

# ALTERNATIVES TO NURSING HOME CARE: A PROPOSAL

With Discussion of Deficiencies in Federally-Assisted  
Programs for Treatment of Long-Term  
Disability

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PREPARED FOR USE BY THE  
SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE

BY STAFF SPECIALISTS AT THE  
LEVINSON GERONTOLOGICAL POLICY INSTITUTE  
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(II)

## PREFACE

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Alarming increases in the cost of Medicare and Medicaid have given rise to widespread efforts to reduce institutionalization, and services, particularly in long-term care facilities.<sup>1</sup>

This trend has produced some increase in efficiency and some resulting reduction in expenditures, but it has also caused concern about (1) the effect upon people denied such treatment, and (2) whether such cutbacks are actually accompanied by the development of satisfactory alternative services, or whether they are primarily holding actions meant to deal in limited fashion with the fiscal pressures of the moment.

Even if the public budgetary situation were more satisfactory, however, there would be compelling reason for concern.

Slowly, it is becoming all-too-clear that far too large a proportion of the health care dollar of the United States is spent on institutionalization. But, while it has become common to criticize this costly practice, comparatively little has been done to combat it. Cutbacks alone will not overcome it; they may even intensify the problem by causing shifts from one kind of institution, such as a nursing home, to a more costly kind of institution, such as a general hospital.

To the Senate Special Committee on Aging, it is clear that the far-reaching changes—including more options to States under Medicaid—are required to reverse or reduce present over-dependence upon nursing homes and other institutions in which our elderly population is disproportionately represented. For that reason, the Committee is issuing a report on "Mental Health Care and the Elderly: Shortcomings in Public Policy." In that study, it is shown that widespread discharges from State mental hospitals can have direct and sometimes unfortunate consequences upon the nursing homes to which they are referred. This trend alone is worthy of careful and sustained attention.

To untangle such problems—and many others related to long-term care of the chronically ill elderly—steps should be taken to establish what should be the first line of defense for the older person: Resources that will enable him to stay at home instead of experiencing the trauma of institutionalization. This ideal is often expressed, but it is infrequently applied.

And yet, as is argued in the report which follows this preface, the costs of needless institutionalization are high.

Dr. Robert Morris, author of the first half of the study, asserts that between 250,000 and 500,000 persons annually are assigned to costly institutions for reasons other than medical needs. He adds:

"The paradox is that our programs are designed to pay too little to keep such persons at home (a national average of \$77.60 per month under Old Age Assistance), but will readily pay an average of perhaps \$400 to \$500 a month to keep the same person in an institution."

In the second half of the report, Morris and others at the Levinson Gerontological Policy Institute, apply their concepts to long-term care

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<sup>1</sup> See Chapter II, "Increasing Concern over Nursing Homes," in DEVELOPMENTS IN AGING—1970, Annual report of the Special Committee on Aging, March 25, 1971.

as it now exists in Massachusetts. They cite a study *indicating that only 37 percent of public welfare institutionalized elderly in that Commonwealth require full-time, skilled nursing home care.*

Applying simple arithmetic, the authors conclude that the needless institutionalization is costing more in public funds than it would cost to develop an efficient system of "Personal Care Organizations" which would enable the elderly and others to receive care in their own homes.

Furthermore, the authors show how their theories are about to be put to a test in a pilot project in Massachusetts.

Questions can and should be raised about assumptions and conclusions reached in the Levinson report. For example, Dr. Lionel Cosin and others in Great Britain—in developing substitutes for institutionalization—are relying not only upon home health care but also upon other resources such as "day hospitals" at which patients can receive outpatient services in a congregate setting for a few hours each day. It can be argued that home health care is certain to cost more than nursing home care because it requires individual attention for one patient at a time, rather than group care. And finally, it can be said that the proposals for financing P.C.O.'s are complex and perhaps unworkable.

Questions such as these require pinpointed research and demonstration which move beyond the conventional clinical study to test alternative administrative and financing arrangements suitable for application in all parts of the country.

Nevertheless, the Levinson Institute has performed a timely and valuable service by producing this study for publication by the Committee on Aging. It provides practical information about the situation in one State, and it provides the basis for widespread discussion of the applicability of similar concepts in other States. In addition, the study offers information that will be useful in (1) discussions of the new Administration orders intended to fulfill President Nixon's pledge to cut off Federal funds to substandard nursing homes, and (2) in forthcoming Congressional debate about proposals for a national health insurance system.

