals do not seem to prescribe care in an entirely idiosyncratic manner. Clusters of perceived home care needs exist. The validity of these shared views could be tested.

21. Two other measures were made of reliability: Cronbach's alpha and Kendall's W. Both point to important patterns of professional care planning. Individual care planners agree well about which patients need more help and which need less, by each planner's personal yardstick. Professionals' rankings of patients by care needs tend to agree well. But professionals tend to disagree about how many hours of home care a particular patient needs in order to live at home in a safe, adequate, and dignified manner. Thus, professional reliability is excellent in certain

respects, but it stops well short of perfect consistency.

For present purposes, what are the meanings of the above findings -- about the extent of agreement among patients, families, and professionals; about the equity and reasonableness of patient and family views; and about the equity, reasonableness, and reliability of professional views -- for the partitioning of influence or control over home care planning?

All three groups -- patients, families, and professionals -- seem to recommend care in reasonable and equitable ways. Professional reliability, particularly about group needs, seems good in many respects. Professional consistency in home care is far from unbroken, as might have been expected following the general review of reliability in Chapter III. But, considering the general obstacles to consistency and the special attributes of long-term care which had been expected to further weaken inter-professional agreement, care planners seem to have acted with surprising congruence.

Partisans of consumers (patients and family) or professionals may seize on selected analyses to support their positions, but no dramatic evidence has really been uncovered for or against dominance of home care planning by any group.

Consequently, whose views of hypothetical home care needs should be used to compare the costs of home and institutional care? In Chapter VIII, averages of professional views were employed because, as analyses in following chapters indicated, professionals wrote home care plans whose prescribed hours appeared equitable, on average, and not unreliable

as well. If estimated home care costs were derived from patient or family recommendations, they would be lower still, and home care would appear therefore somewhat more attractive relative to institutional care.

In the absence of strong evidence for or against control of home care services by any of the three groups, and given the apparently defensible positions of all, it may be possible to devise schemes for home care planning to permit balanced influence by patients, families, and various professionals. An appropriate balance would be struck by granting precedence to group's views in ways which draw on the strengths but circumscribe the weaknesses of each. Illustrations of how this approach might be expected are now offered.

It is fortunate, for example, that professional agreement is clearly worst in an area, household services, where patients and families can be expected to have a good idea what they need. The latter should therefore be permitted wide latitude in determining both total hours of household help required, and how they should be allocated among specific services and delivered by specific providers. Because of the inherent attractiveness of some household services to many persons, young and old, public payers might demand that some sort of overall ceiling be placed on spending. Professionals seem ill-equipped to perform this task because of the wide divergences in their views of needs for household services. One step might be to set an absolute ceiling on the number of hours of household help to be allowed any patient. Another would be to validate need for household help in relation to objectively measured functional ability and independence in instrumental activities of daily

living. A considerable amount of research would be required to learn the proper relationships: what constitutes too much or too little overall help? Even after such standards were in place, patients and their families might be permitted to distribute the total among particular services. Thus, a measure of patient and family choice could be preserved even in the presence of valid and objective data.

A preferable way of validating household needs would consider the impact on outcome, not only services themselves, but the process by which they were planned as well. Effects of objectively planned household services might be compared with effects of services selected by patients themselves -- perhaps subject to the constraint that these cost no more than the first package. This procedure would measure the consequences for patient well-being of both the services and the planning process.

The desire to plan home care objectively (to plan for patients and families rather than with them) seems to stem from several motives: to be able to control, or at least predict, cost; to promote equity among patients; to allocate available resources in ways which do the most to enhance patient well-being; and, in some instances, to permit professionals to retain their present degree of influence over the home care planning process.

Fears of uncontrollable spending ensuing from patient or family influence over care planning find no support in the present study. Patients and families sought less paid help than professionals on average recommended. Patients, families, and professionals all seemed able to plan care equitably; professionals did a somewhat better job. About the effectiveness

of the three sets of hypothetical plans we can only speculate.

In this context, experimentation with the process of care planning and the content of care plans, to learn what does the most for which patients, would be desirable. We need better knowledge of which method of care planning, involving more or less patient and family choice, best enhance outcomes for various patients. The same is required of the content of care itself. Better capacity to measure outcomes is a pre-requisite for both.

As part of any planning process the location of ultimate authority over the cost and content of home care must be fixed. To satisfy legislators and administrators, authority will probably be granted to professionals operating within guidelines. The results of this study indicate, however, that granting to patients or families a share of this authority would on average, yield savings rather than cost increases. Therefore, in the absence of convincing evidence on the comparative effectiveness of plans prepared by the three groups and in view of the possibility that consumer choice in long-term care enhances outcome, increased patient and family influence over planning for household and personal home care services should be permitted experimentally. Administratively, this could be accomplished through cash payments, vouchers, or cooperative care planning. Because cash payments, such as the Veteran's Administration's Aid and Attendance Allowance come to be regarded as general income supplements, vouchers or cooperative care planning should be tried first.

Moving briefly from the question of control over services in a given site (the home) to the question of choice between sites of care (home

versus institution), the findings of this study raise an interesting issue. Suppose a more generous home care benefit were legislated by Congress or a state legislature. Eligibility however, would be restricted to those whose home care would cost only half or three-quarters (as in New York) the cost of institutional care.

In this case, whose view of the needed types, quantities, and providers of home care -- and therefore its cost -- should be allowed to enter the comparison? Suppose the cost of a professionals' home care plan was slightly greater than the cost of institutional care, but, the patient and family together were willing to accept home care cost by only half that of institutional care (and providing only half the hours of care), as the price of remaining at home? Should patients be permitted this choice?

This may well be appropriate, especially if professionals tend to over-estimate "objective" need for services. There is a danger, however, that this plan could become a vehicle for retaining or dumping patients in home care under conditions which could endanger their health, their safety, or even their lives. Witness much of the deinstitutionalization of recent years.

It seems clearly right to permit patient or family choice if costs of care in the two sites are equal. But it may be wrong to exploit most patients' preference for remaining at home to get them to accept a markedly less generous service package. From governments' standpoint, lower cost per person might well be the price for expanded eligibility.

The easy ways out of this dilemma would be to organize paid in-home services more efficiently than is now the case, or to secure markedly

increased provision of unpaid in-home services. Were this accomplished, lower cost would be less likely to mean fewer hours of care. Awaiting these improvements, patients and families might be permitted to choose home care, at the price of accepting reduced levels of services, and measures of objective and subjective outcomes could be closely monitored and compared with outcomes for a control group not allowed such choice.

The costs of home care and nursing home care for the elderly are difficult to compare, given our inability either to measure outcomes of long-term care or to control for the initial characteristics of persons receiving care in the two settings. Not knowing effects, we do not know what services are really required in either setting. Not knowing what services are required, costs cannot be measured with the confidence we would like.

To learn the costs of home and institutional care, this study has obtained estimates of the hypothetical cost of home care for a group of patients in fact about to enter nursing homes. To decide which version of home care costs should appropriately be compared with nursing home costs, and to learn which groups should appropriately influence the home care planning process, the reasonableness and reliability of patients', families', and various professionals' views of home care needs have been measured and analyzed. Subsequent work now aims to validate different views of home care service needs.

APPENDICES

- A. Professional Care Plan
- B. Revised PACE Form
- C. Description of variables characterizing patients
- D. The eighteen professional care plans for one patient
- E. Prescribed hours by service and provides groupings
- F. Mean hours by care planner; service sub-total and total

APPENDIX A

LEVINSON POLICY INSTITUTE
Brandeis University

IAS STUDY
11 May 1977

INSTRUCTIONS FOR PROFESSIONAL CARE PLAN

INTRODUCTION

We are interested in your professional evaluation, from the PACE and also in some cases from having interviewed the patient or known the patient for some time), of what services this patient would need to return home and be maintained for a six-month period following hospital discharge. We seek to learn which types of home care services, and how much of them would be necessary to provide an adequate, safe, and dignified environment for the patient. You should ignore the limitations of currently available services and providers. For example, your plan could call for meals-on-wheels seven days per week, unlimited sitting/homemaker services, and/or physician home visits monthly. Similarly, the current cost of providing such services should not be taken into account when you select the volume of service and the type of provider. We seek your opinion of what constitutes adequate care at home for each patient, as an alternative to institutional placement. We would like your view of the home care needs of each patient, regardless of the types and quantities of services needed to care for the patient at home in a safe, adequate, and dignified manner.

This form is divided into four sets of services: personal care, household, nursing, and other professional care. The format remains virtually identical throughout. Thus, the wording of the questions is consistent. Similarly, use of the codes is consistent. When appropriate, consideration should be given to anticipated changes in patient status over the six months following discharge. Provision is made on the form to change your selection of services and providers every three months.

For each service we will be asking:

1. Would patient need help?
2. The duration in hours and/or minutes of each episode of service.
3. How many times per week would patient need help? (In some instances, we may be asking for the number of times per month or half-year.
4. The provider(s) you would recommend to perform a service and how many times a week each provider would perform it.

COMPLETING THE FORM

1. Most services should be prescribed in the following manner.

Starting with Personal Care Services, in answer to Question 3 on the form, CIRCLE either yes or no for each of the 3-month time periods.

<u>EXAMPLE:</u>				
If you feel the patient needs to be checked periodically during months 1-2-3, but not in months 4-5-6, indicate as follows:				
	<u>Months 1-2-3</u>		<u>Months 4-5-6</u>	
Periodic Checking	<u>yes</u>	no	yes	<u>no</u>

If a service is required for both of the 3-month periods, complete the subsequent questions about that service for each time period. Fill in all boxes.

If a service is not required for one of the 3-month periods, CIRCLE the no. The boxes for this service, for this time, should be left blank.

If the service is not required at all, CIRCLE no under each time period, leave all boxes empty, and proceed to the next service.

2. The second question requires that you estimate how long each activity would take on each occasion. We seek an estimate of the average time each task or service would take during the relevant 3-month period(s). Each of the three boxes must be filled, indicating hours and minutes.

<u>EXAMPLE:</u>	
If you estimate that it requires 5 minutes to supervise medication, record	
<u>0</u>	<u>05</u>
hrs.	mins.
<u>EXAMPLE:</u>	
If you estimate that heavy housework will require 4½ hrs., record	
<u>4</u>	<u>30</u>
hrs.	mins.

3. The third question about each service asks that you estimate the number of times each service would be needed. The particular time period will vary from question to question. Usually it will be expressed as times per week, although sometimes as times per month. One exception would be for some of the "other professional services," which will be expressed as visits per six months; that is, over the full six months following discharge.

EXAMPLE:

To the question how many time per week would the patient need help bathing, the response may read:

Months 1-2-3

07

Months 4-5-6

03

indicating a reduction of frequency over the six months time period. As two boxes are provided, any digit less than 10 should be recorded with a zero (0) preceding it.

No option exists for daily services; therefore, all prescriptions must be converted to the time period indicated (weeks, months, half-years).

EXAMPLE:

If you feel the patient needs to be fed 3 times daily, but the unit is given as times per week, a 21 should be recorded.

EXAMPLE:

For a patient receiving q.i.d. medications and requiring daily supervision in taking them, 28 should be recorded.

4. The final question requires that you recommend one or several providers to perform each service. We ask that you consider the immediate and/or extended family, neighbors and friends as possible providers. The general ability and willingness of this group to participate as providers is suggested on the PACE form (p. 15). Teaching the patient and/or family should be considered when appropriate.

Referring to the code sheet, list the number(s) of the provider(s) you have selected and the number of times per week you think each should contribute.

<u>Mo. 1-2-3-</u>			<u>Mo. 4-5-6</u>		
P1	<u>11</u>	<u>01</u> wk	P1	<u>21</u>	<u>02</u> wk
P2	<u>21</u>	<u>04</u> wk	P2	<u>51</u>	<u>05</u> wk
P3	<u>51</u>	<u>02</u> wk	P3	<u>00</u>	<u>00</u> wk

The above example indicates that for the first three months an RN (code 11) should bathe the patient once a week (for the purpose of teaching the family). A home health aide (code 21) should do it four times a week, with the family (code 51) bathing the patient on the two remaining occasions. For months 4,5, and 6, the home health aide (21) would bathe the patient twice a week and the family (51) five times a week. Again, as two boxes are provided, any digit less than 10 should have a zero (0) preceding it.

Please check that the total number of times a service is rendered by the sum of all the providers equals the total number of times a week you have indicated that service to be necessary.

In the example above, bathing would have been prescribed 7 times a week for both 3-month periods.

SERVICES REQUIRED INFREQUENTLY OR FOR SHORT DURATION ONLY

A. Initial teaching

If teaching is required only a few times, e.g., teaching of decubitus care on two occasions, combine with other small units of teaching, if any, and include under "Other Teaching," p. 11-12, as the total number of times per month.

B. Short-term nursing services

Combine services and express in episodes per month as in (A) and include under "Other Nursing Services."

PROVIDER CODE SHEET

PAID SERVICES

<u>Medical/Dental</u>		<u>Nursing</u>		<u>Home Care</u>	
MD/DO (prim.)	01	RN	11	Homenaker	21
" (special.)	02	LPN	12	Home Health Aide	22
Dentist	03	Other	19	Personal Care Attendant	23
Other	09			Other	29

Support/Socialization

Social Worker	31
Escort Service	32
Sitting Service	33
Daily Checking Service	34
Other	35

Miscellaneous Therapy

Physical Therapist	41
Physical Therapy Aide	42
Occupational Therapist	43
Recreational Therapist	44
Dietician	45
Dietary Aide	46
Other	49

UNPAID SERVICES

<u>Unpaid Services--Resident</u>		<u>Unpaid Services--Non-Resident</u>		<u>Misc. Services</u>	
Family - resident	51	Family - non-resident	61	Meals-on-Wheels	71
Friend - "	52	Friend - "	62	Laundry/Diaper	72
Other	59	Clergy	63	Heavy Chores	73
		Other	69	Other	79

NOTE: Check through code list to find code for provider selected. Only if this individual or service is not listed should the code for "other" in each category be used. When this occurs, specify the provider's title on the care plan.

EXAMPLES: An inhalation therapist would be coded 4 9 and inhalation therapist written beside the boxes.

A special nurse would be coded 1 9 and the specialty written beside the boxes.

DEFINITION OF SERVICES

1. A definition of service, when necessary, is provided in the first question of each sub-section.

2. Meal Preparation

This could include delivery of prepared meals to the patient's home. Under these circumstances, the number of times a week should be recorded but the estimated time per occasion omitted. Time estimates for meal preparation (Q. 44) would only apply to meals prepared in the home.

The same approach should be used with regard to laundry if a laundry service was selected, and for any other service rendered by a provider outside the patient's home where the cost of the service would include time involved.

DEFINITIONS OF PROVIDERS

R.N.'s are responsible for the nature and quality of all nursing care that patients receive. They are also responsible for carrying out the physician's instructions and for supervising LPN's and other health personnel who perform routine care and treatment of patients. RN's are trained to deal with physical, psychosocial, and teaching needs of patients.

L.P.N.'s provide nursing care and treatment of patients under supervision of a physician or RN. LPN's provide such treatments as catheterization, routine medication, taking vital signs, and some uncomplicated dressing changes. May assist in supervision of homemaker/home health aides.

Home health aides may help patients with bathing, transferring, toilet, exercising, relearning household skills, eating, preparing meals, and taking medications that are ordinarily self-administered.

Homemakers help with shopping, cooking, and light cleaning. They do not tend to the personal, physical needs of the patients.

Personal Care Attendants perform a mixture of LPN, home health aide, and homemaker services in accordance with patient needs.

Escort services provide supervised (escorted) transportation from home to shops, physicians' offices, and other sites. Accompanies patient throughout trip and assists patient when necessary.

Sitting services are the complement for the elderly of children's baby sitters.

Checking services include regular telephone contact and reassurance or brief visits. Does follow-up if problem noted.

Physical therapists evaluate patient to design PT program to restore or maintain maximum functional ability, teach the patient to adapt to his capabilities, and prevent disability following disease, injury or loss of a body part. The therapeutic properties of exercise, heat, cold, electricity, ultrasound, and massage are used to achieve this goal. Physical therapists work to overcome large muscular or neurological problems, such as those involving walking or lifting.

Physical therapist aides work directly under the supervision of a qualified physical therapist, carrying out programs designed by physical therapists.

Occupational therapists evaluate patients and help them regain fine motor skills necessary to perform activities of daily living (cooking, dressing, bathing, and the like). Design and teach use of adaptive devices.

Recreation therapists design activities (music, drama, arts and crafts, etc) for individuals and groups. Goals are entertainment and socialization.

Dieticians/Nutritionists plan and design diets consonant with medical needs and goals.

Dietary Aides work under the supervision of a dietician.

Meals on Wheels: Delivery of prepared meals ready for consumption.

Laundry/Diaper Service: Pickup, cleaning, and delivery of laundry. Included personal garments as well as sheets, towels and other linen.

Heavy Chores: Includes heavy cleaning within the dwelling unit, such as floor washing and waxing, wall and window washing.

DEFINITION OF DISCHARGE SITES

Sheltered, Congregate or Communal Housing

Residents maintain individual dwelling units within a larger complex. Supportive services such as on-call nursing services, checking services, congregate meals and some assistance with personal care are available.

Rest Home - Level IV

Provides protective supervision for persons who need more help than residents of sheltered housing.

Intermediate Care Facility - Level III

Besides room and board, nursing supervision and such personal care services as help with eating, bathing, dressing and walking are provided. Therapy and other services for patients who require them are available. Patients assigned to Level III homes usually require custodial care and some regular LPN care. Usually long term placement.

Skilled Nursing Facility - Level II

Provides care for medically fragile persons or those who require extensive rehabilitation. This level of care is most appropriate for a person whose medical condition is somewhat stabilized. Usually long term placement.

Skilled Nursing Facility - Level I

Similar to Level II but closer to nursing care found in general hospitals. Patients' conditions tend to be less stable than those in Level II facilities. Emphasis is on skilled nursing care and in some cases rehabilitation. Usually short term placement.

Chronic Disease Hospital

Provides care for patients too ill for Skilled Nursing Facilities but who would not benefit from the services of an acute care hospital. No remaining rehabilitation potential. May provide terminal care. Provides more skilled medical management than nursing homes.

Rehabilitation Hospital

Provides short term, active rehabilitation for patients who would benefit from this service. Patients include those who have suffered strokes, fractured limbs, amputations, arthritis, or similar problems.

Acute Hospital

Recommend this alternative if you believe patient will not be ready for discharge from present facility at proposed date of discharge.

SPECIAL INSTRUCTION FOR CONTINUOUS CAREGIVING

If patient requires a full-time caregiver, select a paid or unpaid provider, as patient needs and family circumstances suggest. As in other cases, you need not be bound by the providers on the code sheet.

We are still interested in each patient's discrete service needs, such as bathing, meal preparation, or physical therapy. Therefore, indicate (as for all other patients) the specific services the patient would require. The full-time caregiver would be the provider whenever you consider him or her to be appropriate. (This may seem repetitive, but we will not double-count these services.) Whenever the patient requires skills greater than those possessed by this full-time caregiver, other provider(s) should be selected.

Form # _____ (LPI only) PRESCRIBER'S INITIALS _____ CODE PATIENT'S CODE Page 1

I. PERSONAL CARE SERVICES	Months 1-2-3	Months 4-5-6	For Keypunch Only Care Card 1
<p><u>Caregiving/Supervision...Continuous</u> 1) Would patient need continuous care-giving/supervision? (This means the patient should never be left alone.)</p> <p>(SEE PAGE 9 OF INSTRUCTIONS IF THIS SERVICE IS SERVED.)</p>	<p>circle one YES NO</p>	<p>circle one YES NO</p>	
<p>2) Which providers would you recommend to give this service? How many hours per week per provider? (168 hrs. = 1 week) INSEKI PROVIDER CODES</p>	<p>P1 Wk 11-12 <input type="text"/> <input type="text"/> 13-15 <input type="text"/> <input type="text"/></p> <p>P2 Wk 21-22 <input type="text"/> <input type="text"/> 23-24 <input type="text"/> <input type="text"/></p> <p>P3 Wk 29-30 <input type="text"/> <input type="text"/> 31-32 <input type="text"/> <input type="text"/></p>	<p>P1 Wk 16-17 <input type="text"/> <input type="text"/> 18-20 <input type="text"/> <input type="text"/></p> <p>P2 Wk 25-26 <input type="text"/> <input type="text"/> 27-28 <input type="text"/> <input type="text"/></p> <p>P3 Wk 33-34 <input type="text"/> <input type="text"/> 35-36 <input type="text"/> <input type="text"/></p>	11-36
<p><u>Periodic Checking</u> 3) Would patient need to be checked on periodically?</p>	<p>circle one YES NO</p>	<p>circle one YES NO</p>	
<p>4) How much time would this activity take on each occasion?</p>	<p>Hrs. Mins. 37-39 <input type="text"/> <input type="text"/> <input type="text"/></p>	<p>Hrs. Mins. 40-42 <input type="text"/> <input type="text"/> <input type="text"/></p>	37-70
<p>5) How many times a week would he/she need to be checked?</p>	<p>Wk 43-44 <input type="text"/> <input type="text"/></p>	<p>Wk 45-46 <input type="text"/> <input type="text"/></p>	
<p>6) Which provider(s) would you recommend to provide the service? How many times per week per provider?</p>	<p>P1 Wk 47-48 <input type="text"/> <input type="text"/> 49-50 <input type="text"/> <input type="text"/></p> <p>P2 Wk 55-56 <input type="text"/> <input type="text"/> 57-58 <input type="text"/> <input type="text"/></p> <p>P3 Wk 63-64 <input type="text"/> <input type="text"/> 65-66 <input type="text"/> <input type="text"/></p>	<p>P1 Wk 51-52 <input type="text"/> <input type="text"/> 53-54 <input type="text"/> <input type="text"/></p> <p>P2 Wk 59-60 <input type="text"/> <input type="text"/> 61-62 <input type="text"/> <input type="text"/></p> <p>P3 Wk 67-68 <input type="text"/> <input type="text"/> 69-70 <input type="text"/> <input type="text"/></p>	
<p><u>Bathing</u> 7) Would patient need help bathing? (That means getting to the bathroom, getting in and out of the tub or shower and washing him/herself, OR giving a spongebath)</p>	<p>circle one YES NO</p>	<p>circle one YES NO</p>	
<p>8) How much time would this activity take on each occasion?</p>	<p>Hrs. Mins. 71-73 <input type="text"/> <input type="text"/> <input type="text"/></p>	<p>Hrs. Mins. 74-76 <input type="text"/> <input type="text"/> <input type="text"/></p>	71-80
<p>9) How many times a week would he/she need help to bathe?</p>	<p>Wk 77-78 <input type="text"/> <input type="text"/></p>	<p>Wk 79-80 <input type="text"/> <input type="text"/></p>	
<p>10) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>P1 Wk 11-12 <input type="text"/> <input type="text"/> 13-14 <input type="text"/> <input type="text"/></p> <p>P2 Wk 19-20 <input type="text"/> <input type="text"/> 21-22 <input type="text"/> <input type="text"/></p> <p>P3 Wk 27-28 <input type="text"/> <input type="text"/> 29-30 <input type="text"/> <input type="text"/></p>	<p>P1 Wk 15-16 <input type="text"/> <input type="text"/> 17-18 <input type="text"/> <input type="text"/></p> <p>P2 Wk 23-24 <input type="text"/> <input type="text"/> 25-26 <input type="text"/> <input type="text"/></p> <p>P3 Wk 31-32 <input type="text"/> <input type="text"/> 33-34 <input type="text"/> <input type="text"/></p>	<p>Card 2 11-34</p>

PRESCRIBER'S INITIALS _____

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Page 2

PERSONAL CARE SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Reprint Only Card 2 cont'd
Dressing	circle one YES NO	circle one YES NO	
11) Would patient need help dressing? (Getting his/her clothes from drawers and closet, putting on clothes and shoes, and taking them off.)			
12) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-68
13) How many times a week would he/she need help to dress?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
14) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 45-46 <input type="text"/> 47-48 <input type="text"/> Wk <input type="text"/> P2 53-54 <input type="text"/> 55-56 <input type="text"/> Wk <input type="text"/> P3 61-62 <input type="text"/> 63-64 <input type="text"/> Wk <input type="text"/>	P1 49-50 <input type="text"/> 51-52 <input type="text"/> Wk <input type="text"/> P2 57-58 <input type="text"/> 59-60 <input type="text"/> Wk <input type="text"/> P3 65-66 <input type="text"/> 67-68 <input type="text"/> Wk <input type="text"/>	
Toilet	circle one YES NO	circle one YES NO	
15) Would patient need help with elimina- tion? (Using toilet, bedpan or commode, perineal care, rearranging clothing, emptying bedpan, incontinence care)			
16) How much time would this activity take on each occasion?	69-71 Hrs. Mins. <input type="text"/> <input type="text"/>	72-74 Hrs. Mins. <input type="text"/> <input type="text"/>	69-78
17) How many times a week would he/she need help with elimination?	75-75 Wk <input type="text"/>	77-78 Wk <input type="text"/>	
18) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 11-12 <input type="text"/> 13-14 <input type="text"/> Wk <input type="text"/> P2 19-20 <input type="text"/> 21-22 <input type="text"/> Wk <input type="text"/> P3 27-28 <input type="text"/> 29-30 <input type="text"/> Wk <input type="text"/>	P1 15-16 <input type="text"/> 17-18 <input type="text"/> Wk <input type="text"/> P2 23-24 <input type="text"/> 25-26 <input type="text"/> Wk <input type="text"/> P3 31-32 <input type="text"/> 33-34 <input type="text"/> Wk <input type="text"/>	Card 3 11-34
Transferring	circle one YES NO	circle one YES NO	
19) Would patient need help transferring? (That means help moving from bed to chair, from one chair to another or to a wheelchair)			
20) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-68
21) How many times a week would he/she need help transferring?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
22) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 45-46 <input type="text"/> 47-48 <input type="text"/> Wk <input type="text"/> P2 53-54 <input type="text"/> 55-56 <input type="text"/> Wk <input type="text"/> P3 61-62 <input type="text"/> 63-64 <input type="text"/> Wk <input type="text"/>	P1 49-50 <input type="text"/> 51-52 <input type="text"/> Wk <input type="text"/> P2 57-58 <input type="text"/> 59-60 <input type="text"/> Wk <input type="text"/> P3 65-66 <input type="text"/> 67-68 <input type="text"/> Wk <input type="text"/>	

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PATIENT'S CODE

Page 3

PERSONAL CARE SERVICES CONT'D	Months 1-2-3	Months 4-5-6	FOR Keypunch Only
Supervision of Medication	circle one YES NO	circle one YES NO	Card 3 cont'd
23) Would patient need someone to make sure he/she took the right medicine at the right time?			
24) How much time would this activity take on each occasion?	Hrs. Mins. 69-71 <input type="text"/> <input type="text"/>	Hrs. Mins. 72-74 <input type="text"/> <input type="text"/>	69-78
25) How many times a week would he/she need help taking medicine?	Wk 75-76 <input type="text"/> <input type="text"/>	Wk 77-78 <input type="text"/> <input type="text"/>	Card 4
26) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 11-12 <input type="text"/> <input type="text"/> 13-14 <input type="text"/> <input type="text"/> P2 Wk 19-20 <input type="text"/> <input type="text"/> 21-22 <input type="text"/> <input type="text"/> P3 Wk 27-28 <input type="text"/> <input type="text"/> 29-30 <input type="text"/> <input type="text"/>	P1 Wk 15-16 <input type="text"/> <input type="text"/> 17-18 <input type="text"/> <input type="text"/> P2 Wk 23-24 <input type="text"/> <input type="text"/> 25-26 <input type="text"/> <input type="text"/> P3 Wk 31-32 <input type="text"/> <input type="text"/> 33-34 <input type="text"/> <input type="text"/>	11-34
Turning in Bed	circle one YES NO	circle one YES NO	
27) Would patient need help turning in bed?			
28) How much time would this activity take on each occasion?	Hrs. Mins. 35-37 <input type="text"/> <input type="text"/>	Hrs. Mins. 38-40 <input type="text"/> <input type="text"/>	33-68
29) How many times a week would he/she need help turning in bed?	Wk 41-42 <input type="text"/> <input type="text"/>	Wk 43-44 <input type="text"/> <input type="text"/>	
30) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 45-46 <input type="text"/> <input type="text"/> 47-48 <input type="text"/> <input type="text"/> P2 Wk 53-54 <input type="text"/> <input type="text"/> 55-56 <input type="text"/> <input type="text"/> P3 Wk 61-62 <input type="text"/> <input type="text"/> 63-64 <input type="text"/> <input type="text"/>	P1 Wk 49-50 <input type="text"/> <input type="text"/> 51-52 <input type="text"/> <input type="text"/> P2 Wk 57-58 <input type="text"/> <input type="text"/> 59-60 <input type="text"/> <input type="text"/> P3 Wk 65-66 <input type="text"/> <input type="text"/> 67-68 <input type="text"/> <input type="text"/>	
Grooming	circle one YES NO	circle one YES NO	
31) Would patient need help washing his/her face, cleaning teeth, combing hair, and (for men) shaving/(for women) applying makeup?			
32) How much time would this activity take on each occasion?	Hrs. Mins. 69-71 <input type="text"/> <input type="text"/>	Hrs. Mins. 72-74 <input type="text"/> <input type="text"/>	69-78
33) How many times per week would patient need help with grooming?	Wk 75-76 <input type="text"/> <input type="text"/>	Wk 77-78 <input type="text"/> <input type="text"/>	Card 5
34) Which provider(s) would you recommend to give the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 11-12 <input type="text"/> <input type="text"/> 13-14 <input type="text"/> <input type="text"/> P2 Wk 19-20 <input type="text"/> <input type="text"/> 21-22 <input type="text"/> <input type="text"/> P3 Wk 27-28 <input type="text"/> <input type="text"/> 29-30 <input type="text"/> <input type="text"/>	P1 Wk 15-16 <input type="text"/> <input type="text"/> 17-18 <input type="text"/> <input type="text"/> P2 Wk 23-24 <input type="text"/> <input type="text"/> 25-26 <input type="text"/> <input type="text"/> P3 Wk 31-32 <input type="text"/> <input type="text"/> 33-34 <input type="text"/> <input type="text"/>	11-34

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Page 4

PERSONAL CARE SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Keypunch Only
<u>Eating and Drinking</u>	circle one	circle one	Card 5 cont'd
35) Would patient need help with eating and drinking? (This does not include food preparation, just eating and drinking)	YES NO	YES NO	
36) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	
37) How many times a week would patient need help with eating and drinking?	41-42 <input type="text"/> Wk	43-44 <input type="text"/> Wk	35-68
38) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> 47-48 <input type="text"/> Wk P2 <input type="text"/> 53-54 <input type="text"/> 55-56 <input type="text"/> Wk P3 <input type="text"/> 61-62 <input type="text"/> 63-64 <input type="text"/> Wk	49-50 P1 <input type="text"/> 51-52 <input type="text"/> Wk P2 <input type="text"/> 57-58 <input type="text"/> 59-60 <input type="text"/> Wk P3 <input type="text"/> 65-66 <input type="text"/> 67-68 <input type="text"/> Wk	
<u>II. HOUSEHOLD SERVICES</u>	Months 1-2-3	Months 4-5-6	
<u>Shopping</u>	circle one	circle one	
39) Would patient need help with shopping? (Food and other supermarket items)	YES NO	YES NO	
40) How much time would this activity take on each occasion?	69-71 Hrs. Mins. <input type="text"/> <input type="text"/>	72-74 Hrs. Mins. <input type="text"/> <input type="text"/>	69-78
41) How many times a week would patient need help with shopping?	75-76 <input type="text"/> Wk	77-78 <input type="text"/> Wk	
42) Which provider(s) would you recommend to provide the service? How many times a week per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="text"/> 13-14 <input type="text"/> Wk P2 <input type="text"/> 19-20 <input type="text"/> 21-22 <input type="text"/> Wk P3 <input type="text"/> 27-28 <input type="text"/> 29-30 <input type="text"/> Wk	15-15 P1 <input type="text"/> 17-18 <input type="text"/> Wk P2 <input type="text"/> 23-24 <input type="text"/> 25-26 <input type="text"/> Wk P3 <input type="text"/> 31-32 <input type="text"/> 33-34 <input type="text"/> Wk	Card 6 11-34
<u>Meal Preparation</u>	Months 1-2-3	Months 4-5-6	
43) Would patient need help with meal preparation? (Cooking and getting meals for her/himself and washing up afterwards)	circle one YES NO	circle one YES NO	
44) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-68
45) How many times per week would patient need help with meal preparation?	41-42 <input type="text"/> Wk	43-44 <input type="text"/> Wk	
46) Which provider(s) would you recommend to give the services? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> 47-48 <input type="text"/> Wk P2 <input type="text"/> 53-54 <input type="text"/> 55-56 <input type="text"/> Wk P3 <input type="text"/> 61-62 <input type="text"/> 63-64 <input type="text"/> Wk	49-50 P1 <input type="text"/> 51-52 <input type="text"/> Wk P2 <input type="text"/> 57-58 <input type="text"/> 59-60 <input type="text"/> Wk P3 <input type="text"/> 65-66 <input type="text"/> 67-68 <input type="text"/> Wk	

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Page 5

HOUSEHOLD SERVICES CONT'D	Months 1-2-3	Months 4-5-6	FOR REVISION ONLY
<p><u>Telephone</u></p> <p>47) Does patient need telephone installation? (See PAGE p. 13)</p> <p>48) Would patient need help with using the telephone?</p> <p>49) How much time would this activity take on each occasion?</p> <p>50) How many times per week would patient need help with the phone?</p> <p>51) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>69-71 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>75-76 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>11-12 <input type="text"/> <input type="text"/> 13-14 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>19-20 <input type="text"/> <input type="text"/> 21-22 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>27-28 <input type="text"/> <input type="text"/> 29-30 <input type="text"/> <input type="text"/></p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>72-74 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>77-78 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>15-16 <input type="text"/> <input type="text"/> 17-18 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>23-24 <input type="text"/> <input type="text"/> 25-26 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>31-32 <input type="text"/> <input type="text"/> 33-34 <input type="text"/> <input type="text"/></p>	<p>Card 6 cont'd</p> <p>69-78</p> <p>Card 7</p> <p>11-34</p>
<p><u>Transportation</u></p> <p>52) Would patient need someone to transport or escort him/her to places like church/synagogue, a meeting, the doctor, shopping or to visit friends?</p> <p>53) How much time would this activity take on each occasion?</p> <p>54) How many times per week would patient need help to go out?</p> <p>55) Which provider(s) would you recommend to give the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>Months 1-2-3</p> <p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>35-37 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>41-42 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>45-46 <input type="text"/> <input type="text"/> 47-48 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>53-54 <input type="text"/> <input type="text"/> 55-56 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>61-62 <input type="text"/> <input type="text"/> 63-64 <input type="text"/> <input type="text"/></p>	<p>Months 4-5-6</p> <p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>38-40 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>43-44 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>49-50 <input type="text"/> <input type="text"/> 51-52 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>57-58 <input type="text"/> <input type="text"/> 59-60 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>65-66 <input type="text"/> <input type="text"/> 67-68 <input type="text"/> <input type="text"/></p>	<p>35-68</p>
<p><u>Socialization</u></p> <p>56) Would patient need visitors to keep him/her company?</p> <p>57) How much time would this activity take on each occasion?</p> <p>58) How many times per week would patient need a visitor?</p> <p>59) Which provider(s) would you recommend to provide the service? How many times per week per provider?</p>	<p>Months 1-2-3</p> <p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>69-71 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>75-76 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>11-12 <input type="text"/> <input type="text"/> 13-14 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>19-20 <input type="text"/> <input type="text"/> 21-22 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>27-28 <input type="text"/> <input type="text"/> 29-30 <input type="text"/> <input type="text"/></p>	<p>Months 4-5-6</p> <p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>72-74 <input type="text"/> <input type="text"/></p> <p>Wk</p> <p>77-78 <input type="text"/> <input type="text"/></p> <p>P1 <input type="text"/> <input type="text"/> Wk</p> <p>15-16 <input type="text"/> <input type="text"/> 17-18 <input type="text"/> <input type="text"/></p> <p>P2 <input type="text"/> <input type="text"/> Wk</p> <p>23-24 <input type="text"/> <input type="text"/> 25-26 <input type="text"/> <input type="text"/></p> <p>P3 <input type="text"/> <input type="text"/> Wk</p> <p>31-32 <input type="text"/> <input type="text"/> 33-34 <input type="text"/> <input type="text"/></p>	<p>69-78</p> <p>Card 8</p> <p>11-34</p>