To the Subcommittee on Long-Term Care of the Senate Special Committee on Aging, the report is valuable because it provides information and arguments which should be explored further, preparatory to publication of a subcommittee report which will discuss, in depth, findings from its 2-year study of "Trends in Long-Term Care."

In addition, we are sure that this report will be of help to those now preparing for the White House Conference on Aging during the week of November 28, 1971, and to those who will administer three newly approved area-wide projects on "Alternatives to Long-Term Care" under the Older Americans Act.

Clearly, interest in the problems, and possible improvements, in care of the chronically ill elderly is rising. This document can be of help in assuring that such concern results in positive results, including development of a genuine, and much-needed, national policy on long-term care.

FRANK CHURCH, *Chairman,*  
*U.S. Senate, Special Committee on Aging,*

FRANK E. MOSS, *Chairman,*  
*Subcommittee on Long-Term Care*

# CONTENTS

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	Page
Preface .....	III
Part One: Long Term Disability:	
A Missing Dimension in Medical Care and Public Welfare reform.....	1
Impact of disability on Medical and Welfare Programs.....	1
Estimated Volume of Need for Personal Care at Home.....	3
Limitations in Current Programs.....	4
Alternatives to Institutionalizing Solutions.....	5
Improved Use of Current Allocations.....	6
Indemnity or Capitation bases for Payment.....	7
Estimated Cost of Alternative Solutions.....	8
Potential Providers of Personal Care.....	9
The Need for Field Testing.....	9
Relationship to Health Maintenance Organizations.....	10
Manpower Considerations.....	10
Relationship of C.P.O. to Other Organizations.....	11
Part Two: Mobilizing Community Resources to Provide Alternatives to Nursing Home care:	
Introduction .....	13
Necessary for Alternatives to Institutional Living.....	13
I. Limitations of Partial Solutions.....	15
A. Medicare and Medicaid.....	15
B. Housing .....	16
C. Existing Community Agencies.....	16
D. Coordination of Services.....	16
II. A Proposed Personal Care Service System: The Massachusetts Model .....	17
A. Nature of Needed Services.....	17
B. Estimated Costs Per Case.....	18
C. Source of Financial Support.....	19
D. Estimates of Population to be Covered.....	19
E. Criteria for Selection of Client Population.....	20
F. Projected Program Costs.....	21
G. Agency Linkages.....	22
H. Alternatives in Administration.....	22
I. Manpower Requirements and Implications.....	22
III. Role of Federal Government.....	23
Summary .....	24
Appendix: Personal Care Service System Proposal:	
Letter from James J. Callahan, Jr., Assistant Commissioner for Medical Assistance; to Dr. Robert Morris, Levinson Gerontological Policy Institute, Brandeis, University, Sept. 10, 1971.....	25
Letter from Gerald F. Nugent, ACSW, Regional Administrator; to Dr. Robert Morris, Levinson Gerontological Policy Institute, Brandeis University, Oct. 7, 1971.....	25
Letter from Sol S. Boskind, ACSW, Executive Director; to Dr. James Callahan, Assistant Commissioner, Massachusetts Department of Public Welfare, Boston, Mass., Oct. 8, 1971.....	26

## PART ONE

### LONG TERM DISABILITY

#### A Missing Dimension in Medical Care and Public Welfare Reform

(By Robert Morris, Director,\* Levinson Gerontological Policy Institute,  
Brandeis University)

The current efforts to alter national programs of public welfare and of medical care are a response to well-publicized deficiencies in our health and welfare systems, but the search for a more satisfactory public policy has been delayed by a tangle of many conflicting views. One of these concerns the responsibility for certain social and health problems for which no program wishes to be held responsible—the long-term sick, handicapped, and disabled *whose conditions are not likely to improve quickly*.\*\* They represent many of the dark hazards of human existence which we can neither avoid nor overcome, nor can they be longer ignored. They represent limitations in science. They require sustained long-term attention to social, economic, and psychological matters, without much change in medical condition. The required tasks are often simple human ones of household and personal care, satisfied without elaborate technology or specialized skill.<sup>1</sup>

#### IMPACT OF DISABILITY ON MEDICAL AND WELFARE PROGRAMS

Highly professionalized programs prefer to use the maximum skills of their staffs and thus are judged by rapid turnover—diagnosis, treatment, recovery, and discharge. A kind of professional Gresham's law is at work in which high skill, high cost services drive out low skill, low cost ones in our major health systems. Major medical and social agencies seldom consider the slow-moving, long-term case as their primary responsibility; they are to be "referred" to some "other agency" for social, economic, and psychological conditions.