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PATIENT'S CODE

Page 6

HOUSEHOLD SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Review Only
Light Housework	circle one YES NO	circle one YES NO	Card 8 cont'd
60) Would patient need help with light housework? (Such as dusting, picking-up, and bedmaking)			
61) How much time would this activity take on each occasion?	35-37 Hrs. <input type="text"/> Mins. <input type="text"/>	38-40 Hrs. <input type="text"/> Mins. <input type="text"/>	35-68
62) How many times per week would patient need help with light housekeeping?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
63) Which provider(s) would you recommend to provide the service? How many times a week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> Wk <input type="text"/>	49-50 P1 <input type="text"/> Wk <input type="text"/>	
	53-54 P2 <input type="text"/> Wk <input type="text"/>	57-58 P2 <input type="text"/> Wk <input type="text"/>	
	61-62 P3 <input type="text"/> Wk <input type="text"/>	65-66 P3 <input type="text"/> Wk <input type="text"/>	
Heavy Housework	circle one YES NO	circle one YES NO	
64) Would patient need help with heavy housework? (scrubbing floors, washing windows, cleaning the refrigerator)			
65) How much time would this activity take on each occasion?	69-71 Hrs. <input type="text"/> Mins. <input type="text"/>	72-74 Hrs. <input type="text"/> Mins. <input type="text"/>	69-78
66) How many times per month would patient need help with heavy housework?	75-76 Mo <input type="text"/>	77-78 Mo <input type="text"/>	
67) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="text"/> Mo <input type="text"/>	15-16 P1 <input type="text"/> Mo <input type="text"/>	Card 9
	19-20 P2 <input type="text"/> Mo <input type="text"/>	23-24 P2 <input type="text"/> Mo <input type="text"/>	11-36
	27-28 P3 <input type="text"/> Mo <input type="text"/>	31-32 P3 <input type="text"/> Mo <input type="text"/>	
Laundry	circle one YES NO	circle one YES NO	
68) Would patient need help with the laundry? (getting clothes washed, dried, and ironed)			
69) How much time would this activity take on each occasion?	35-37 Hrs. <input type="text"/> Mins. <input type="text"/>	38-40 Hrs. <input type="text"/> Mins. <input type="text"/>	35-68
70) How many times per month would patient need help with laundry?	41-42 Mo <input type="text"/>	43-44 Mo <input type="text"/>	
71) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> Mo <input type="text"/>	49-50 P1 <input type="text"/> Mo <input type="text"/>	
	53-54 P2 <input type="text"/> Mo <input type="text"/>	57-58 P2 <input type="text"/> Mo <input type="text"/>	
	61-62 P3 <input type="text"/> Mo <input type="text"/>	65-66 P3 <input type="text"/> Mo <input type="text"/>	

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	Months 1-2-3	Months 4-5-6	For Key punch Only
HOUSEHOLD SERVICES CONT'D			
<u>Management of Personal Affairs</u>	circle one	circle one	
72) Would patient need help with paying bills, writing and mailing letters, picking up medicine, and doing extra shopping?	YES NO	YES NO	Card 9 cont'd
73) How much time would this activity take on each occasion?	Hrs. Mins. 69-71 <input type="checkbox"/> <input type="checkbox"/>	Hrs. Mins. 72-74 <input type="checkbox"/> <input type="checkbox"/>	69-78
74) How many times per month would patient need help with management of personal affairs?	Mo 75-76 <input type="checkbox"/>	Mo 77-78 <input type="checkbox"/>	Card 10
75) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="checkbox"/> 13-14 Mo <input type="checkbox"/> 19-20 P2 <input type="checkbox"/> 21-22 Mo <input type="checkbox"/> 27-28 P3 <input type="checkbox"/> 29-30 Mo <input type="checkbox"/>	15-16 P1 <input type="checkbox"/> 17-18 Mo <input type="checkbox"/> 23-24 P2 <input type="checkbox"/> 25-26 Mo <input type="checkbox"/> 31-32 P3 <input type="checkbox"/> 33-34 Mo <input type="checkbox"/>	11-34
III. NURSING SERVICES			
76) Would patient need bowel and/or bladder training?	circle one	circle one	
77) How much time would this activity take on each occasion?	Hrs. Mins. 35-37 <input type="checkbox"/> <input type="checkbox"/>	Hrs. Mins. 38-40 <input type="checkbox"/> <input type="checkbox"/>	35-68
78) How many times per week would this be needed?	Wk 41-42 <input type="checkbox"/>	Wk 43-44 <input type="checkbox"/>	
79) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-45 P1 <input type="checkbox"/> 47-48 Wk <input type="checkbox"/> 53-54 P2 <input type="checkbox"/> 55-56 Wk <input type="checkbox"/> 61-62 P3 <input type="checkbox"/> 63-64 Wk <input type="checkbox"/>	49-50 P1 <input type="checkbox"/> 51-52 Wk <input type="checkbox"/> 57-58 P2 <input type="checkbox"/> 59-60 Wk <input type="checkbox"/> 65-66 P3 <input type="checkbox"/> 67-68 Wk <input type="checkbox"/>	
80) Would patient need decubitus care?	circle one	circle one	
81) How much time would this activity take on each occasion?	Hrs. Mins. 69-71 <input type="checkbox"/> <input type="checkbox"/>	Hrs. Mins. 72-74 <input type="checkbox"/> <input type="checkbox"/>	69-78
82) How many times per week would this be needed?	Wk 75-76 <input type="checkbox"/>	Wk 77-78 <input type="checkbox"/>	Card 11
83) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="checkbox"/> 13-14 Wk <input type="checkbox"/> 19-20 P2 <input type="checkbox"/> 21-22 Wk <input type="checkbox"/> 27-28 P3 <input type="checkbox"/> 29-30 Wk <input type="checkbox"/>	15-16 P1 <input type="checkbox"/> 17-18 Wk <input type="checkbox"/> 23-24 P2 <input type="checkbox"/> 25-26 Wk <input type="checkbox"/> 31-32 P3 <input type="checkbox"/> 33-34 Wk <input type="checkbox"/>	11-34

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NURSING SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Keypunch Only
84) Would patient need <u>wound care</u> ?	circle one YES NO	circle one YES NO	Card 11 cont'd
85) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-68
86) How many times per week would this be needed?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
87) Which provider(s) would you recommend to provide this service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> 47-48 Wk <input type="text"/> 53-54 P2 <input type="text"/> 55-56 Wk <input type="text"/> 61-62 P3 <input type="text"/> 63-64 Wk <input type="text"/>	49-50 P1 <input type="text"/> 51-52 Wk <input type="text"/> 57-58 P2 <input type="text"/> 59-60 Wk <input type="text"/> 65-66 P3 <input type="text"/> 67-68 Wk <input type="text"/>	
88) Would patient need <u>eye care</u> ?	circle one YES NO	circle one YES NO	
89) How much time would this activity take on each occasion?	69-71 Hrs. Mins. <input type="text"/> <input type="text"/>	72-74 Hrs. Mins. <input type="text"/> <input type="text"/>	69-78
90) How many times per week would this be needed?	75-76 Wk <input type="text"/>	77-78 Wk <input type="text"/>	
91) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="text"/> 13-14 Wk <input type="text"/> 19-20 P2 <input type="text"/> 21-22 Wk <input type="text"/> 27-28 P3 <input type="text"/> 29-30 Wk <input type="text"/>	15-16 P1 <input type="text"/> 17-18 Wk <input type="text"/> 23-24 P2 <input type="text"/> 25-26 Wk <input type="text"/> 31-32 P3 <input type="text"/> 33-34 Wk <input type="text"/>	Card 12 11-34 27
92) Would patient need <u>bladder irrigation</u> ?	circle one YES NO	circle one YES NO	
93) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-68
94) How many times per week would this be needed?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
95) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> 47-48 Wk <input type="text"/> 53-54 P2 <input type="text"/> 55-56 Wk <input type="text"/> 61-62 P3 <input type="text"/> 63-64 Wk <input type="text"/>	49-50 P1 <input type="text"/> 51-52 Wk <input type="text"/> 57-58 P2 <input type="text"/> 59-60 Wk <input type="text"/> 65-66 P3 <input type="text"/> 67-68 Wk <input type="text"/>	

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NURSING SERVICES CONT'D	Months 1-2-3		Months 4-5-6		For Key punch Only Card 12 Cont'd Card 13 11-34
	circle one YES NO		circle one YES NO		
96) Would patient need <u>suctioning and/or chest PT</u> ?					
97) How much time would this activity take on each occasion?	Hrs. Mins.	Hrs. Mins.			69-78
98) How many times per week would this be needed?	75-76 <input type="text"/> <input type="text"/> Wk		77-78 <input type="text"/> <input type="text"/> Wk		
99) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1	13-14 <input type="text"/> <input type="text"/> Wk	P1	17-18 <input type="text"/> <input type="text"/> Wk	11-34
	P2	21-22 <input type="text"/> <input type="text"/> Wk	P2	25-26 <input type="text"/> <input type="text"/> Wk	
	P3	29-30 <input type="text"/> <input type="text"/> Wk	P3	33-34 <input type="text"/> <input type="text"/> Wk	
	11-12 <input type="text"/> <input type="text"/> Wk	15-16 <input type="text"/> <input type="text"/> Wk			
100) Would patient need <u>inhalation/IPPB therapy</u> ?	circle one YES NO		circle one YES NO		
101) How much time would this activity take on each occasion?	Hrs. Mins.	Hrs. Mins.			35-68
102) How many times per week would this be needed?	41-42 <input type="text"/> <input type="text"/> Wk		43-44 <input type="text"/> <input type="text"/> Wk		
103) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1	47-48 <input type="text"/> <input type="text"/> Wk	P1	51-52 <input type="text"/> <input type="text"/> Wk	
	P2	55-56 <input type="text"/> <input type="text"/> Wk	P2	59-60 <input type="text"/> <input type="text"/> Wk	
	P3	63-64 <input type="text"/> <input type="text"/> Wk	P3	67-68 <input type="text"/> <input type="text"/> Wk	
	45-46 <input type="text"/> <input type="text"/> Wk	49-50 <input type="text"/> <input type="text"/> Wk			
104) Would patient need <u>other oxygen therapy</u> ?	circle one YES NO		circle one YES NO		
105) How much time would this activity take on each occasion?	Hrs. Mins.	Hrs. Mins.			69-78
106) How many times per week would this be needed?	75-76 <input type="text"/> <input type="text"/> Wk		77-78 <input type="text"/> <input type="text"/> Wk		
107) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1	13-14 <input type="text"/> <input type="text"/> Wk	P1	17-18 <input type="text"/> <input type="text"/> Wk	Card 14 11-34
	P2	21-22 <input type="text"/> <input type="text"/> Wk	P2	25-26 <input type="text"/> <input type="text"/> Wk	
	P3	29-30 <input type="text"/> <input type="text"/> Wk	P3	33-34 <input type="text"/> <input type="text"/> Wk	
	11-12 <input type="text"/> <input type="text"/> Wk	15-16 <input type="text"/> <input type="text"/> Wk			

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NURSING SERVICES CONT'D	Months 1-2-3		Months 4-5-6		For Lev punch Only Card 14 cont'd
	circle one YES NO		circle one YES NO		
108) Would patient need <u>range of motion exercises</u> ?					
109) How much time would this activity take on each occasion?	35-37	Hrs. <input type="text"/> Mins. <input type="text"/>	38-40	Hrs. <input type="text"/> Mins. <input type="text"/>	35-68
110) How many times per week would this be needed?		41-42 <input type="text"/> Wk		43-44 <input type="text"/> Wk	
111) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46	P1 <input type="text"/> 47-48 <input type="text"/> Wk	49-50	P1 <input type="text"/> 51-52 <input type="text"/> Wk	
	53-54	P2 <input type="text"/> 55-56 <input type="text"/> Wk	57-58	P2 <input type="text"/> 59-60 <input type="text"/> Wk	
	61-62	P3 <input type="text"/> 63-64 <input type="text"/> Wk	65-66	P3 <input type="text"/> 67-68 <input type="text"/> Wk	
112) Would patient need <u>nutritional/diet supervision</u> ?					
113) How much time would this activity take on each occasion?	69-71	Hrs. <input type="text"/> Mins. <input type="text"/>	72-74	Hrs. <input type="text"/> Mins. <input type="text"/>	69-78
114) How many times per week would this be needed?		75-76 <input type="text"/> Wk		77-78 <input type="text"/> Wk	Card 15
115) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	11-12	P1 <input type="text"/> 13-14 <input type="text"/> Wk	15-16	P1 <input type="text"/> 17-18 <input type="text"/> Wk	11-34
	19-20	P2 <input type="text"/> 21-22 <input type="text"/> Wk	23-24	P2 <input type="text"/> 25-26 <input type="text"/> Wk	
	27-28	P3 <input type="text"/> 29-30 <input type="text"/> Wk	31-32	P3 <input type="text"/> 33-34 <input type="text"/> Wk	
116) Would patient need <u>medications administered</u> ?					
117) How much time would this activity take on each occasion?	35-37	Hrs. <input type="text"/> Mins. <input type="text"/>	38-40	Hrs. <input type="text"/> Mins. <input type="text"/>	35-40
118) How many times per week would this be needed?		41-42 <input type="text"/> Wk		43-44 <input type="text"/> Wk	
119) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46	P1 <input type="text"/> 47-48 <input type="text"/> Wk	49-50	P1 <input type="text"/> 51-52 <input type="text"/> Wk	
	53-54	P2 <input type="text"/> 55-56 <input type="text"/> Wk	57-58	P2 <input type="text"/> 59-60 <input type="text"/> Wk	
	61-62	P3 <input type="text"/> 63-64 <input type="text"/> Wk	65-66	P3 <input type="text"/> 67-68 <input type="text"/> Wk	

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NURSING SERVICES CONT'D	Months 1-2-3	Months 4-5-6	FOI Reattach Only
120) Would patient need <u>monitoring of vital signs, mental and neurological status?</u>	circle one YES NO	circle one YES NO	Card 15 cont'd
121) How much time would this activity take on each occasion?	69-71 Hrs. Mins. <input type="text"/> <input type="text"/>	72-74 Hrs. Mins. <input type="text"/> <input type="text"/>	69-78
122) How many times per week would this be needed?	75-76 Wk <input type="text"/>	77-78 Wk <input type="text"/>	Card 15
123) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	11-12 P1 <input type="text"/> Wk <input type="text"/> 13-14 P2 <input type="text"/> Wk <input type="text"/> 19-20 P3 <input type="text"/> Wk <input type="text"/> 27-28 P3 <input type="text"/> Wk <input type="text"/>	15-16 P1 <input type="text"/> Wk <input type="text"/> 17-18 P2 <input type="text"/> Wk <input type="text"/> 23-24 P2 <input type="text"/> Wk <input type="text"/> 25-26 P3 <input type="text"/> Wk <input type="text"/> 31-32 P3 <input type="text"/> Wk <input type="text"/> 33-34 P3 <input type="text"/> Wk <input type="text"/>	11-34
124) Would patient need <u>foot care?</u>	circle one YES NO	circle one YES NO	
125) How much time would this activity take on each occasion?	35-37 Hrs. Mins. <input type="text"/> <input type="text"/>	38-40 Hrs. Mins. <input type="text"/> <input type="text"/>	35-63
126) How many times per week would this be needed?	41-42 Wk <input type="text"/>	43-44 Wk <input type="text"/>	
127) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	45-46 P1 <input type="text"/> Wk <input type="text"/> 47-48 P2 <input type="text"/> Wk <input type="text"/> 53-54 P2 <input type="text"/> Wk <input type="text"/> 55-56 P3 <input type="text"/> Wk <input type="text"/> 61-62 P3 <input type="text"/> Wk <input type="text"/>	49-50 P1 <input type="text"/> Wk <input type="text"/> 51-52 P1 <input type="text"/> Wk <input type="text"/> 57-58 P2 <input type="text"/> Wk <input type="text"/> 59-60 P2 <input type="text"/> Wk <input type="text"/> 65-66 P3 <input type="text"/> Wk <input type="text"/> 67-68 P3 <input type="text"/> Wk <input type="text"/>	
128) Would patient need <u>teaching in an area other than those already prescribed?</u> Specify: _____	circle one YES NO (LPI only) 69-70 <input type="text"/>	circle one YES NO (LPI only) 71-72 <input type="text"/>	69-73
129) How much time would this activity take on each occasion?	73-75 Hrs. Mins. <input type="text"/> <input type="text"/>	76-78 Hrs. Mins. <input type="text"/> <input type="text"/>	
130) How many times per week would this be needed?	11-12 Wk <input type="text"/>	13-14 Wk <input type="text"/>	Card 17
131) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	15-16 P1 <input type="text"/> Wk <input type="text"/> 17-18 P2 <input type="text"/> Wk <input type="text"/> 23-24 P2 <input type="text"/> Wk <input type="text"/> 25-26 P3 <input type="text"/> Wk <input type="text"/> 31-32 P3 <input type="text"/> Wk <input type="text"/> 33-34 P3 <input type="text"/> Wk <input type="text"/>	19-20 P1 <input type="text"/> Wk <input type="text"/> 21-22 P1 <input type="text"/> Wk <input type="text"/> 27-28 P2 <input type="text"/> Wk <input type="text"/> 29-30 P2 <input type="text"/> Wk <input type="text"/> 35-36 P3 <input type="text"/> Wk <input type="text"/> 37-38 P3 <input type="text"/> Wk <input type="text"/>	11-38

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NURSING SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Recap Only Card 17 cont'd
132) Would patient need additional teaching? Specify: _____	circle one YES NO (LPI only) 39-40 <input type="checkbox"/>	circle one YES NO (LPI only) 41-42 <input type="checkbox"/>	39-76
133) How much time would this activity take on each occasion?	Hrs. Mins. 43-45 <input type="checkbox"/>	Hrs. Mins. 46-48 <input type="checkbox"/>	
134) How many times per week would this be needed?	Wk 49-50 <input type="checkbox"/>	Wk 51-52 <input type="checkbox"/>	
135) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 53-54 <input type="checkbox"/> P2 Wk 61-62 <input type="checkbox"/> P3 Wk 69-70 <input type="checkbox"/>	P1 Wk 57-58 <input type="checkbox"/> P2 Wk 65-66 <input type="checkbox"/> P3 Wk 73-74 <input type="checkbox"/>	
136) Would patient need other nursing services? Specify (a): _____	circle one YES NO (LPI only) 77-78 <input type="checkbox"/>	circle one YES NO (LPI only) 79-80 <input type="checkbox"/>	77-80
137) How much time would this activity take on each occasion?	Hrs. Mins. 11-13 <input type="checkbox"/>	Hrs. Mins. 14-16 <input type="checkbox"/>	Card 18
138) How many times per week would this be needed?	Wk 17-18 <input type="checkbox"/>	Wk 19-20 <input type="checkbox"/>	11-46
139) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 21-22 <input type="checkbox"/> P2 Wk 29-30 <input type="checkbox"/> P3 Wk 37-38 <input type="checkbox"/>	P1 Wk 25-26 <input type="checkbox"/> P2 Wk 33-34 <input type="checkbox"/> P3 Wk 41-42 <input type="checkbox"/>	
140) Would patient need other nursing services? Specify (b): _____	circle one YES NO (LPI only) 45-46 <input type="checkbox"/>	circle one YES NO (LPI only) 47-48 <input type="checkbox"/>	45-74
141) How much time would this activity take on each occasion?	Hrs. Mins. 49-51 <input type="checkbox"/>	Hrs. Mins. 52-54 <input type="checkbox"/>	
142) How many times per week would this be needed?	Wk 55-56 <input type="checkbox"/>	Wk 57-58 <input type="checkbox"/>	
143) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)	P1 Wk 59-60 <input type="checkbox"/> P2 Wk 67-68 <input type="checkbox"/> P3 Wk 11-12 <input type="checkbox"/>	P1 Wk 63-64 <input type="checkbox"/> P2 Wk 71-72 <input type="checkbox"/> P3 Wk 15-16 <input type="checkbox"/>	Card 19 11-18

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OTHER NURSING SERVICES CONT'D	Months 1-2-3	Months 4-5-6	For Key punch Only
<p>144) Would patient need other nursing services? Specify (c): _____</p> <p>145) How much time would this activity take on each occasion?</p> <p>146) How many times per week would this be needed?</p> <p>147) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one YES NO</p> <p>(LPI only) 19-20 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>23-25 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>29-30 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 33-34 <input type="checkbox"/><input type="checkbox"/> 35-36 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 41-42 <input type="checkbox"/><input type="checkbox"/> 43-44 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 49-50 <input type="checkbox"/><input type="checkbox"/> 51-52 <input type="checkbox"/><input type="checkbox"/></p>	<p>circle one YES NO</p> <p>(LPI only) 21-22 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>26-28 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>31-32 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 37-38 <input type="checkbox"/><input type="checkbox"/> 39-40 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 45-46 <input type="checkbox"/><input type="checkbox"/> 47-48 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 53-54 <input type="checkbox"/><input type="checkbox"/> 55-56 <input type="checkbox"/><input type="checkbox"/></p>	<p>Card 19 cont'd</p> <p>19-56</p>
<p>148) Would patient need other nursing services? Specify (d): _____</p> <p>149) How much time would this activity take on each occasion?</p> <p>150) How many times per week would this be needed?</p> <p>151) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one YES NO</p> <p>(LPI only) 57-58 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>61-63 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>67-68 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 71-72 <input type="checkbox"/><input type="checkbox"/> 73-74 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 11-12 <input type="checkbox"/><input type="checkbox"/> 13-14 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 19-20 <input type="checkbox"/><input type="checkbox"/> 21-22 <input type="checkbox"/><input type="checkbox"/></p>	<p>circle one YES NO</p> <p>(LPI only) 59-60 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>64-66 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>69-70 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 75-76 <input type="checkbox"/><input type="checkbox"/> 77-78 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 15-16 <input type="checkbox"/><input type="checkbox"/> 17-18 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 23-24 <input type="checkbox"/><input type="checkbox"/> 25-26 <input type="checkbox"/><input type="checkbox"/></p>	<p>57-79</p> <p>Card 20</p> <p>11-26</p>
<p>152) Would patient need other nursing services? Specify (e): _____</p> <p>153) How much time would this activity take on each occasion?</p> <p>154) How many times per week would this be needed?</p> <p>155) Which provider(s) would you recommend to provide the service? How many times per week per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one YES NO</p> <p>(LPI only) 27-28 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>31-33 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>37-38 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 41-42 <input type="checkbox"/><input type="checkbox"/> 43-44 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 49-50 <input type="checkbox"/><input type="checkbox"/> 51-52 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 57-58 <input type="checkbox"/><input type="checkbox"/> 59-60 <input type="checkbox"/><input type="checkbox"/></p>	<p>circle one YES NO</p> <p>(LPI only) 29-30 <input type="checkbox"/><input type="checkbox"/></p> <p>Hrs. Mins.</p> <p>34-36 <input type="checkbox"/><input type="checkbox"/></p> <p>Wk</p> <p>39-40 <input type="checkbox"/><input type="checkbox"/></p> <p>P1 Wk 45-46 <input type="checkbox"/><input type="checkbox"/> 47-48 <input type="checkbox"/><input type="checkbox"/></p> <p>P2 Wk 53-54 <input type="checkbox"/><input type="checkbox"/> 55-56 <input type="checkbox"/><input type="checkbox"/></p> <p>P3 Wk 61-62 <input type="checkbox"/><input type="checkbox"/> 63-64 <input type="checkbox"/><input type="checkbox"/></p>	<p>27-64</p>

IV. OTHER PROFESSIONAL SERVICES

MONTHS 1-6

For
Keypunch
Only

156) Primary Medical Care
How many times would patient need to see a primary care provider during the 6 months following discharge?

65-66 /6 mo.

Card 20
Con't

157) Which provider(s) would you recommend to provide this service and how many times per provider?

P1 /6 mo.
67-68 69-70
P2 /6 mo.
71-72 73-74
P3 /6 mo.
75-76 77-78

65-78

158) Would patient need to see a medical specialist(s) during the 6 months following discharge?

circle one
YES NO

Card 21
11-22

159) Which specialist(s) and how many times during this period? Type of Specialist:

Spec. /6 mo.
11-12 13-14
Spec. /6 mo.
15-16 17-18
Spec. /6 mo.
19-20 21-22

160) Would patient need to see a dentist during the 6 months following discharge?

circle one
YES NO

23-24

161) How many times would patient need to see a dentist during the 6 months following discharge?

23-24 /6 mo.

162) Would patient need to see a podiatrist during the 6 months following discharge?

circle one
YES NO

25-26

163) How many times would patient need to see a podiatrist during the 6 months following discharge?

25-26 /6 mo.

PRESCRIBER'S INITIALS _____

CODE

PATIENT'S CODE

Page 15

OTHER PROFESSIONAL SERVICES CONT'D	Months 1-2-3	Months 4-5-6	
<p><u>Physical Therapy</u></p> <p>154) Would patient need physical therapy during the 6 months following discharge?</p> <p>155) How much time would this activity take on each occasion?</p> <p>156) How many times per month would physical therapy be needed?</p> <p>157) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>27-29 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>33-34 <input type="checkbox"/></p> <p>P1 Mo</p> <p>37-39 <input type="checkbox"/> 39-40 <input type="checkbox"/></p> <p>P2 Mo</p> <p>45-46 <input type="checkbox"/> 47-48 <input type="checkbox"/></p> <p>P3 Mo</p> <p>53-54 <input type="checkbox"/> 55-56 <input type="checkbox"/></p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>30-32 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>35-36 <input type="checkbox"/></p> <p>P1 Mo</p> <p>41-42 <input type="checkbox"/> 43-44 <input type="checkbox"/></p> <p>P2 Mo</p> <p>49-50 <input type="checkbox"/> 51-52 <input type="checkbox"/></p> <p>P3 Mo</p> <p>57-58 <input type="checkbox"/> 59-60 <input type="checkbox"/></p>	<p>For Keypunch Only</p> <p>Card 21 Cont'd</p> <p>27-60</p>
<p><u>Occupational Therapy</u></p> <p>168) Would patient need occupational therapy during the 6 months following discharge?</p> <p>169) How much time would this activity take on each occasion?</p> <p>170) How many times per month would occupational therapy be needed?</p> <p>171) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>61-63 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>67-68 <input type="checkbox"/></p> <p>P1 Mo</p> <p>71-72 <input type="checkbox"/> 73-74 <input type="checkbox"/></p> <p>P2 Mo</p> <p>11-12 <input type="checkbox"/> 13-14 <input type="checkbox"/></p> <p>P3 Mo</p> <p>19-20 <input type="checkbox"/> 21-22 <input type="checkbox"/></p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>64-66 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>69-70 <input type="checkbox"/></p> <p>P1 Mo</p> <p>75-76 <input type="checkbox"/> 77-78 <input type="checkbox"/></p> <p>P2 Mo</p> <p>15-16 <input type="checkbox"/> 17-18 <input type="checkbox"/></p> <p>P3 Mo</p> <p>23-24 <input type="checkbox"/> 25-26 <input type="checkbox"/></p>	<p>Card 22</p> <p>11-26</p> <p>61-78</p>
<p><u>Psychotherapy/Counseling</u></p> <p>172) Would patient need psychotherapy/counseling during the 6 months following discharge?</p> <p>173) How much time would this activity take on each occasion?</p> <p>174) How many times per month would psychotherapy/counseling be needed?</p> <p>175) Which provider(s) would you recommend to provide the service? How many times per month per provider? (Include patient and/or family teaching, if appropriate)</p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>27-29 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>33-34 <input type="checkbox"/></p> <p>P1 Mo</p> <p>37-38 <input type="checkbox"/> 39-40 <input type="checkbox"/></p> <p>P2 Mo</p> <p>45-46 <input type="checkbox"/> 47-48 <input type="checkbox"/></p> <p>P3 Mo</p> <p>53-54 <input type="checkbox"/> 55-56 <input type="checkbox"/></p>	<p>circle one</p> <p>YES NO</p> <p>Hrs. Mins.</p> <p>30-32 <input type="checkbox"/> <input type="checkbox"/></p> <p>Mo</p> <p>35-36 <input type="checkbox"/></p> <p>P1 Mo</p> <p>41-42 <input type="checkbox"/> 43-44 <input type="checkbox"/></p> <p>P2 Mo</p> <p>49-50 <input type="checkbox"/> 51-52 <input type="checkbox"/></p> <p>P3 Mo</p> <p>57-58 <input type="checkbox"/> 59-60 <input type="checkbox"/></p>	<p>25-60</p>

PRESCRIBER'S INITIALS _____ CODE PATIENT'S CODE Page 16

OTHER PROFESSIONAL SERVICES CONT'D

Lab Work

176) Would patient need lab. services during the 6 months following discharge?

MONTHS 1-6
circle one

YES NO

177) Which lab. test and how many times would you order them during this 6 month period?

LAB TEST

#TIMES/6 MONTHS

_____	61-62	<input type="checkbox"/>	<input type="checkbox"/>
_____	63-64	<input type="checkbox"/>	<input type="checkbox"/>
_____	65-66	<input type="checkbox"/>	<input type="checkbox"/>
_____	67-68	<input type="checkbox"/>	<input type="checkbox"/>
_____	69-70	<input type="checkbox"/>	<input type="checkbox"/>
_____	71-72	<input type="checkbox"/>	<input type="checkbox"/>
_____	73-74	<input type="checkbox"/>	<input type="checkbox"/>
_____	75-76	<input type="checkbox"/>	<input type="checkbox"/>
_____	77-78	<input type="checkbox"/>	<input type="checkbox"/>
_____	79-80	<input type="checkbox"/>	<input type="checkbox"/>
_____	11-12	<input type="checkbox"/>	<input type="checkbox"/>
_____	13-14	<input type="checkbox"/>	<input type="checkbox"/>

For
Keypunch
Only

Card 22
cont'd

61-80

Card 23

11-14

(columns
15-30
reserved)

Prescriber's Initials _____ Code: Patient's Code Page 17

a) GOALS FOR HOME CARE

For this patient, first rank the following goals for home care, together with any other you may have. Then estimate the percentage of home care effort which you believe should be devoted to each goal over the 6 months following discharge.

RANK (1-4)	THERAPEUTIC GOALS	% HOME CARE EFFORT DEVOTED TO GOAL	COMMENTS
	Rehabilitation		
	Stabilize and Maintain		
	Dignified Terminal Care		
	Other Specify:		

b) LIFE EXPECTANCY

1. If this patient were discharged home and received the package of services you prescribed, delivered with average quality and effectiveness, how long would you expect this patient to live?

_____ years, months

2. If this patient were discharged to the appropriate long term care facility and received care of average quality and effectiveness, how long would you expect this patient to live?

_____ years, months

c) DISCHARGE OPTIONS

From the list of discharge sites below, select and rank in order of appropriateness the three most suitable sites of discharge for this patient, for the two successive 3-month periods following discharge. (1=best, 2=2nd best, 3=3rd best) The most appropriate site is that which you believe to be in the patient's overall best interest. (Care at home would include the services you have already prescribed.) Definitions of the other discharge sites listed are found on page 8 of the Care Plan Instructions.

<u>Discharge Options</u>	<u>Months 1-2-3</u> (Rank 1-9)	<u>Months 4-5-6</u> (Rank 1-9)
Own Home	_____	_____
Sheltered, Congregate or } Communal Housing	_____	_____
Rest Home (Level IV)	_____	_____
Intermediate Care Facility (Level III)	_____	_____
Skilled Nursing Facility (Level II)	_____	_____
Skilled Nursing Facility (Level I)	_____	_____
Chronic Disease Hospital	_____	_____
Rehab. Hospital	_____	_____
Acute Hospital	_____	_____

Prescriber's Initials _____ Code Patient's Code Page 18

- d) 1. Check which of the five variables in the PACE form listed below significantly influenced your selection of home care services for this patient.
2. Think of the three most important of these factors.
3. Rank these three in order of importance. i.e. 1=most, 3=least of the three.

Check	Variables in PACE	Rank (1-3)
	Medical Diagnoses & Treatments	
	Functional Status	
	Instrumental Activities of Daily Living	
	Relative/Neighbor/Friend Availability/Support	
	Special Personality/Family or Cultural Characteristics	

e) What extra information would you have liked to have seen in the PACE form?

f) (FOR CONSULTANTS VISITING WITH PATIENT ONLY)

1. Did you observe anything about this patient which differed from the information in the PACE form?

Circle one

YES NO

If yes, please describe:

2. Did you make any observations important to the home care plan that were omitted from the PACE form?

Circle one

YES NO

If yes, please describe:

PLEASE BE CERTAIN THE COLORED COVER SHEET IS ATTACHED TO THE FRONT OF THIS CARE PLAN WHEN COMPLETED!

APPENDIX B

Levinson Policy Institute
Brandeis University

IAS
5/10/77
FINAL

COVER SHEET FOR PAGE FORM

PATIENT'S NAME _____ FACILITY _____

PATIENT'S CODE FLOOR/ROOM # _____

PERSON COMPLETING FORM: _____

PRINCIPAL CAREGIVER (Record here answer to Q5, P15 of PAGE Form)	Phone #
_____	_____
ALTERNATIVE CAREGIVER (1) _____	_____
ALTERNATIVE CAREGIVER (2) _____	_____

GENERAL INSTRUCTIONS

1. Unless otherwise specified, all data should be obtained from the most reliable source, i.e. patient's chart, physician, nurse, or other hospital employee. In Section N, pre-hospital psychosocial information should be sought from the Principal or Alternative Caregiver.
2. Please print or write very clearly with a black or dark blue ball point pen.

Levinson Policy Institute
Brandeis University

PACE SCREENING FORM

IAS 8/29/77
FINAL

PATIENT'S CODE

FACILITY _____

- * ANSWERS TO THE FOLLOWING QUESTIONS WILL DETERMINE IF THIS PATIENT WILL BE A FULL OR LIMITED PARTICIPANT IN THIS STUDY, OR WILL BE SCREENED OUT.
- * Full participation requires that Q1, 2A, 3, 4A, and 5A be answered YES.
- * Patients not meeting all criteria for full participation may be considered for limited participation.
- * Limited participation requires an answer of YES to: Q1, 2A or 2B, 4A or 4B, and 5B. Q3 may be answered YES or NO.
- * Patients not meeting all criteria for full or limited participation must be screened out of the study.
- * CIRCLE ONE: FULL PARTICIPANT LIMITED PARTICIPANT SCREENED OUT

- | | |
|---|----------------|
| | Circle One |
| 1. Is it anticipated that this patient will be discharged to a Long Term Care Facility for 2 months or more? (In the case of terminal patients, circle YES regardless of anticipated length of stay.) | 1 YES NO |
| 2.A. PHYSICIAN: In your opinion, would it be medically safe for this patient to be a full participant in the study? | 2A YES NO |
| B. IF NO, do you agree to this patient's inclusion in the study as a limited participant? | 2B YES NO |
| 2.A. or B. . Physician signature _____ | |
| 3. DISCHARGE PLANNER: Would patient be able to understand the nature of the study and respond to questions? | 3 YES NO |
| 4.A. DISCHARGE PLANNER: Could patient cope with the emotional stress of thinking about home care well enough to be a full participant? | 4A YES NO |
| B. IF NO, could patient be included as a limited participant? | 4B YES NO |
| 5.A. FOR FULL PARTICIPANTS: Has the patient signed the consent form? | 5A YES NO |
| B. FOR LIMITED PARTICIPANTS ONLY: Has the patient's legally authorized representative signed the consent form? | 5B YES NO |

<p>6. <u>SUMMARY OF PACE COMPLETION</u></p> <p><u>COMPLETE</u></p> <p style="text-align: center;">Is patient available for consultant visits?</p> <p>If NO: Check reason: 1) Patient discharged <input type="checkbox"/></p> <p style="padding-left: 100px;">2) Patient unable to continue <input type="checkbox"/></p> <p><u>INCOMPLETE</u></p> <p>If incomplete, check reason below:</p> <p style="padding-left: 20px;">Patient refused to continue interview <input type="checkbox"/></p> <p style="padding-left: 20px;">Patient unable to understand <input type="checkbox"/></p> <p style="padding-left: 20px;">Patient unable to cope emotionally <input type="checkbox"/></p> <p style="padding-left: 20px;">Patient's condition deteriorated <input type="checkbox"/></p> <p style="padding-left: 20px;">Patient died before PACE completed <input type="checkbox"/></p> <p style="padding-left: 20px;">Patient discharged <input type="checkbox"/></p> <p style="padding-left: 20px;">Other (specify) _____ <input type="checkbox"/></p>	<p style="text-align: right;">COMPLETED BY _____</p> <p style="text-align: right;">Date of Completion <input type="text"/></p> <p style="text-align: right;">Circle YES NO</p>
--	---

PACE Screening Form

-2-

Patient's Code

A. Date of Admission _____ B. Surg. Procedures this hospitalization:

Reason(s) for current hosp. admission: _____

C. Diagnosis(es) (List in approximate order of importance)

Approximate Date of Onset

D. Disabling Conditions*

Approximate Date of Onset

E. (1) SUMMARY OF ALL KNOWN HOSP. ADMISSIONS & DISCHARGES IN PAST 12 MONTHS
(List most recent 6 only)

	<u>Date of Admission</u>	<u>Hospital</u>	<u>Length of Stay</u>	<u>Reason for Admission</u>	<u>Place of Discharge</u>
a)					
b)					
c)					
d)					
e)					
f)					

*Medical, functional, intellectual, or emotional conditions affecting the patient's ability to perform customary self-care, mobility, and household tasks.