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\*\* Rehabilitation is a necessary but not sufficient remedy for these cases, since certain disabilities persist after the rehabilitation period.

<sup>1</sup> This conclusion is supported by two recent analyses: "Home Health Services Study," conducted by the Columbia University School of Public Health, and submitted to the Health Research Council of the City of New York and the Social Security Administration, HEW (April, 1971); and research conducted by the Levinson Gerontological Policy Institute, Brandeis University, in Kistin, Harris, Morris, "An Alternative to Institutional Care for the Elderly and Disabled: A Proposal for a New Policy," (April, 1971); Caro and Morris, "Personal Care for the Severely Disabled: Organizing and Financing Care," (June, 1971); and Morris and Harris, "Home Health Services in Massachusetts, 1971: Their Role in Care of the Long-Term Sick," (July, 1971).

*But*, those "other agencies," if they exist at all, are also unable to or are reluctant to take sustained responsibility for this type of person. As a result, major medical organizations are burdened with patients they should not have and, as a last resort, move them into quasi-medical nursing institutions—that is, nursing homes which 25–50 percent of the patients do not require.<sup>2</sup> The results of this process crop up in both the health and welfare debates. Another "law" is at work, this one a kind of Parkinson's law, in which high cost medical services are used *inappropriately* to care for persons whose need is mainly social, whenever more appropriate social provision is not available.

Some 18 million persons, between the ages of 18 and 64, and another 15 million elderly *may* be affected. They have some chronic physical conditions which can limit their freedom of movement or make them dependent functionally in some degree. *But*, only a small percentage of these large totals, perhaps 1½ million adults, require the intervention of any public program beyond that now available. The larger total represents the pool of demand which confronts organized health and welfare services. (See Tables 1, 2, 3). They suffer from the prolonged consequences of stroke, heart disease, cancer, arthritis, emphysema, industrial and automobile accidents. Except for rehabilitation, which is limited to those who can return to work, the medical system is not designed to meet the long-term needs of such disabled.

Public welfare is equally at a disadvantage in dealing with this population. It combines in its mission help for those who are temporarily without funds but who could enter the labor market if work is available, and help for those whose need for income support will continue for indefinitely long periods of time—the aged with insufficient Social Security benefits, the permanently disabled, the blind. The growth of public assistance costs, especially in the family assistance category, has aroused so much dissatisfaction that the public has lost sight of the differences in these two groups of assistance categories. As a result, public welfare usually limits its work to providing a generally low level of income, and has not been able to build effective programs for meeting the needs of either group.

In many ways, public welfare is a twentieth century poor house without walls, containing a hodgepodge of human misery too complex for any one form of care, and without the means to develop appropriately specialized services for each type of need. As a result, large numbers of the disabled are forced into nursing homes or into mental hospitals at a very high charge to the public treasury, simply because public programs could not give attention to alternative ways of meeting their needs outside of institutions.

The proposed separation of aged and disabled categories from presumably employable family units will not, of itself, solve this problem. The simple provision of minimum income for food, clothing, and shelter is not responsive to the additional requirements of the long-term disabled.

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<sup>2</sup> Op. cit. Numerous local studies repeat this figure of medically unnecessary institutionalization.

## ESTIMATED VOLUME OF NEED FOR PERSONAL CARE AT HOME

Certain measures can be used to narrow the large estimates of disability—minor to severe—which could affect civilians now living at home to a more realistic figure of persons who would be aided by a "personal care in the home" program and whose condition also justifies some public intervention.

A reasonable estimate produces a figure of just over 1,700,000 persons to whose needs first attention should be directed (Tables 1, 2, 3). A high estimate yields approximately 3 million persons. The mentally ill have been excluded as being too difficult to identify for a mass program. The mentally retarded have also been excluded, although their requirements are more easy to define. Mild limitations in function have also been omitted, leaving only those who are in fact confined to home for some measurable physical illness or injury or handicap, or who are severely limited in movement and mobility. To these numbers are added persons in nursing homes and other long-term institutions who can be expected to live at home if alternate services are provided.

TABLE 1.—TOTAL POPULATION POTENTIALLY ELIGIBLE FOR LONG-TERM PERSONAL CARE, 1971\*

	Total	Age 18 to 64	Age 65 plus
Not in institutions:			
Low estimate.....	3,842,000	2,278,000	1,564,000
High estimate.....	7,805,000	5,499,000	2,306,000
Now in institutions:			
Low estimate.....	124,200	6,600	117,600
High estimate.....	248,500	13,200	235,300

\* Source: Estimates by Agnes Brewster based on extrapolations from published surveys of the National Center for Health Statistics, National Health Center, and Social Security Administration.

TABLE 2.—NONINSTITUTIONALIZED PERSONS AGE 18 TO 64 SEVERELY DISABLED, AND FUNCTIONALLY LIMITED OR DEPENDENT, BY SEX AND AGE, 1966

[In thousands]

Age	All	Mental	All except mental	Severely disabled	Severely limited functionally or dependent
<b>BOTH SEXES</b>					
Total, aged 18 to 64.....	17,752	1,101	16,651	5,499	2,278
18 to 44.....	6,562	577	5,985	1,555	641
45 to 54.....	5,072	268	4,804	1,712	563
55 to 64.....	6,118	256	5,863	2,232	1,074
<b>MALES</b>					
Total, aged 18 to 64.....	8,430	463	7,967	2,386	1,019
18 to 44.....	3,060	238	2,822	778	302
45 to 54.....	2,456	110	2,346	778	272
55 to 64.....	2,914	115	2,799	830	445
<b>FEMALES</b>					
Total, aged 18 to 64.....	9,322	638	8,684	3,113	1,259
18 to 44.....	3,502	339	3,163	777	339
45 to 54.....	2,616	158	2,458	934	291
55 to 64.....	3,204	141	3,064	1,402	629

Sources: Haber, Lawrence D., "Disabling Effects of Chronic Disease and Impairment," *Journal of Chronic Disease*, 1971 (reprint). "The Epidemiology of Disability II. The Measurement of Functional Capacity Limitations," Report No. 10, S.S. Survey of the Disabled (July, 1970).



TABLE 3.—THE NONINSTITUTIONAL AGED WHO WOULD MAKE USE OF A HOME HELP BENEFIT<sup>1</sup>

[In thousands]

Condition	Both sexes	Male	Female
<b>Estimate 1:</b>			
Total aged, 1966 .....	17,723	7,727	9,996
No chronic conditions .....	2,553	1,208	1,345
With chronic conditions .....	15,170	6,519	8,651
No mobility limitations .....	11,852	5,164	6,688
Some limitations on mobility .....	3,318	1,355	1,963
Some trouble getting around .....	1,361	570	791
Need help .....	1,114	468	646
Confined to home .....	843	317	526
Total needing help or confined to home .....	1,957	785	1,172
Having nervous or mental problems .....	151	70	81
Potentially eligible for a home aid program, 1966 .....	1,806	715	1,091
<b>Estimate 2:</b>			
Population aged 65 and over unable to carry on major activity .....	2,441	1,672	769
Estimated as having nervous or mental problems .....	400	300	100
Potentially eligible population, 1966 .....	2,041	1,372	669
Adjusted eligible population, 1970 .....	2,306	1,550	756
<b>Estimate 3: Best estimate likely to use help<sup>2</sup> .....</b>	<b>1,564</b>	<b>808</b>	<b>756</b>

<sup>1</sup> National Center for Health Statistics: "Chronic Conditions and Limitations of Activity and Mobility: United States—July 1965–June 1967," Series 10, No. 61, data from the National Health Survey, Vital and Health Statistics, U.S. Department of Health, Education, and Welfare, Public Health Service, HSMHA.

<sup>2</sup> Levinson Gerontological Policy Institute, Brandeis University, Waltham, Mass.

## LIMITATIONS IN CURRENT PROGRAMS

Other special purpose programs have evolved over the years—disability insurance, housing, etc. Their limitations are outlined in an accompanying report.<sup>3</sup> The sum of these hitherto partial efforts still leaves the disabled as an ignored and overlooked segment of American society. This neglect is not due to cruelty nor to hard-heartedness nor to penury. It is due, rather, to an optimistic over-reliance upon two remedies to all human ills: medical therapy and income payments.