PACE Screening Form

-3-

Patient's Code

E. (2) SUMMARY OF KNOWN LONG TERM CARE FACILITIES

(Admissions and discharges in last 2 years)

(Refer to Q H(1) below, for types of long term care facilities)

Date of Admission	Length of Stay	Type of Facility	Reason for Adm.	Place of Discharge

F. SOCIO.-DEMOGRAPHIC (Check appropriate boxes)

Birth Date: Mo. Da. Yr.

Birth Place: specify state or country

USA _____

Other _____

Sex: Male

Height _____

City or Town of Residence Prior to Hospitalization: _____

Female

Weight _____

Race:

- Caucasian American Indian
- Negro Oriental
- Other _____

Ethnic Origin:

- Irish Jewish
- Italian Spanish
- Anglo-Saxon Black American
- Other _____

Religious Preference: None

- Catholic Protestant
- Jewish
- Other: _____

Languages usually spoken:

- English
- Other: _____

Marital Status:

- Single Divorced
- Married Separated
- Widowed

Duration of Status _____ years

Education:

Years of schooling completed: _____ years

Car in Household: YES NO

Usual Living Arrangements:

- Single family home Elderly housing Rented room(s) in pvt. home
- 2-3 family home Other apartment Rooming house
- Other: _____ Own Rent

Person(s) With Whom Patient Resides:

- Alone With spouse
- With others: Specify relationship _____

Usual Occupation: Specify

- Housewife/househusband

Employment Status:

- Currently employed Not in Labor Market
- Currently unemployed Retired
- Never employed

PACE Screening Form

-4-

Patient's Code

G. ANTICIPATED DATE OF DISCHARGE
(Barring placement difficulties) Mo Da Yr

H. (1) ANTICIPATED SITE OF DISCHARGE

- | | |
|---|--|
| <input type="checkbox"/> Rehab. Hospital | <input type="checkbox"/> Level 2 SNF |
| <input type="checkbox"/> Chronic Disease Hospital | <input type="checkbox"/> Level 3 ICF |
| <input type="checkbox"/> Level 1 SNF | <input type="checkbox"/> Level 4 Best Home |

(2) How long is patient expected to remain at site of discharge?
_____ years _____ months

Check box if indefinite placement

(3) If less than 6 months, what is next expected place of residence?

INSTRUCTIONS FOR HOSPITAL COORDINATOR

1. When PACE screening form is completed, if patient is not participating in the study, detach cover sheet and forward screening form to Levinson Policy Institute.
2. If patient is participating in the study, staple cover sheet and PACE screening form to PACE form. PACE form is now ready for completion by Discharge Planner.

I. FUNCTIONING STATUS

Ask the patient the following questions about his/her PRE-HOSPITAL FUNCTIONAL PERFORMANCE. The patient may volunteer all necessary information as to how they accomplished a functional activity eliminating the need for some or all further questions in that category.

Social Worker/Discharge Planner should use her/his best judgement to check appropriate category or categories and supply needed information under ANTICIPATED CAPACITY ON DISCHARGE for each functional status.

CODES: DK = Doesn't know
NA = Not asked

Introduction: "I would like to ask you how you did certain activities of daily living before you came to the hospital. Let's start with walking . . ."

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
1. <u>WALKING</u> (Indicate to patient a distance of @50 yds. i.e., "down the hall, to the desk and back" "BEFORE YOU CAME TO THE HOSPITAL . . . a. "Were you able to walk 50 yards without help of any kind...such as another person or a cane or brace?" (walks without help)		
b. "Did you use equipment but no other person to help you walk?" (uses equipment, no human help)		
c. "Did another person help you?" (human help only)		
d. "How many persons were needed at one time to help you?" (number of persons helping)		
e. "Did you use both equipment and another person's help?" (human help and equipment)		
f. "Were you unable to walk at all?" (unable to walk)		
g. "What kind of special equipment did you use?" (e.g. prosthesis, crutches, special shoes) (name of equipment)		

Patient's Code

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
2. <u>STAIRCLIMBING</u> "BEFORE YOU CAME TO THE HOSPITAL..."		
a. "Were you able to climb stairs without help of any kind?" (climbs stairs without help)		
b. "Did you use equipment but no other person to help you climb stairs?" (uses equipment, no human help)		
c. "Did another person help you?" (human help only)		
d. "How many persons were needed at one time to help you?" (number of persons helping)		
e. "Did you use both equipment and another person's help?" (human help and equipment)		
f. "Were you unable to climb stairs at all?" (unable to climb stairs)		
g. "What kind of special equipment did you use?" (railing, grab bars) (name equipment)		
3. <u>WHEELING</u> (DOES NOT APPLY IF PATIENT CAN WALK) "BEFORE YOU CAME TO THE HOSPITAL..."		
a. "Were you able to use a wheelchair without help of any kind?" (such as a power source) (wheels without help)		
b. "Did you use an electric wheelchair without help from another person?" (uses adaptive device, no human help)		
c. "Did you use a non-electric wheelchair without help from another person?" (human help only)		
d. "Were you wheeled by another person?" (is wheeled)		
e. "How many persons were needed at one time to help you?" (number of persons helping)		
f. "Were you unable to use a wheelchair because you were confined to your bed or chair?" (is not wheeled, bedfast, chairfast)		
g. "What kind of special equipment did you use?" (regular, electric wheelchair) (name of equipment)		

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
<p>4. <u>TRANSFERRING TO CHAIR AND BED</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to transfer from your bed to a chair (or wheelchair, if applicable) and from one chair to another without help of any kind?" (transfers without help)</p> <p>b. "Did you use equipment but no other person to help you transfer?" (uses equipment, no human help)</p> <p>c. "Did another person help you?" (human help only)</p> <p>d. "Were you transferred by another person?" (is transferred)</p> <p>e. "How many persons were needed at one time to help or transfer you?" (number of persons helping)</p> <p>f. "Were you unable to transfer at all?" (is not transferred, bedfast)</p> <p>g. "What kind of special equipment did you use?" (sliding board, lift) (name of equipment)</p>		
<p>5. <u>TRANSFERRING TO TUB OR SHOWER</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to get in and out of a bathtub or shower stall without help of any kind?" (transfers without help)</p> <p>b. "Did you use equipment but no other person to help you transfer?" (uses equipment, no human help)</p> <p>c. "Did another person help you?" (human help only)</p> <p>d. "Were you transferred by another person?" (is transferred)</p> <p>e. "How many persons were needed at one time to help or transfer you?" (number of persons helping)</p> <p>f. "Were you unable to get in and out of a tub or shower at all?" (is not transferred, bedfast)</p> <p>g. "What kind of special equipment did you use?" (name of equipment)</p>		

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
<p>6. <u>BATHING</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to prepare your bath or sponge bath, then wash and dry yourself without help of any kind?" (does not mean transfer) (bathes without help)</p> <p>b. "Did you use equipment but no other person to help you bathe?" (uses equipment, no human help)</p> <p>c. "Did another person help you?" (human help only)</p> <p>d. "Did you use both equipment and another person's help?" (human help and equipment)</p> <p>e. "Were you bathed by another person?" (is bathed)</p> <p>f. "How many persons were needed at one time to help or to bathe you?" (number of persons helping)</p> <p>g. "What kind of special equipment did you use?" (name of equipment)</p>		
<p>7. <u>TOILET</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to get on and off the toilet, clean yourself, and adjust your clothing without help of any kind?" (uses toilet without help)</p> <p>b. "Did you use equipment but no other person to help?" (uses equipment, no human help)</p> <p>c. "Did another person help you?" (human help only)</p> <p>d. "How many persons were needed at one time to help?" (number of persons helping)</p> <p>e. "Did you use both equipment and another person's help?" (human help and equipment)</p> <p>f. "Were you unable to use the toilet at all?" (unable to use toilet)</p> <p>g. "What kind of special equipment did you use?" (grab bar, special seat) (name of equipment)</p>		

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
<p>8. <u>BLADDER FUNCTION</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p>		
<p>a. "With respect to bladder control, did you have complete control without any accidents?" (continent)</p>		
<p>b. "Did you have occasional accidents, less than once a week?" (incontinent, less than once a week)</p>		
<p>c. "Did you have accidents once a week or more, but just at night?" (incontinent once a week or more, night only)</p>		
<p>d. "Did you have accidents once a week or more, day and night?" (incontinent, once a week or more, day and night)</p>		
<p>e. (1) "Did you have an indwelling catheter, ostomy, or other diversion?" If yes, ask name of device and go on to e. (2). (2) "Did you care for your device yourself?" If no, ask e. (3). (3) "Did you need help in caring for your device?"</p>		
<p>9. <u>BOWEL FUNCTION</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p>		
<p>a. "With respect to bowel control, did you have complete control without any accidents?" (continent)</p>		
<p>b. "Did you have occasional accidents, less than once a week?" (incontinent, less than once a week)</p>		
<p>c. "Did you have any accidents once a week or more?" (incontinent, once a week or more)</p>		
<p>d. (1) "Did you have an ostomy or other diversion?" (If yes, ask name of device and ask d. (2). (2) "Did you care for your ostomy yourself?" (If no, ask d. (3). (3) "Did you need help in caring for your ostomy?"</p>		

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
<p>10. <u>DRESSING</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to dress yourself without help of any kind?" (This includes gathering and arranging your clothing) (dresses without help)</p> <p>b. "Did you use equipment but no other person to help you dress?" (uses equipment, no human help)</p> <p>c. "Did another person help you?" (human help only)</p> <p>d. "Were you dressed by another person?" (is dressed)</p> <p>e. "How many persons were needed at one time to help or to dress you?" (number of persons helping)</p> <p>f. "Were you unable to get dressed?" (is not dressed)</p> <p>g. "What kind of special equipment did you use?" (zipper chain) (name of equipment)</p>		
<p>11. <u>GROOMING</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p> <p>a. "Were you able to clean your teeth or dentures and do daily grooming such as shaving, (applying makeup) and combing your hair without help of any kind?" (grooms without help)</p> <p>b. "Did you use equipment but no other person to help you?" (uses equipment, no human help)</p> <p>c. "Did another person help you, but no equipment?" (human help only)</p> <p>d. "Did you use equipment and another person's help?" (human help and equipment)</p> <p>e. "Were you groomed by another person?" (is groomed)</p> <p>f. "What kind of special equipment did you use?" (name of equipment)</p>		

Patient's code

FUNCTION	PRE-HOSPITAL PERFORMANCE	ANTICIPATED CAPACITY ON DISCHARGE
<p>12. <u>EATING/FEEDING</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p>		
<p>a. "Were you able to eat and drink without help of any kind?" (eat from a dish, tray or table with or without prior preparation such as meat being cut, bread buttered) (feeds self without help)</p>		
<p>b. "Did you use equipment but no other person to help?" (uses equipment, no human help)</p>		
<p>c. "Did another person help you?" (human help only)</p>		
<p>d. "Did you use equipment and another person's help?" (human help and equipment)</p>		
<p>e. "Were you fed by another person?" (If yes, ask: "Were you spoon fed, tube fed, or fed parenterally?")</p>		
<p>(1) (is spoon fed)</p>		
<p>(2) (is tube fed)</p>		
<p>(3) (fed parenterally)</p>		
<p>f. "What kind of special equipment did you use?" (spork, rocking knife) (name of equipment)</p>		
<p>13. <u>MOBILITY LEVEL</u> "BEFORE YOU CAME TO THE HOSPITAL..."</p>		
<p>a. "Were you able to go outside without help of any kind?" (goes outside without help)</p>		
<p>b. "Did you use equipment but no other person to help you go outside?" (uses equipment, no human help)</p>		
<p>c. "Did another person help you go outside?" (human help only)</p>		
<p>d. "Were you unable to go outside but able to go out of your own room?" (confined to home)</p>		
<p>e. "How many persons were needed at one time to help you leave your room?" (number of persons helping)</p>		
<p>f. "Were you confined to your own room?" (confined to room)</p>		
<p>g. "What kind of special equipment did you use?" (wheelchair, walker, crutches, cane) (name of equipment)</p>		

J. INSTRUMENTAL ACTIVITIES OF DAILY LIVING PRIOR TO HOSPITALIZATION

Introduction: Now I'd like to ask you how you did certain household activities before you came to the hospital.

(Check appropriate box and indicate who provided help, if applicable.)

	<u>Check Category</u>	<u>Helper's Relation to Patient</u>
<u>BEFORE YOU CAME TO THE HOSPITAL did you go</u>		
<u>shopping for groceries and clothes. . .</u>		
(1) Without help (taking care of all shopping needs yourself)	<input type="checkbox"/>	
(2) Could you have done the shopping though someone did it for you?	<input type="checkbox"/>	_____
(3) With some help (need someone to go with you to help on all shopping trips) Who helped you?	<input type="checkbox"/>	_____
(4) Or were you completely unable to do any shopping? Who did it?	<input type="checkbox"/>	_____
. . . . <u>did you do your housework. . .</u>		
(1) Without help (can clean floors, windows, refrigerator, etc.)	<input type="checkbox"/>	
(2) Could you have done it though someone did it for you?	<input type="checkbox"/>	_____
(3) With some help (can do light housework, but need help with heavy work) Who helped you?	<input type="checkbox"/>	_____
(4) Or were you completely unable to do any housework? Who did it?	<input type="checkbox"/>	_____
. . . . <u>did you prepare your own meals. . .</u>		
(1) Without help (plan and cook full meals yourself)	<input type="checkbox"/>	
(2) Could you have done it though someone did it for you?	<input type="checkbox"/>	_____
(3) With some help (can prepare some things but unable to cook full meals yourself) Who helped you?	<input type="checkbox"/>	_____
(4) Or were you completely unable to prepare your own meals? Who did it?	<input type="checkbox"/>	_____
. . . . <u>did you do your laundry. . .</u>		
(1) Without help (take care of all laundry yourself)	<input type="checkbox"/>	
(2) Could you have done it though someone did it for you?	<input type="checkbox"/>	_____
(3) With some help (can do small items only) Who helped you?	<input type="checkbox"/>	_____
(4) Or were you completely unable to do your own laundry? Who did it?	<input type="checkbox"/>	_____

Patient's Code

BEFORE YOU CAME TO THE HOSPITAL did you take your medicine on your own. . .

- (1) Without help (in the right doses at the right time)
- (2) Could you have done it though someone did it for you?
- (3) With some help (able to take medicine if someone prepares it for you and/or reminds you to take it)
- (4) Or was someone needed to administer as couldn't/wouldn't take without help? Who administered your medicine?

. . . . did you use public transportation or drive your own car to get to places further than walking distance. . .

- (1) Without help (can travel alone on buses, taxis, or drive own car)
- (2) Could you have done it though someone did it for you?
- (3) With some help (need someone to help you or go with you when traveling) Who helped you?
- (4) Unable to travel unless emergency arrangements were made for specialized vehicle like ambulance.

. . . . did you handle your own money. . .

- (1) Without help (write checks, pay bills, etc.)
- (2) Could you have done it though someone did it for you?
- (3) With some help (day to day, but needs help in budgeting, etc.)
- (4) Did someone else do this for you?

DO YOU HAVE A TELEPHONE AT HOME?

Yes

No

. . . . did you use the telephone. . .

- (1) Without help
- (2) Could you have done it though someone did it for you?
- (3) With some help (can answer phone or dial operator in an emergency, but need a special phone or help in getting the number or dialing). Who helped you?
- (4) Did someone else do this for you?

K. ARCHITECTURAL BARRIERS IN PATIENT'S HOME

(Ask Patient)

- 1. Do you have to climb stairs to get into your home? Yes No
- 2. Do you have to climb stairs inside your home, to get to your room or the bathroom? Yes No
- 3. Is there anything else about your home that would make it difficult for you to get around and do the things you did before? (list) Yes No

- 4. (DISCHARGE PLANNER:) List needed architectural modifications or mechanical devices, e.g. ramp, inclinator.

L. PATIENT'S HOUSEHOLD COMPOSITION PRIOR TO HOSPITALIZATION

(List all members of household and be as specific as possible as to when they are at home)

(1) "Who were you living with just before coming to the hospital?"

(2) "When were they usually at home?"

	<u>Relationship to Patient</u>	<u>When at Home</u>			
		<u>Weekday</u>		<u>Weekend</u>	
		<u>Day</u>	<u>Night</u>	<u>Day</u>	<u>Night</u>
0.	Lived Alone				
1.	_____				
2.	_____				
3.	_____				
4.	_____				
5.	_____				
6.	_____				

-15-

Patient's Code

(3) "Did relatives & friends visit you at home?"

(4) "How frequently did they visit?"

Visiting Family/Neighbors

Frequency of Visits Prior to Hosp.

(5) "Is there one person you feel particularly close to and who you rely on most for help?"