This limiting approach is found in all federally supported programs for the blind, the permanently disabled, vocational rehabilitation, and medical care. We have relied upon medicine (and latterly upon rehabilitation) to remove or to overcome nearly all the hazards of existence. If we cannot wholly prevent disease and injury, some therapy is expected to patch individuals up well enough for them to go on living without further help. Thus, both Medicare and Medicaid spend \$12.7 billion of public funds annually,<sup>4</sup> but 67 percent goes for doctors' bills, drugs, and for hospital treatment. The 0.3 percent devoted to home health care is paid for short-term, nursing-related care. When these measures fail, some 32 percent of funds are paid for short-term care in nursing homes, mainly to remove patients from hospitals which want to keep only active treatment cases, but such substitute care is available only for a few months.

<sup>3</sup> "Mobilizing Community Resources to Provide Alternatives to Nursing Home Care," A model developed by the Levinson Gerontological Policy Institute, Waltham, Mass., see part II of this report.

<sup>4</sup> "Public Assistance—Hospital and Medical Care Payments, 1970," Social Security Bulletin, vol. 34, No. 5, p. 28, table M-2.

When medical therapy fails, our programs next provide substitute income for those unable to work. But suspicions about anyone who is not working for a wage makes it difficult to distinguish between those who could work (if work is available) and those who are too handicapped to work, although willing. As a result, money payments are not only submarginal; they are given on the assumption that marginal payments for food, clothing, and shelter are sufficient. The severely handicapped, however, have additional needs if they are not to lose their homes and their natural community and family ties—some physical or personal care, some help with home maintenance, or with ambulation, perhaps more costly than average housing to permit self-care at home. Lacking provision for these additional items, between 250,000 and 500,000 persons<sup>5</sup> annually end up in even more costly institutions for reasons other than medical need. The paradox is that our programs are designed to pay too little to keep such persons at home (a national average of \$77.60 per month under Old Age Assistance),<sup>6</sup> but will readily pay an average of perhaps \$400–\$500 a month to keep the same person in an institution.

This situation leads to an unfortunate spiral effect. While we pay generously for active treatment, and modestly for basic shelter, we pay nothing to reinforce the natural life system arrangements to which the disabled can turn in their own communities. The entire burden is placed upon family and neighbors who usually help for a time, until they are virtually bankrupted in money and energy; then the unfortunate individual is removed to a nursing home. Instead of reinforcing and conserving these natural family and friendship supports, they are permitted to exhaust themselves until only much more costly alternatives remain available.

The explanation for this seemingly illogical policy lies, perhaps, in a natural reluctance to face the fact that there are some hazards of human existence which cannot be prevented or removed by therapy. There are some ugly handicaps with which individuals can and do survive and with which society must also learn to live. This reluctance to consider ongoing handicap also produces a grave imbalance in our public policy and in our service programs. These conditions call for a mix of medical and social provision, but our current pattern is heavily balanced on the side of medicine, and grossly under-developed on the side of social provision.

It is because of this imbalance, and because the disabled are troublesome to both our health and our welfare systems, that fresh thinking about the disabled may help unravel the difficulties which both welfare and medical reform confront today.

## ALTERNATIVES TO INSTITUTIONALIZING SOLUTIONS

The defects in current health and welfare programs can be corrected within the bounds of current legislative discussion by two relatively simple measures:

### **1. Assurance of a stable financial and administrative foundation for the development of Personal Care Organizations (P.C.O.)**

<sup>5</sup> These numbers represent new admissions in the normal turnover of long-term institutions due to discharge or death.

<sup>6</sup> National average Old Age Assistance payments \$77.60. Social Security Bulletin, vol. 34, No. 5 (May, 1971), p. 51, table M-26.

for the long-term disabled, at least for those whose handicap has physiological basis.

2. A public policy which rewards community living rather than institution living—a public policy to supplement the natural personal care resources of those disabled whose condition is unlikely to change, to enable them to continue living as a part of normal community life.

A system of Personal Care Organization has not emerged naturally for several reasons:

1. Individuals share the general confidence in medical treatment and do not know when or how to anticipate conditions which will not disappear. Physicians are ill-equipped to give guidance about the personal care requirements in these cases once the period of active treatment is over.

2. With a few exceptions, the medical professions assume that the patient, or another professional, or a non-medical organization will pick up substantial responsibility. But no other system exists in the United States to which adequate referral can be made.

3. A thin network of home nursing and homemaker agencies has developed but their work has, historically, been conditioned by the need to conserve scarce resources, so they have concentrated on short-term care for persons whose conditions will improve. This network, in its limited form, reaches between 2 and 8 percent of the persons who need these services.

4. Public financial incentives have reinforced help for short periods of time only: Medicare limits its home health services to 100 visits in a benefit period. The income of the elderly, who constitute over half of the population at risk, is too limited to permit private purchase of home care over long periods of time.

5. Hospital based home care programs have concentrated upon hospital type services delivered to a patient's home, meaning that they have concentrated upon high cost, highly specialized activities and not upon less costly home and personal care services.

This gap in the American system contrasts sharply with the pattern prevailing in other Western European countries whose health and welfare systems have accepted the inevitability of disability without recovery. In the United Kingdom, for example, a widespread network of home help services has grown up over the past two decades, financed by local government in large part but assisted by national grants-in-aid. In typical low income industrial areas, a public social services department will employ hundreds of full- and part-time home helps—at a ratio of 1 for each 1200 citizens—to perform relatively unskilled household tasks for the elderly and disabled intermittently but for indefinite lengths of time. By contrast, one of the best provided for areas in the United States—eastern Massachusetts—with a comparable population has only one-fourth that number available for relatively brief and limited periods of time.

#### IMPROVED USE OF CURRENT ALLOCATIONS

A network of personal care services can be brought into being in the United States through an improved use of present funds already allocated. These are found in the approximately 2 billion dollars ex-

pended annually for nursing home care, one-fourth to one-half of which is now spent for patients who do not, medically, need such a level of care. A more flexible use of public assistance payments and of the funds now available only for nursing home care through Medicaid would provide a sufficiently secure financial basis to encourage the emergence of personal care organizations of the type needed. Financing needs to be linked to some such basic flow or pipeline of support in order for service providers to invest their own efforts to create the services needed. This is relatively easy to plan for, since \$1.8 billion annually is now spent for nursing home care alone from public funds.<sup>7</sup>

Once in being, this network can also be used by consumers capable of paying for some or all of the services from their private income, thus conserving natural family and friendship resources to contribute to the costs of care for longer periods of time. This personal care system also becomes a major resource for doctors and for hospitals—to reduce the use of high cost facilities when that is not necessary.

More than a secure financial base is required for a successful result. Funds are necessary under conditions which: (1) increase consumer choices; (2) build an incentive for providers to be imaginative in what services they provide; and (3) reward adequate low cost service rather than unnecessary high cost service. The first of these simply permit consumers to remain in their normal surroundings if they wish, and to use to the full those self-helping associations of self, of family and friends which remain to the patient.

The second and third are more radical proposals. Hitherto, service providers are paid (or rewarded) for doing certain legally, clearly specified things, for which compensation is paid. This requires early prediction of what will work in countless varied human situations; and then it is difficult to change the service if the situation changes. A nurse may be needed for two weeks, and only a shopping aide thereafter. But each change requires *advance* approval. There is cumbersome checking by administrators to see that contracted-for services are given as specified without regard to the suitability of those services for the case at hand. The incentive for the provider today is to give as many of those specified services as he can, with only secondary attention to whether or not they "fit" the user's situation.

A payment system is required which expects the provider to first look at the results which are desired, and then encourages imaginative use of whatever decent services will produce that result.

## INDEMNITY OR CAPITATION BASES FOR PAYMENT

Two payment mechanisms could produce these results: payments of cash or indemnity type benefits to consumers under clearly specified conditions of disability; or capitation type payments to providers. Cash payments maximize consumer choice, but are likely to be more costly; a larger number of persons are likely to be covered by any workable eligibility definitions; and professional controls are at a minimum. Capitation payments to providers reduce these limitations and permit more professional and experimental control of a new pro-

<sup>7</sup> "Medical Care Outlays for Three Age Groups: Young, Intermediate, and Aged," *Social Security Bulletin*, vol. 34, No. 5 (May 1971), p. 8, table 3.

gram. However, it is handicapped by the fact that, in our health or welfare programs, there is little precedent for reimbursement based upon defined results or outcomes. Such an approach, while proposed for health services under the so-called health maintenance option, has not hitherto been suggested for social services.

**The capitation approach can most readily be recommended at this time for it can be introduced through a number of existing public programs and does not require any radically new administrative structure to start with. Public welfare agencies, as now organized or as reorganized under any of the proposed reform measures, could apply some of their current funds by contract with existing service providers or could even underwrite new service units of their own.<sup>8</sup>**

This approach could also be used within the present Medical program. It can equally be used as part of the present, or to be enlarged Medicare program. And, with equal ease, it could be adapted to the Permanent and Total Disability sections of the Old Age, Survivors, and Disability Insurance Act.