(Record name on PACE cover sheet)

Relationship to Patient

(6) "Where does this person live?"
(Check appropriate box)

same house/apartment

elsewhere in same bldg.

within 10 minutes
(walk or drive)

elsewhere

(7) "Does (name person) visit you regularly in the hospital?" Yes No

(8) "We'd like to ask (name person) a few questions as part of the study. If he/she is not available, is there someone else who visits you here we could talk with?"

(Record name on PACE cover sheet)

Relationship to Patient

(9) "Is there anyone else?"

Relationship to Patient

(Record name of PACE cover sheet)

M. INFORMAL SUPPORT NETWORK (Assessment by DISCHARGE PLANNER based on knowledge of patient and family network)

(1) Is the network of family and friends able to provide the help needed at discharge?

All help Some help No help Family unsure

(2) Is the network of family and friends willing to provide the help needed at discharge?

All help Some help No help Family unsure

(3) Would the family be willing to maintain the patient at home if supportive outside services were provided?

Yes No

N. PSYCHOSOCIAL

Ask principal caregiver for evaluation of patient's pre-hospital behavior. Seek this information by phone if unable to obtain in person. Discharge planner should indicate current evaluation. If there is no principal caregiver, ask questions of patient.

1. RECENT DEATH OF FAMILY MEMBER OR CLOSE FRIEND Yes No

IF YES, RELATIONSHIP TO PATIENT _____

2. ORIENTATION: Time, Place, and Person - Check one item

- Oriented
- Disoriented partially
- Disoriented intermittently

3. FOLLOWS INSTRUCTIONS - Check one item

- Follows complex instructions
- Follows simple instructions

4. BEHAVIOR - Check each item

	<u>Pre-Hospital</u>			<u>Current</u>		
	Never	Sometimes	Freq.	Never	Sometimes	Freq.
Talks with others						
Visits with others						
Helps others						
Helps self						
Smiles, laughs						
Apprehensive, Fearful Anxious						
Lethargic						
Withdrawn						
Cries						
Irritable						
Demanding, Angry, Agitated, Hostile						
Restless						
Wandering						
Hallucinates						
Disruptive, Noisy						
Abusive to self						
Abusive to others, assaultive, combative						
Other : specify						

O. IMPAIRMENT ITEMS

-17-

Patient's Code

<u>Date</u>	<u>AMPUTATIONS</u> <u>Extremity Amputated</u>	<u>Prosthesis (if any)</u>

PARALYSES/PARESIS
Type

Date of Onset

Location (if applicable)

SENSORY IMPAIRMENTS AND COMPENSATION (CURRENT)

<u>Sense</u>	<u>No Impairment</u>	<u>Impairment</u>	<u>Complete Loss</u>	<u>Type of Impairment &/or Comp.</u>
<u>Sight</u>				
<u>Hearing</u>				
<u>Speech</u>				
<u>Touch</u>				

DENTITION

	<u>No Teeth Missing</u>	<u>3 Pairs Opposing Teeth</u>	<u><3 Pairs Opposing Teeth</u>	<u>All Teeth Missing</u>
<u>Natural Teeth</u>				

Compensation:

- DENTURES Don't fit
 Needs, but lacks
 Doesn't use
- PARTIAL Upper Lower
 FULL Upper Lower

P. ACTIVE MOTION OF LIMBS (CURRENT)

Criteria for Evaluation

- Good (3)** - All muscle groups of the limb complete full range of motion of the joints against moderate or greater resistance. No limitation due to contracture pain, spasticity, diminished sensibility, etc.
- Fair (2)** - All muscle groups of the limb complete available range of motion against gravity. Any limitation due to contracture, pain, spasticity, etc., still permits ordinary use of the limb.
- Poor (1)** - Some active motion in the limb or it is used as a helper, includes amputation with functional prosthesis.
- Null (0)** - No motion and/or usefulness, includes amputation without functional prosthesis.

(Circle appropriate numbers according to above criteria.)

<u>LIMBS</u>	<u>Good</u>	<u>Fair</u>	<u>Poor</u>	<u>Null</u>
R Upper	3	2	1	0
L Upper	3	2	1	0
R Lower	3	2	1	0
L Lower	3	2	1	0

-20- Patient's Code

5. SPECIAL PROCEDURES IN HOSPITAL

(Describe treatments currently being administered and check if they are likely to be continued at discharge)

Current Procedure	Treatment	Provider's Title	Check If Likely to Continue After Discharge
1. Bowel &/or Bladder Training			
2. Decubitus(i) (Site)(s)			
3. Wound Care (Site)			
4. Eye Care			
5. Irrigation - Bladder	Type & Frequency:		
6. Ostomy Care			
7. Suctioning	Location, Frequency:		
8. Inhalation IPPB			
9. Oxygen RX. Route: _____			
10. Turning	Schedule:		

-21- Patient's Code

Current Procedure	Treatment	Provider's Title	Check If Likely to Continue After Discharge
11. Teaching: Foot care _____ Ostomy care _____ Medications _____ Diet _____ Gait Training _____ Prosthetic Training _____ Other _____	Check Instruction Started or Planned:		
12. Range of Motion Exercises	Sites, Types, & Frequency:		
13. Nutrition -Diet	Specify:		
-Food &/or Fluid Supplements	Specify Type & Schedule:		
-Food &/or Fluid Restrictions	Specify Type & Schedule:		
14. Monitoring - (e.g. Vital signs Neurological signs	Specify:		
15. Other	Specify		

-22- Patient's Code _____

T. SPECIAL PERSONALITY, FAMILY OR CULTURAL CHARACTERISTICS INFLUENCING
PATIENT'S NEEDS (Observations of Discharge Planner)

NOTE TO HOSPITAL COORDINATOR: Complete Item 6, Summary of PACE completion,
on screening form.

APPENDIX C

DESCRIPTION OF PATIENT CHARACTERISTICS

In chapters VII and VIII were reported the results of several sets of regression analyses. The same sixteen independent variables were used in each regression. They were selected, it is felt, on reasonable grounds: based on theory and selected early analyses of variance, they were expected to be associated with the costs and hours of home care prescribed by professionals, and with the extent of agreement about costs and hours. Now follows an explanation of how these variables were defined and coded, along with an indication of why it was thought reasonable to include them.

1. Age. Calculated from PACE screening form, page 2. Greater age was, other things equal, expected to be associated with need for more help. This variable is not categorized; it is continuous in units of years.

2. Resides with. Calculated from PACE, page 14. The more people the patient resided with, the greater was expected to be need for home care (because presence of others in household would enable disabled patients to live at home longer than had they been alone), and the greater the proportion of total hours prescribed for unpaid providers. This variable is not categorized; it is continuous in number of persons.

3. Marital status. Given on PACE screening form, page 3. This variable correlated badly with the number of persons residing with the patients ($R = .045$). Categorized as 0 = not married (single, widowed, or divorced) and 1 = married.

4. Anticipated discharge site. Given on PACE screening form, page 4. This is informed opinion of patient's discharge planner. It was expected that patients being discharged to "higher" levels of institutional care would require more home care. Categorized as 1 = rehabilitation hospital or chronic disease hospital; 2 = Medicare SNF (Massachusetts level I); 3 = Medicaid SNF (II); 4 = Medicaid SNF (III). An inverse relation thus would be expected to obtain between, for example, anticipated discharge site and cost of institutional care or cost of home care--because "higher" levels of anticipated sites of discharge were assigned lower interval codes.

5. Indefinite placement. Given on PACE screening form, page 4. This also is informed opinion of actual discharge planner. Patients expected to be placed indefinitely were expected to require more hours of care per week, because they were more disabled. Coded as 0 = no; 1 = yes.

6. Number of medical diagnoses. Calculated from page 2 of PACE screening form. Although little data linking specific diagnoses with more or less costly long-term care have been reported, it was thought that patients with more identified diagnoses might be thought to require more care. This variable is not categorized; it is continuous in number of diagnoses.

7. Number of disabling conditions. Calculated from page 2 of PACE screening form. Expected to be a subset of variable no. 6, in that some medical diagnoses might not be functionally disabling.

Continuous in number of conditions.

8. Number of known hospital discharges (in past year). Calculated from page 2 of PACE screening form. Thought to be a good predictor of medical instability. Continuous in number of discharges.

9. Number of long-term care facility discharges (in past two years). Calculated from page 3 of PACE screening form. As no. 8. Continuous in number of discharges.

10. Number of current medications (in hospital). Calculated from PACE, p. 19. As no. 8. Continuous in number of medications.

11. Percent of nursing services used. Calculated from pages 20-21 of PACE. As no 8. Continuous in number used divided by $N = 15 \times 100$.

12. Psychosocial percent positive. Calculated from PACE, page 16. Better psychosocial status thought to be associated with need for less care, particularly for continuous supervision. Continuous in items 1-5 (sometimes or frequently) + items 6-17 (never) divided by $N = 17 \times 100$.

13. Anticipated Barthel (ADL). Calculated from pages 5-11 of PACE. Thought that higher functional ability would be associated with reduced home care needs. Calculated in accordance with Granger's modifications of the original Barthel index. (These modifications are found at conclusion of this Appendix.)

14. Barthel change. Calculated from pages 5-11 of PACE, scored as Granger suggests. As no. 8, Barthel change was thought to be associated with medical instability. Calculated by subtracting pre-hospital Barthel from anticipated Barthel. Thus, the greater the value of this

variable, the greater the decline in Barthel score.

15. Pre-hospital independence in instrumental activities of daily living (IADL). Calculated from pages 12-13 of PACE form. Independence thought to indicate less need for home care, particularly household help. Continuous in percent positive; total of scores 1 or 2 divided by $N = 8$.

16. Maintain at home. Recorded on page 15 of PACE. Assessment by patient's discharge planner of whether the patient's informal support network would be willing to maintain the patient at home if supportive outside formal services were provided. Categorized as 0 = no; 1 = yes.

Frequency distributions, means medians, and standard deviations for these and other patient characteristics now follow.

FREQUENCY DISTRIBUTIONS

VAR(1)	MONTH OF BIRTH	N=	\$0	MEAN=	7.160	MEDIAN=	6.800	SD=	3.304		
VALUE	1.000	2.000	3.000	4.000	5.000	6.000	7.000	8.000	9.000		
FREQUENCY	3	2	5	4	3	4	5	3	1		
PERCENTAGE	6.00%	4.00%	10.00%	8.00%	6.00%	8.00%	10.00%	6.00%	2.00%		
CUMULATIVE	6.00%	10.00%	20.00%	28.00%	34.00%	42.00%	52.00%	58.00%	60.00%		
VALUE	10.000	11.000	12.000								
FREQUENCY	10	7	3								
PERCENTAGE	20.00%	14.00%	6.00%								
CUMULATIVE	80.00%	94.00%	100.00%								

VAR(2)	YEAR OF BIRTH	N=	\$0	MEAN=	53.060	MEDIAN=	64.500	SD=	42.246		
VALUE	0.000	1.000	3.000	4.000	5.000	6.000	7.000	8.000	9.000		
FREQUENCY	2	2	2	2	3	1	1	2	2		
PERCENTAGE	4.00%	4.00%	4.00%	4.00%	6.00%	2.00%	2.00%	4.00%	4.00%		
CUMULATIVE	4.00%	8.00%	12.00%	16.00%	22.00%	24.00%	26.00%	30.00%	34.00%		
VALUE	11.000	13.000	15.000	16.000	26.000	33.000	36.000	37.000	38.000		
FREQUENCY	1	1	1	2	1	1	2	1	1		
PERCENTAGE	2.00%	2.00%	2.00%	4.00%	2.00%	2.00%	4.00%	2.00%	2.00%		
CUMULATIVE	36.00%	38.00%	40.00%	44.00%	46.00%	48.00%	52.00%	54.00%	56.00%		
VALUE	89.000	90.000	91.000	92.000	93.000	94.000	95.000	97.000	98.000		
FREQUENCY	2	2	1	5	5	2	1	1	3		
PERCENTAGE	4.00%	4.00%	2.00%	10.00%	10.00%	4.00%	2.00%	2.00%	6.00%		
CUMULATIVE	60.00%	64.00%	66.00%	76.00%	86.00%	90.00%	92.00%	94.00%	100.00%		

VAR(3)	AGE	N=	\$0	MEAN=	77.920	MEDIAN=	79.500	SD=	9.393		
VALUE	51.000	61.000	63.000	64.000	65.000	68.000	69.000	70.000	71.000		
FREQUENCY	1	2	1	1	1	2	2	1	2		
PERCENTAGE	2.00%	4.00%	2.00%	2.00%	2.00%	4.00%	4.00%	2.00%	4.00%		
CUMULATIVE	2.00%	6.00%	8.00%	10.00%	12.00%	16.00%	20.00%	22.00%	26.00%		
VALUE	72.000	73.000	74.000	75.000	76.000	77.000	78.000	79.000	80.000		
FREQUENCY	2	3	1	1	1	2	1	1	2		
PERCENTAGE	4.00%	6.00%	2.00%	2.00%	2.00%	4.00%	2.00%	2.00%	4.00%		
CUMULATIVE	30.00%	36.00%	38.00%	40.00%	42.00%	46.00%	48.00%	50.00%	54.00%		
VALUE	82.000	83.000	84.000	85.000	86.000	87.000	88.000	90.000	95.000		
FREQUENCY	1	1	5	5	3	1	2	4	1		
PERCENTAGE	2.00%	2.00%	10.00%	10.00%	6.00%	2.00%	4.00%	8.00%	2.00%		
CUMULATIVE	56.00%	58.00%	68.00%	78.00%	84.00%	86.00%	90.00%	98.00%	100.00%		

FREQUENCY DISTRIBUTIONS

VAR(4)	RACE		N=	50	MEAN=	1.000	MEDIAN=	0.500	SD=	0.0
	CAUCASIAN									
	VALUE	1.000								
	FREQUENCY	50								
	PERCENTAGE	100.00%								
	CUMULATIVE	100.00%								
VAR(5)	SEX		N=	50	MEAN=	0.240	MEDIAN=	0.0	SD=	0.427
	FEMALE	MALE								
	VALUE	0.000	1.000							
	FREQUENCY	38	12							
	PERCENTAGE	76.00%	24.00%							
	CUMULATIVE	76.00%	100.00%							
VAR(6)	RESIDES WITH		N=	50	MEAN=	0.940	MEDIAN=	0.300	SD=	0.908
	VALUE	0.000	1.000	2.000	3.000	4.000				
	FREQUENCY	19	20	8	1	2				
	PERCENTAGE	38.00%	40.00%	16.00%	2.00%	4.00%				
	CUMULATIVE	38.00%	78.00%	94.00%	96.00%	100.00%				
VAR(7)	MARITAL STATUS		N=	50	MEAN=	3.700	MEDIAN=	4.167	SD=	1.540
	SINGLE	MARRIED	DIVORCED	WIDOWED						
	VALUE	1.000	2.000	4.000	5.000					
	FREQUENCY	3	16	1	30					
	PERCENTAGE	6.00%	32.00%	2.00%	60.00%					
	CUMULATIVE	6.00%	38.00%	40.00%	100.00%					
VAR(8)	ANTIC. DISCH. SITE		N=	50	MEAN=	3.040	MEDIAN=	3.429	SD=	0.946
	REHAB. HOSP	CHRON. DIS.	LEVEL 1 SNF	LEVEL 2 SHF	LEVEL 3 ICF					
	VALUE	1.000	2.000	3.000	4.000	5.000				
	FREQUENCY	1	3	12	21	13				
	PERCENTAGE	2.00%	6.00%	24.00%	42.00%	26.00%				
	CUMULATIVE	2.00%	8.00%	32.00%	74.00%	100.00%				

FREQUENCY DISTRIBUTIONS

VAR(9)	INDEFINITE PLACEMENT		N=	50	MEAN=	0.660	MEDIAN=	0.265	SD=	0.466
	NO	YES								
VALUE	0.000	1.000								
FREQUENCY	16	34								
PERCENTAGE	32.00%	68.00%								
CUMULATIVE	32.00%	100.00%								

VAR(10)	# OF DIAGNOSES		N=	50	MEAN=	4.000	MEDIAN=	3.500	SD=	1.647
VALUE	1.000	2.000	3.000	4.000	5.000	6.000	7.000			
FREQUENCY	2	8	9	12	8	6	5			
PERCENTAGE	4.00%	16.00%	18.00%	24.00%	16.00%	12.00%	10.00%			
CUMULATIVE	4.00%	20.00%	38.00%	62.00%	78.00%	90.00%	100.00%			

VAR(11)	# OF DISABLING CONDITION		N=	50	MEAN=	2.620	MEDIAN=	2.158	SD=	1.310
VALUE	1.000	2.000	3.000	4.000	5.000	6.000	7.000			
FREQUENCY	12	10	19	6	1	1	1			
PERCENTAGE	24.00%	20.00%	38.00%	12.00%	2.00%	2.00%	2.00%			
CUMULATIVE	24.00%	44.00%	82.00%	94.00%	96.00%	98.00%	100.00%			

VAR(12)	# KNOWN HOSPITAL DISCHAR		N=	50	MEAN=	0.920	MEDIAN=	0.071	SD=	1.163
VALUE	0.000	1.000	2.000	3.000	4.000	5.000				
FREQUENCY	24	14	7	3	1	1				
PERCENTAGE	48.00%	28.00%	14.00%	6.00%	2.00%	2.00%				
CUMULATIVE	48.00%	76.00%	90.00%	96.00%	98.00%	100.00%				

VAR(13)	# KNOWN LTC ADMISSIONS		N=	50	MEAN=	0.200	MEDIAN=	0.0	SD=	0.447
VALUE	0.000	1.000	2.000							
FREQUENCY	41	8	1							
PERCENTAGE	82.00%	16.00%	2.00%							
CUMULATIVE	82.00%	98.00%	100.00%							