In such a plan, individuals are identified as entitled to certain assistance because of a condition determined to be present, as is now the case. They would be entitled to certain "personal care" benefits or assistance from an approved provider. The objective of the benefit can be simply stated as provision of maximum alternatives to institutional care for the disabled. The maximum level of payments would have to be sufficient to assure a full range of alternatives, but could still be pitched at slightly less than the average cost of institutional or nursing home care. Providers would be checked or monitored by a quality control check-up by the administering public agency, through means which need to be developed. They would also be subject to the check of consumer satisfaction expressed through transfer to other providers by a voucher system, through appeals mechanisms or through some form of consumer representation in the provider agency.

## ESTIMATED COST OF ALTERNATIVE SOLUTIONS

Projection of costs to a potential user population is hazardous, lacking tested data concerning the cost of service units and about the distribution of required service units in a given population. Crude approximations can be derived from various partial studies.<sup>9</sup>

The following estimates are limited to persons over 65 for whom most extensive data is available concerning severity of disability (Table 3). Homebound persons are assumed to need more visits per week than those "having trouble getting around." The cost *per visit* is estimated since the time required for a visit is unknown. Hourly charges are expected to range from \$2-\$8 per hour, depending upon the skill required. It is assumed that minimum skill staff is required.

<sup>8</sup> Details of this approach have been proposed for the Commonwealth of Massachusetts and are outlined in "Mobilizing Community Resources to Provide Alternatives to Nursing Home Care," reported as part II to this report.

<sup>9</sup> Robert Morris and Elizabeth Harris, "Home Health Services in Massachusetts, 1971: Their Role in Care of the Long-Term Sick," Working Paper Levinson Gerontological Policy Institute, Waltham, Mass. (July, 1971); and Agnes Brewster, "Estimating the Need for and Cost of Personal Care Services."

TABLE 4.—COST ESTIMATES—DISABLED NONINSTITUTIONAL POPULATION OVER 65 YEARS

Category	Potentially eligible		Volume of personal care at home visits required	Cost per visit	Annual cost
	Number				
Homebound.....	625, 000		2 per week	\$7	\$437, 920, 000
With trouble getting around.....	938, 400		1 per week	7	328, 440, 000
Total.....	1, 563, 400				736, 360, 000

As much as \$500,000,000 of this projected sum may be secured from payments now made unnecessarily for institutional care, provided support is given for changing the direction of current programs during a "start-up" year or two.

This estimate is advanced solely to suggest a "ball park" figure. It can be increased by raising the number of visits, the length of visits, the hourly wage, or by increasing the number of persons defined as eligible. Equally, it can be reduced in any of these variables. The most likely reduction could be made in restricting the definition of eligibility to those over 75 years of age (markedly reducing numbers); or to those with more marked disability (i.e., homebound only); or by requiring some cost-sharing by consumers or their families. It is often argued that group care is more economical than home care. This overlooks two facts:

1. The staff/patient ratio ranges from 1 in 2 in extended care facilities to 1 in 4, 6, or 8 in good nursing homes. Home care for the moderately handicapped can be delivered with a ratio of 1 in 4.
2. Institutions cannot make use of residents' residual self-help capacity nor the help of family and friends, so that higher staff ratios result.

## POTENTIAL PROVIDERS OF PERSONAL CARE

The proposed P.C.O.'s can evolve out of several organizations which now exist in a primitive or thinly dispersed form. Visiting Nurses Associations and homemaker services are the best developed. They need only modify their objectives and employment patterns to encompass intermittent but long-sustained care by unskilled as well as by highly skilled workers. Hospital and medically based home care programs could add such a function to their other medical functions. Senior citizen organizations could qualify to sponsor or to administer a P.C.O. as could neighborhood associations of several kinds. The public social service centers contemplated as a part of welfare reform (H.R. 1) could also undertake such responsibilities.

Whatever the auspices, a sponsor would of course need to meet the performance standards fixed by the agency administering the payments from public funds, a protection already tested in many current programs supported by Federal or State funds, and by private insurance and private philanthropy.