VAR(14)	PREHOSPITAL BARTHEL SCOR		N=	50	MEAN=	77.120	MEDIAN=	82.500	SD=	23.577
VALUE	25.000	27.000	32.000	35.000	37.000	47.000	52.000	55.000	57.000	
FREQUENCY	1	1	1	2	3	1	1	1	1	
PERCENTAGE	2.00%	2.00%	2.00%	4.00%	6.00%	2.00%	2.00%	2.00%	2.00%	
CUMULATIVE	2.00%	4.00%	6.00%	10.00%	16.00%	18.00%	20.00%	22.00%	24.00%	
VALUE	67.000	69.000	70.000	74.000	75.000	79.000	80.000	85.000	89.000	
FREQUENCY	1	1	2	1	2	1	4	2	2	
PERCENTAGE	2.00%	2.00%	4.00%	2.00%	4.00%	2.00%	8.00%	4.00%	4.00%	
CUMULATIVE	26.00%	28.00%	32.00%	34.00%	38.00%	40.00%	48.00%	52.00%	56.00%	

FREQUENCY DISTRIBUTIONS

VALUE	90.000	94.000	95.000	99.000	100.000					
FREQUENCY	4	1	4	1	12					
PERCENTAGE	8.00%	2.00%	8.00%	2.00%	24.00%					
CUMULATIVE	64.00%	66.00%	74.00%	76.00%	100.00%					
VAR(15)	ANTICIPATED DARTHIEL		N=	50	MEAN=	49.040	MEDIAN=	45.750	SD=	21.104
VALUE	5.000	10.000	15.000	17.000	20.000	25.000	30.000	32.000	35.000	
FREQUENCY	1	1	1	2	1	1	1	3	1	
PERCENTAGE	2.00%	2.00%	2.00%	4.00%	2.00%	2.00%	2.00%	6.00%	2.00%	
CUMULATIVE	2.00%	4.00%	6.00%	10.00%	12.00%	14.00%	16.00%	22.00%	24.00%	
VALUE	37.000	40.000	42.000	47.000	52.000	55.000	57.000	60.000	62.000	
FREQUENCY	3	1	6	4	2	1	4	2	2	
PERCENTAGE	6.00%	2.00%	12.00%	8.00%	4.00%	2.00%	8.00%	4.00%	4.00%	
CUMULATIVE	30.00%	32.00%	44.00%	52.00%	56.00%	58.00%	66.00%	70.00%	74.00%	
VALUE	67.000	69.000	70.000	75.000	80.000	85.000	99.000			
FREQUENCY	1	1	3	3	2	2	1			
PERCENTAGE	2.00%	2.00%	6.00%	6.00%	4.00%	4.00%	2.00%			
CUMULATIVE	76.00%	78.00%	84.00%	90.00%	94.00%	98.00%	100.00%			
VAR(16)	PREHOSPITAL IADL		N=	50	MEAN=	40.500	MEDIAN=	27.009	SD=	31.941
VALUE	0.000	13.000	25.000	30.000	50.000	63.000	75.000	80.000	100.000	
FREQUENCY	8	8	7	9	1	6	4	2	5	
PERCENTAGE	16.00%	16.00%	14.00%	18.00%	2.00%	12.00%	8.00%	4.00%	10.00%	
CUMULATIVE	16.00%	32.00%	46.00%	64.00%	66.00%	78.00%	86.00%	90.00%	100.00%	
VAR(17)	INFORMAL SUPPORT		N=	50	MEAN=	2.160	MEDIAN=	1.605	SD=	0.463
	ALL HELP	SOME HELP	NO HELP							
VALUE	1.000	2.000	3.000							
FREQUENCY	2	30	10							
PERCENTAGE	4.00%	76.00%	20.00%							
CUMULATIVE	4.00%	80.00%	100.00%							
VAR(18)	INFORMAL SUPPORT WILLING		N=	50	MEAN=	2.200	MEDIAN=	1.600	SD=	0.529
	ALL HELP	SOME HELP	NO HELP	FAMILY UNSUR						
VALUE	1.000	2.000	3.000	4.000						
FREQUENCY	1	40	7	2						
PERCENTAGE	2.00%	80.00%	14.00%	4.00%						
CUMULATIVE	2.00%	82.00%	96.00%	100.00%						

FREQUENCY DISTRIBUTIONS

VAR(19)	MAINTAIN AT HOME		N=	50	MEAN=	0.740	MEDIAN=	0.324	SD=	0.439
	NO	YES								
VALUE	0.000	1.000								
FREQUENCY	13	37								
PERCENTAGE	26.00%	74.00%								
CUMULATIVE	26.00%	100.00%								

VAR(20)	ITEMS 1-6		N=	49	MEAN=	1.400	MEDIAN=	0.654	SD=	1.308
VALUE	0.000	1.000	2.000	3.000	4.000	BLANK				
FREQUENCY	16	13	8	8	4	1				
PERCENTAGE	32.65%	26.53%	16.33%	16.33%	8.16%					
CUMULATIVE	32.65%	59.18%	75.51%	91.84%	100.00%					

VAR(21)	ITEMS 7-17		N=	48	MEAN=	7.521	MEDIAN=	7.500	SD=	2.291
VALUE	2.000	3.000	4.000	5.000	6.000	7.000	8.000	9.000	10.000	
FREQUENCY	1	2	1	5	7	8	6	8	5	
PERCENTAGE	2.08%	4.17%	2.08%	10.42%	14.50%	16.67%	12.50%	16.67%	10.42%	
CUMULATIVE	2.08%	6.25%	8.33%	18.75%	33.33%	50.00%	62.50%	79.17%	89.58%	
VALUE	11.000	12.000	BLANK							
FREQUENCY	4	1	2							
PERCENTAGE	8.33%	2.08%								
CUMULATIVE	97.92%	100.00%								

VAR(22)	# OF CURRENT MEDICATIONS		N=	50	MEAN=	5.500	MEDIAN=	4.400	SD=	2.975
VALUE	0.000	1.000	2.000	3.000	4.000	5.000	6.000	7.000	8.000	
FREQUENCY	1	3	3	8	8	5	1	5	8	
PERCENTAGE	2.00%	6.00%	6.00%	16.00%	16.00%	10.00%	2.00%	10.00%	16.00%	
CUMULATIVE	2.00%	8.00%	14.00%	30.00%	46.00%	56.00%	58.00%	68.00%	84.00%	
VALUE	9.000	10.000	11.000	14.000						
FREQUENCY	5	1	1	1						
PERCENTAGE	10.00%	2.00%	2.00%	2.00%						
CUMULATIVE	94.00%	96.00%	98.00%	100.00%						

VAR(23)	% NURS, SERS, USED		N=	50	MEAN=	31.600	MEDIAN=	28.333	SD=	15.116
VALUE	0.000	7.000	13.000	20.000	27.000	33.000	38.000	40.000	41.000	
FREQUENCY	2	2	4	6	9	9	1	4	1	
PERCENTAGE	4.00%	4.00%	8.00%	12.00%	18.00%	18.00%	2.00%	8.00%	2.00%	
CUMULATIVE	4.00%	8.00%	16.00%	28.00%	46.00%	64.00%	66.00%	74.00%	76.00%	

FREQUENCY DISTRIBUTIONS

VALUE	47.000	50.000	53.000	60.000
FREQUENCY	3	1	6	2
PERCENTAGE	6.00%	2.00%	12.00%	4.00%
CUMULATIVE	82.00%	84.00%	96.00%	100.00%

VAR(24)	# CUR. NUR. SERS. USED	N=	50	MEAN=	4.620	MEDIAN=	3.800	SD=	2.705
VALUE	0.000	1.000	2.000	3.000	4.000	5.000	6.000	7.000	8.000
FREQUENCY	4	2	7	4	10	5	6	3	3
PERCENTAGE	8.00%	4.00%	14.00%	8.00%	20.00%	10.00%	12.00%	6.00%	6.00%
CUMULATIVE	8.00%	12.00%	26.00%	34.00%	54.00%	64.00%	76.00%	82.00%	88.00%
VALUE	9.000	12.000							
FREQUENCY	5	1							
PERCENTAGE	10.00%	2.00%							
CUMULATIVE	98.00%	100.00%							

VAR(25)	ACTUAL DISCH. SITE	N=	50	MEAN=	4.700	MEDIAN=	3.692	SD=	2.587
	REHAD. HOSP. CHRON DIS. H	LEVEL 1 SNF	LEVEL 2 NURS	LEVEL 3 ICF	PUBLIC MEDIC	COUNTY HOSPI	VA REHAD.	STILL IN HOS	
VALUE	1.000	2.000	3.000	4.000	5.000	6.000	7.000	8.000	9.000
FREQUENCY	1	7	0	13	11	1	1	1	1
PERCENTAGE	2.00%	14.00%	16.00%	26.00%	22.00%	2.00%	2.00%	2.00%	2.00%
CUMULATIVE	2.00%	16.00%	32.00%	58.00%	80.00%	82.00%	84.00%	86.00%	88.00%
	HOME	DIED							
VALUE	10.000	11.000							
FREQUENCY	3	3							
PERCENTAGE	6.00%	6.00%							
CUMULATIVE	94.00%	100.00%							

VAR(26)	CARE IN ACT. DISCH. SITE	N=	50	MEAN=	4.340	MEDIAN=	3.667	SD=	1.818
	REHABILITATI	CHRONIC	LEVEL 1	LEVEL 2	LEVEL 3	N.A.			
VALUE	1.000	2.000	3.000	4.000	5.000	8.000			
FREQUENCY	2	5	8	15	13	7			
PERCENTAGE	4.00%	10.00%	16.00%	30.00%	26.00%	14.00%			
CUMULATIVE	4.00%	14.00%	30.00%	60.00%	86.00%	100.00%			

VAR(30)	PSYCHOSOCIAL	N=	40	MEAN=	52.574	MEDIAN=	50.000	SD=	18.462
VALUE	11.765	23.529	29.412	35.294	41.176	47.059	52.941	58.824	64.706
FREQUENCY	1	3	4	4	3	7	4	8	3
PERCENTAGE	2.03%	6.25%	8.33%	8.33%	6.25%	14.58%	8.33%	16.67%	6.25%
CUMULATIVE	2.03%	8.33%	16.67%	25.00%	31.25%	45.83%	54.17%	70.83%	77.08%

FREQUENCY DISTRIBUTIONS

VALUE	70.588	70.471	82.353	88.235	BLANK
FREQUENCY	5	2	1	3	7
PERCENTAGE	10.42%	4.17%	2.00%	6.29%	
CUMULATIVE	87.50%	91.67%	93.75%	100.00%	

VAR(34)	BARTHEL CHANGE	N=	50	MEAN=	27.280	MEDIAN=	26.000	SD=	21.407
VALUE	-15.000	-5.000	0.000	5.000	9.000	10.000	15.000	20.000	19.000
FREQUENCY	1	1	6	3	1	2	2	1	1
PERCENTAGE	2.00%	2.00%	12.00%	6.00%	2.00%	4.00%	4.00%	2.00%	2.00%
CUMULATIVE	2.00%	4.00%	16.00%	22.00%	24.00%	28.00%	32.00%	34.00%	36.00%
VALUE	20.000	22.000	23.000	25.000	27.000	28.000	29.000	33.000	37.000
FREQUENCY	3	2	1	1	2	2	1	1	1
PERCENTAGE	6.00%	4.00%	2.00%	2.00%	4.00%	4.00%	2.00%	2.00%	2.00%
CUMULATIVE	42.00%	46.00%	48.00%	50.00%	54.00%	58.00%	60.00%	62.00%	64.00%
VALUE	38.000	40.000	43.000	47.000	48.000	53.000	58.000	63.000	68.000
FREQUENCY	2	2	4	1	2	2	1	2	1
PERCENTAGE	4.00%	4.00%	8.00%	2.00%	4.00%	4.00%	2.00%	4.00%	2.00%
CUMULATIVE	68.00%	72.00%	80.00%	82.00%	86.00%	90.00%	92.00%	96.00%	98.00%
VALUE	83.000								
FREQUENCY	1								
PERCENTAGE	2.00%								
CUMULATIVE	100.00%								

VAR(45)	ACTUAL DISCH. SITE	N=	41	MEAN=	3.634	MEDIAN=	3.269	SD=	1.099
	HOSP	LEVEL 1	LEVEL 2	LEVEL 3		BLANK			
VALUE	2.000	3.000	4.000	5.000		9			
FREQUENCY	9	8	13	11					
PERCENTAGE	21.95%	19.51%	31.71%	26.83%					
CUMULATIVE	21.95%	41.46%	73.17%	100.00%					

VAR(48)	ANTIC. DISCH. SITE	N=	50	MEAN=	3.860	MEDIAN=	3.429	SD=	0.895
	HOSP,	LEVEL 1	LEVEL 2	LEVEL 3					
VALUE	2.000	3.000	4.000	5.000					
FREQUENCY	4	12	21	13					
PERCENTAGE	8.00%	24.00%	42.00%	26.00%					
CUMULATIVE	8.00%	32.00%	74.00%	100.00%					

CONVERSION FROM PACE FORM TO BARTHEL SCORES (C. Granger - 4/77)

<u>MOBILITY LEVEL</u>		<u>TRANSFERRING (bed and chair)</u>	
Goes outside without help		Transfers without help	15
Goes outside with help of equipment		Uses equipment, device (no human help)	15
Devices, (no human help)		Human help only	7
Goes outside with human help, with or without equipment, devices		Human help & equipment, device	7
Confined to facility/home but gets outside room		Is transferred (does not participate)	0
Confined to room		Is not transferred (bedfast)	0
		Number of persons helping	
		Name equipment, devices:	
<u>WALKING (for 50 yds)</u>		<u>WHEELING (score only if not walking)</u>	
Walks without help	15	Does not wheel - walks	0
Uses equipment, device (no human help)	15	Wheels without help (does not walk)	5
Human help only	10	Uses adaptive device (no walking or help)	5
Human help & equipment, device	10	Human help & adaptive device	0
Does not walk	0	Is wheeled (does not participate)	0
Number of persons helping		Is not wheeled (bedfast or chairfast)	0
Name of equipment, device		Number of persons helping	
		Name of adaptive devices	
<u>BATHING (and transfer tub/shower)</u>		<u>STAIR CLIMBING</u>	
Bathes without help & trs.tub/shower)	5	Climbs stairs without help	10
Uses equipment, device (no human help but not independent in trs.tub/shower)	4	Uses equipment, device (no human help)	10
Human help only	0	Human help only	5
Human help & equipment, device	0	Human help & equipment, device	5
Is bathed	0	Does not climb stairs	0
Number of persons helping		Numbers of persons helping	
Name of equipment, devices		Name of equipment, devices	
<u>DRESSING</u>		<u>TOILETTING (and transfers & perineal care)</u>	
Dresses without help	10	Uses toilet room without help	10
Uses equipment, device (no human help)	10	Uses equipment, device (no human help)	9
Human help only	5	Human help only	5
Human help & equipment, device	3	Human help & equipment, device	5
Is dressed	0	Does not use toilet room	0
Is not dressed	0	Number of persons helping	
Number of persons helping		Name of equipment, devices	
Name of equipment, devices			
<u>GROOMING</u>		<u>BOWEL FUNCTION</u>	
Grooms without help	5	Continent	10
Uses adaptive device (no human help)	5	Incontinent less than once a week	5
Human help only	0	Incontinent once a week or more	0
Human help & adaptive device	0	"Ostomy" or other problem with self-care	10
Is groomed	0	"Ostomy" or other problem without self-care	5
Number of persons helping		Type of ostomy (self-care or other) or other problem	
Name of adaptive devices			
<u>EATING/FEEDING</u>		<u>BLADDER FUNCTION</u>	
Feeds self without help	10	Continent	10
Uses adaptive device (no human help)	5	Incontinent less than once a week	5
Human help only	0	Incontinent once/wk or more, night only	5
Human help & adaptive device	0	Incontinent once/wk or more, night & day	5
Spoon fed	0	Indwelling catheter with self-care	10
Tube fed	0	Indwelling catheter without self-care	5
Fed parenterally	0	"Ostomy" or other problem, self-care	10
Number of persons helping		"Ostomy" or other problem, no self-care	5
		Type of ostomy or catheter care	

APPENDIX D

A sample print-out of one patients prescribed hours. The four pages form one table. Services and service sub-totals appear in left-hand margin. Individual prescribers -- physicians (MDC), discharge planners (DPC), home health planners (HHC), and the hospital planners -- and means of groups head the columns. Hours prescribed by individuals and by means of groups appear in the matrix.

MONTHS: 1-6

TABLE 1-A- 2.11 BY PATIENT ANALYSIS OF HOURS AND MEAN HOURS
(SERVICE BY PRESCRIBER BY PATIENT)

PATIENT: 4049 1

SERVICE	PRESCRIBER											
	MDC1	MDC2	MDC3	MDC4	MDC5	MEAN MDC	DPC1	DPC2	DPC3	DPC4	DPC5	MEAN DPC
<u>PERSONAL</u>												
CONCARE	70.10	136.29	-2.00	0.0	142.97	69.87	62.84	0.0	0.0	92.49	0.0	31.07
PERCH	0.0	0.0	1.67	0.0	0.0	0.33	1.17	0.0	10.50	0.0	22.00	6.73
BATH	3.50	1.50	2.25	2.00	1.75	2.20	0.50	2.63	2.63	7.00	0.67	2.68
DRESS	3.50	2.33	5.00	0.88	1.75	2.69	1.75	3.50	0.88	4.67	2.92	2.74
TOIL	4.67	7.00	5.21	3.50	1.17	4.31	4.00	7.00	3.50	11.67	0.29	5.29
TRANSFER	0.0	0.0	2.33	0.29	1.17	0.76	0.07	3.50	1.17	5.00	0.0	1.95
SUPERMED	0.0	1.75	1.46	1.63	2.33	1.43	3.50	1.17	0.50	3.50	0.46	1.84
TURNCED	0.0	0.0	0.0	0.0	0.0	0.0	0.47	0.0	0.0	0.0	0.04	0.10
GROOM	0.0	0.0	1.75	0.0	0.0	0.35	0.0	0.0	0.0	0.0	0.42	0.00
EATDRINK	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
SUBTOTAL	81.77	140.87	19.67	8.29	151.14	81.95	74.30	17.79	19.25	124.33	26.79	52.49
% OF TOTAL	77.76	86.50	32.60	25.85	88.04	----	71.50	30.93	41.25	70.37	63.30	----
<u>HOUSE</u>												
SHOPP	0.0	2.00	2.00	1.50	0.25	1.15	0.75	1.50	1.50	1.00	0.50	1.05
MEALPREP	10.50	7.00	5.03	9.00	10.50	8.57	10.50	7.00	8.75	21.00	3.67	10.36
TELEP	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
TRNSPORT	1.50	4.00	2.00	2.00	2.00	2.10	1.50	1.50	1.75	1.00	0.92	1.33
SOCIAL	2.00	0.0	2.50	2.00	1.00	1.50	2.25	1.00	8.00	3.00	1.88	3.40
LTHOUSE	4.00	3.50	2.00	1.80	0.0	2.27	4.00	3.50	1.00	7.00	2.33	3.57
HVYHOUSE	1.84	1.84	0.92	1.84	0.23	1.33	0.92	2.30	0.46	0.92	0.15	0.95
LAUNDRY	1.33	0.92	2.59	0.92	0.25	1.21	2.30	0.50	0.92	1.84	0.92	3.31
PERSNHGT	0.0	0.46	0.92	0.0	0.92	0.46	0.23	0.50	0.52	0.0	0.19	0.38
SUBTOTAL	21.22	19.72	18.76	19.14	15.15	10.00	22.45	19.70	23.30	35.76	10.56	22.36
% OF TOTAL	20.18	11.46	31.11	59.65	8.82	----	21.60	43.17	49.97	20.24	24.94	----

MONTHS: 1-6

TABLE 1-A- 2.2: BY PATIENT ANALYSIS OF HOURS AND MEAN HOURS
(SERVICE BY PRESCRIBER BY PATIENT)

PATIENT 4 49 1

SERVICE	PRESCRIBER:											
	HHC1	HHC2	HHC3	HHC4	HHC5	MEAN HHC	MEAN CON	MDH	DMH	FMH	MEAN HOS	MEAN ALL
<u>PERSONAL</u>												
CONCARE	120.71	82.70	0.0	139.50	0.0	70.18	57.04	121.00	76.25	127.91	100.41	65.60
PERCH	0.0	0.0	7.00	0.0	5.25	2.45	3.17	0.0	0.0	0.0	0.0	2.64
BATH	1.50	5.25	4.00	1.50	3.00	3.05	2.64	1.75	1.75	0.75	1.42	2.44
DRESS	7.00	4.67	4.67	7.00	2.33	5.13	3.52	14.00	1.75	3.50	6.42	4.00
TOIL	4.67	4.33	0.0	17.50	0.0	5.31	4.97	4.67	2.63	0.0	2.43	4.55
TRANSFER	0.0	2.92	0.0	0.0	0.0	0.58	1.10	1.75	0.0	0.0	0.58	1.01
SUPERVED	4.00	2.33	3.50	0.0	1.04	2.17	1.82	1.17	0.87	2.33	1.46	1.76
TURNGED	0.0	0.0	0.0	0.0	0.0	0.0	0.03	0.0	0.0	0.0	0.0	0.03
GROOM	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.12
EATDRINK	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
SUBTOTAL	145.87	102.24	19.17	165.50	11.62	86.80	74.44	144.41	83.25	134.49	120.72	82.15
% OF TOTAL	81.15	72.83	30.77	89.82	29.75	----	----	85.52	90.69	78.74	----	----
<u>HOUSE</u>												
SHOPP	1.00	3.00	2.00	1.00	3.00	2.00	1.40	1.00	0.50	1.50	1.00	1.33
MEALPREP	21.00	10.50	15.75	10.50	10.00	13.55	10.82	10.50	2.63	21.00	11.33	10.92
TELEP	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
TRNSPORT	0.50	1.00	1.00	1.00	0.50	0.80	1.40	2.00	1.00	1.00	1.33	1.45
SOCIAL	2.00	1.50	3.00	0.0	5.00	2.30	2.40	0.0	1.00	0.0	0.33	2.05
LTHOUSE	3.00	7.00	7.00	4.00	4.00	5.00	3.61	7.00	0.50	7.00	4.83	3.82
HVYHOUSE	0.69	0.92	0.92	0.0	1.30	0.70	1.02	0.46	0.35	0.92	0.58	0.95
LAUNDRY	1.38	0.92	0.92	0.46	1.04	1.10	1.21	0.92	0.46	1.84	1.07	1.19
PERSNIGT	0.46	0.46	0.0	0.92	0.52	0.47	0.44	0.92	0.32	0.0	0.35	0.42
SUBTOTAL	30.03	25.30	30.59	17.88	26.24	26.01	22.39	22.80	6.55	33.26	20.87	22.13
% OF TOTAL	16.71	18.02	49.11	9.62	67.15	----	----	13.50	7.13	19.47	----	----

MONTHS: 1-6

TABLE 1-A- 2.31 BY PATIENT ANALYSIS OF HOURS AND MEAN HOURS
(SERVICE BY PRESCRIBER BY PATIENT)

PATIENT: 4 49 1

SERVICE	PRESCRIBER:											
	MDC1	MDC2	MDC3	MDC4	MDC5	MEAN MDC	DPC1	DPC2	DPC3	DPC4	DPC5	MEAN DPC
<u>NURSE</u>												
BOHEBLA	0.0	0.0	4.88	0.75	0.0	1.13	0.0	0.0	0.0	0.0	0.30	0.07
DECUB	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
HOUND	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
EYECARE	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
BLADIRG	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
SUCHPT	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
INHIFPD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
OTOXTER	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
ROMX	0.0	0.0	1.25	0.0	0.0	0.25	0.0	2.33	0.0	0.0	0.79	0.62
NUTRIET	0.50	0.25	0.75	0.17	5.25	1.30	4.67	0.50	1.38	10.75	0.21	3.50
MEDADMIN	0.0	1.17	2.75	0.0	0.0	0.75	0.0	0.0	0.25	0.50	0.0	0.15
NONVISIN	0.25	0.08	2.33	0.03	0.0	0.55	0.17	1.17	0.46	0.33	0.29	0.40
FOOTCARE	0.0	0.0	1.17	0.33	0.08	0.32	0.33	0.0	0.0	2.33	0.33	0.60
TCHOTHER	0.0	0.0	5.42	0.0	0.0	1.00	0.62	2.25	0.33	0.50	0.42	0.05
NUROTHER	0.0	0.0	0.0	0.0	0.0	0.0	0.75	0.0	0.50	0.0	0.0	0.27
SUBTOTAL	0.75	1.50	18.54	1.33	5.33	5.49	6.54	6.25	3.04	14.50	2.42	6.55
% OF TOTAL	0.71	0.07	30.74	4.16	3.11	----	6.29	13.69	6.52	8.21	5.71	----
<u>OTH PRO</u>												
PRIMED	0.04	0.04	0.12	0.04	0.04	0.05	0.12	0.12	0.12	0.06	0.00	0.10
SPECHED	0.0	0.0	0.0	0.10	0.0	0.02	0.0	0.0	0.08	0.02	0.06	0.03
DENTIST	0.0	0.0	0.02	0.02	0.0	0.01	0.0	0.0	0.0	0.0	0.0	0.0
PODIAT	0.0	0.02	0.02	0.06	0.02	0.02	0.0	0.06	0.0	0.12	0.02	0.04
PT	1.30	1.61	1.90	1.04	0.0	1.35	0.40	0.69	0.46	0.52	0.75	0.56
OT	0.0	0.0	0.53	0.58	0.0	0.23	0.0	0.0	0.0	0.0	1.16	0.23
PSYCH	0.0	0.35	0.72	0.69	0.0	0.35	0.12	1.04	0.33	1.30	0.50	0.68
SUBTOTAL	1.48	2.01	3.35	3.32	0.06	2.03	0.63	1.90	1.04	2.09	2.56	1.64
% OF TOTAL	1.35	1.17	5.55	10.34	0.03	----	0.61	4.16	2.22	1.18	6.05	----
TOTAL	105.16	172.10	60.32	32.00	171.60	108.27	103.92	45.64	46.63	176.60	42.33	77.76

MONTHS: 1-6

TABLE 1-A- 2.4: BY PATIENT ANALYSIS OF HOURS AND MEAN HOURS
(SERVICE BY PRESCRIBER BY PATIENT)

PATIENT: 4 49 1

SERVICE:	PRESCRIBER:											
	HHC1	HHC2	HHC3	HHC4	HHC5	MEAN HHC	MEAN CON	MDH	DPI	PIH	MEAN NOS	MEAN ALL
<u>NURSE</u>												
ECHELDLA	0.50	0.0	3.50	0.0	0.0	0.00	0.67	0.0	0.00	0.0	0.17	0.58
DECUB	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
HOURD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
EYECARE	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
BLADIRG	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
SUCHPT	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
INHIPPD	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
OTOXTHR	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
ROMX	0.0	0.0	2.33	0.0	0.0	0.47	0.45	0.0	0.0	0.0	0.0	0.37
NUTROJET	0.50	2.50	0.20	0.50	0.0	0.74	1.87	0.33	0.25	1.00	0.53	1.65
MEDADHIN	0.0	0.25	0.0	1.75	0.0	0.40	0.44	1.17	0.0	0.50	0.56	0.46
MONVISIN	0.17	1.00	1.00	0.25	0.75	0.63	0.56	0.00	0.25	0.17	0.17	0.49
FOOTCARE	0.0	2.33	2.33	0.0	0.0	0.93	0.62	0.0	0.0	1.17	0.39	0.50
TCROTHER	0.0	0.50	0.0	0.0	0.0	0.07	0.67	0.0	0.0	0.0	0.0	0.56
NUROTHER	0.58	0.75	0.0	0.0	0.0	0.27	0.10	0.0	0.25	0.0	0.03	0.16
SUBTOTAL	1.75	7.21	9.37	2.50	0.75	4.32	5.45	1.50	1.25	2.03	1.09	4.06
% OF TOTAL	0.97	5.13	15.04	1.34	1.92	----	----	0.94	1.36	1.66	----	----
<u>OTH PRO</u>												
PRINED	0.04	0.06	0.06	0.04	0.12	0.06	0.07	0.04	0.06	0.12	0.07	0.07
SPECHED	0.0	0.0	0.0	0.0	0.0	0.0	0.02	0.02	0.0	0.06	0.03	0.02
DENTIST	0.0	0.0	0.0	0.0	0.0	0.0	0.00	0.0	0.0	0.0	0.0	0.00
PODIAT	0.0	0.06	0.12	0.0	0.0	0.03	0.03	0.0	0.0	0.04	0.01	0.03
PT	1.15	3.45	2.30	0.0	0.35	1.45	1.12	0.0	0.69	0.0	0.23	0.97
DT	0.46	0.69	0.0	0.0	0.0	0.23	0.23	0.0	0.0	0.0	0.0	0.19
PSYCH	0.46	1.33	0.69	0.0	0.0	0.51	0.51	0.0	0.0	0.0	0.0	0.43
SUBTOTAL	2.11	5.64	3.17	0.04	0.46	2.20	1.99	0.06	0.75	0.21	0.34	1.71
% OF TOTAL	1.17	4.02	5.00	0.02	1.10	----	----	0.03	0.82	0.12	----	----
TOTAL	179.77	140.39	62.29	105.92	39.00	121.49	104.27	160.05	91.79	170.80	143.81	110.06

Appendix E

Hours of Care By Service and Provider Categories

APPENDIX E

Hours of Care prescribed by the Average of Professionals:
Agreement and Distribution by Service: A) personal care

<u>SERVICE</u>	<u>X HOURS</u>	<u>S.D.HOURS</u>	<u>COV HOURS</u>	<u>%TOTAL</u>	<u>%SUBTOTAL</u>
Continuous Care	63.2	46.4	100.5%	50.6%	73.8%
Periodic Checking	2.0	5.5	268.8	1.6	2.3
Bathing	2.8	1.8	70.3	2.2	3.3
Dressing	3.0	1.8	80.9	2.4	3.5
Toilet	4.9	3.2	86.5	3.9	5.7
Transferring	2.7	1.9	113.6	2.2	3.2
Supervision of Medications	1.4	1.2	121.6	1.1	1.6
Turning In Bed	1.3	1.4	184.7	1.0	1.5
Grooming	2.0	1.4	120.2	1.6	2.3
Eating-Drinking	2.4	1.9	181.5	1.9	2.8
S.T.Personal Care	85.6	45.8	67.6%	68.6%	100.0%

1 COV= Individual Patient's S.D. ÷ \bar{X} , averaged over 50 patients

APPENDIX E

Hours of Care Prescribed by the Average of Professionals:
Agreement and Distribution of Service: B) Household

<u>SERVICE</u>	<u>X HOURS</u>	<u>S.D.HOURS</u>	<u>COV HOURS</u>	<u>%TOTAL</u>	<u>%SUBTOTAL</u>
Shopping	1.7	0.9	52.1%	1.4%	5.7%
Meal Preparation	13.8	7.6	56.5	11.1	46.5
Telephone	0.1	0.2	278.8	0.1	0.3
Transportation	1.6	1.6	107.5	1.3	5.4
Socialization	3.7	4.0	104.3	3.0	12.5
Light Housework	5.1	3.7	72.7	4.1	17.2
Heavy Housework	1.2	0.9	74.5	1.0	4.0
Laundry	1.8	1.2	64.3	1.4	6.1
Management of Personal Affairs	0.7	0.6	90.0	0.5	2.4
S.T. HOUSEHOLD	29.7	12.3	41.2%	23.8%	100.0%

APPENDIX E

Hours of Care Prescribed by the Average of Professionals:
Agreement and Distribution by Service: C) Nursing

<u>SERVICE</u> ¹	<u>X HOURS</u>	<u>S.D.HOURS</u>	<u>COV HOURS</u>	<u>%TOTAL</u>	<u>%SUB-TOTAL</u>
Bowel & Bladder Care	1.3	1.7	212.1%	1.0%	17.6%
Decubitus Care	0.6	0.9	266.6	0.5	8.1
Range-Of-Motion Exercises	0.9	1.3	192.3	0.7	12.2
Nutrition-Diet	0.9	1.5	209.7	0.7	12.2
Administration Of Medications	0.8	1.1	187.4	0.8	10.8
Monitoring Vital Sigas	0.7	0.7	115.4	6.6	9.5
Other Nursing	2.2	NA	NA	1.8	29.7
S. T. Nursing	7.4	5.7	87.5%	5.9%	100.0%

¹ Selected nursing services only.

APPENDIX E

Hours of Care Prescribed by the Average of Professionals:
Agreement and Distribution by Service: D) Medical-Therapeutic

<u>SERVICE</u>	<u>X HOURS</u>	<u>S.D.HOURS</u>	<u>COV HOURS</u>	<u>%TOTAL</u>	<u>%SUBTOTAL</u>
Primary Medical Care	0.08	0.05	68.5%	0.1%	3.8%
Specialist Med. Care	0.02	0.03	225.3	*	1.0
Dentist	0.01	0.01	230.3	*	0.5
Podiatrist	0.01	0.02	183.9	*	0.5
Physical Therapy	1.4	1.4	142.6	1.0	66.7
Occupational Therapy	0.3	0.5	214.8	0.2	14.3
Psychotherapy	0.2	0.4	211.2	0.2]	9.5
S.T. MEDICAL THERAPEUTIC	2.1	1.8	100.3%	1.7%	100.0%

* less than 0.05%

APPENDIX E

Hours of Care Prescribed by the Average of Professionals:
Agreement and Distribution by Selected Providers

<u>PROVIDER</u>	<u>X HOURS</u>	<u>S.D.HOURS</u>	<u>COV HOURS</u>	<u>% OF TOTAL</u>
Registered nurse	2.1	4.7	185.2%	1.7%
LPN	3.3	8.1	343.7	2.6
Homemaker	5.9	10.9	225.9	4.7
Personal care attendant	32.0	42.4	162.2	25.6
Social worker	0.2	0.4	232.9	0.2
Sitting Service	7.5	16.3	270.1	6.0
Companion	0.6	2.4	415.3	0.5
Resident family	33.7	26.6	152.6	27.0
Resident friend	0.1	0.5	403.9	0.1
Non-resident family	5.1	6.6	152.7	4.1
Non-resident friend	1.3	2.0	199.8	1.0
Total	124.8	48.8	41.7%	95.2%

APPENDIX E

Hours of Care Prescribed by the Average of Professionals:
Agreement and Distribution by Provider Sub-totals

<u>PROVIDER S.T.</u>	<u>X HOURS</u>	<u>COV HOURS</u>	<u>% OF TOTAL</u>
Medical	0.1	75.1%	0.1%
Nursing	5.4	189.6	4.3
Care	66.1	69.6	52.9
Support	9.2	193.7	7.4
Therapy	1.9	119.8	1.5
Miscellaneous	1.6	158.3	1.3
Unpaid-Resident	33.9	157.1	27.2
-Non-Resident	6.8	119.8	5.4
-total	40.7	82.8	32.6
Paid	84.2	56.8	67.4
Skilled	7.1	142.0	5.7
Unskilled	117.8	44.9	94.3
TOTAL	124.8	41.7%	100.0%

Appendix F

Mean Hours By Care Planner: Service Sub-totals and Total

mean hours¹ prescribed for

<u>Care planner</u>	<u>personal care</u>	<u>household</u>	<u>nursing</u>	<u>medical therapeutic</u>	<u>TOTAL</u>
MDC-1	97	34	4.8	2.5	138
-2	126	24	3.9	1.7	156
-3	35	26	9.6	3.6	74
-4	104	22	8.0	3.7	138
-5	110	18	4.1	1.2	134
\bar{X} MDC	95	25	5.5	2.5	128
DPC-1	95	33	8.6	1.8	138
-2	31	30	5.8	1.3	69
-3	70	24	3.3	1.0	98
-4	116	29	9.5	1.1	155
-5	92	25	10.6	2.3	130
\bar{X} DPC	81	28	7.6	1.5	118
HHC-1	86	28	7.1	1.9	123
-2	105	35	12.7	4.2	157
-3	51	35	11.7	2.7	101
-4	122	17	4.4	0.6	144
-5	24	50	2.9	1.3	79
\bar{X} HHC	78	33	7.8	2.1	121
\bar{X} CON	84	29	7.0	2.0	122
MD-H	102	39	7.7	2.9	152
DP-H	101	34	10.0	2.3	148
FN-H	90	37	9.9	2.4	139
\bar{X} HOSP	98	37	9.2	2.5	146
TOTAL	87	30	7.4	2.1	125

¹across 50 patients

²MDC=physician consultant
 DPC=discharge planner consultant
 HHC=home health consultant
 CON=Consultant

MDH=hospital physician
 DPH="discharge planner"
 FNH="floor nurse"

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