## THE NEED FOR FIELD TESTING

It is obvious that several technical administrative aspects need to be further developed, but these cannot adequately be developed in an artificial laboratory. The evidence sufficiently supports such an ap-

proach to warrant field testing in a number of real life situations so that solutions to these technical problems do not remain abstract and theoretical. Such issues include: the more precise definition of populations to be covered; testing of alternate quality control measures; selection of effective entry paths to eligibility; more exact measurement of essential volume and intensity of service patterns; checking manpower alternatives; and measuring cost levels more accurately than can be done under present conditions.

## RELATIONSHIP TO HEALTH MAINTENANCE ORGANIZATIONS

It is conceivable that Health Maintenance Organizations as proposed in current legislation (HMO) could also develop P.C.O.'s (Personal Care Organizations) as part of their offerings. However, the H.M.O.'s are concerned mainly with the proper business of physicians—the diagnosis, treatment, and cure of illness and the maintenance of health. Their concern is unlikely, on past performance, to extend to a variety of homely personal care tasks which are necessary in those cases where medical treatment has failed to produce the desired recovery. In such cases, the long-term need is for a mix of mainly social and personal and home care services, with occasional medical ratification of disability. It would be better to consider Personal Care Options or Personal Care Organizations as a parallel system upon which health systems can draw as needed.

Medical groups or H.M.O.'s could provide such a parallel system under their general sponsorship if they are prepared to recognize the differences between medical and personal care and are ready to maximize use of less costly alternatives. It is more likely that P.C.O.'s will be developed by nursing organizations, social agencies, public agencies, and even by proprietary agencies. Through such an open approach the most effective sponsorship will be established by competition over time rather than being arbitrarily imposed on the basis of inadequate evidence.

## MANPOWER CONSIDERATIONS

The manpower aspects of the subject are especially important. In a period of full employment, requisite personnel can be secured only by transfer from other tasks. Fortunately, or unfortunately, the present economic situation is one of ambiguity about manpower needs in basic industry as seen through the continuing level of unemployment, especially for those with little skill. The proposed P.C.O. system requires many levels of skill or experience, but its base manpower requires limited specialization and limited skill. It therefore offers special advantages and opportunities for unskilled workers in the labor force. Employment can be generated for persons of all ages and at all levels of education.

The greatest risk in the personnel picture lies in the chance that these tasks will be considered so menial that no one can be induced to accept such work. While this risk is real, the situation is not to be confused with the insecure, menial, and often degrading work of an hourly maid or hourly cleaning man or woman. The care of the dis-

abled, after their medical care period has elapsed, calls for a system comparable to the hospital or the nursing home system—formal organizations which can guarantee regular work hours and work weeks throughout the year; regular pay and competitive fringe benefits; and a kind of dignified quasi-professional occupation.

Such a system has the further advantage of offering career advancement possibilities, since it will need to deliver work at varying levels of skill at home, ranging from the attendant or mobility aide to the supervising nurse; from the intermittent shopping aide to the semi-skilled and skilled home repair man; from the field worker to the administrator.

Above all, the manpower requirements are maximally flexible, calling for part-time as well as full-time workers so that men and women with varying family commitments can be drawn in to work for varying lengths of time in any week.

## RELATIONSHIP OF P.C.O. TO OTHER ORGANIZATIONS

The question is usually raised about the appropriate relationship between various service providers—between home care and rehabilitation and medicine and income maintenance. It would be convenient if a single organization could be given responsibility for all the manifold requirements which human beings may have, but such a totalitarian approach escapes our technical capacity in a complex society as well as being repugnant to our ethical ideas. It would be equally convenient if simple cash payments to individuals could assure the meeting of all needs, but this approach would seem to overstrain our present financial resources.

A more feasible approach seems to be filling the one gap which obstructs the reform of both our health and our welfare systems, namely, the underwriting of a network of personal care organizations, based upon existing elementary forms of such agencies as is found in home nursing and homemaker services. This network would provide a missing resource upon which both health and welfare agencies now depend, but which they lack. The work of these P.C.O.'s would have to be linked to medical care agencies, when necessary, and to rehabilitation agencies when they are authorized to rehabilitate the disabled for self-care as well as for work, but this linkage is relatively easy when the necessary functional parts (treatment, rehabilitation, and care) are present, a situation which does not now prevail.

Most of the data on which these views are based are drawn from urban experiences in the United States and Western Europe. Obviously, similar needs are found in rural and thinly populated areas. There is insufficient data to predict with any confidence that this approach will serve rural areas as well as it will serve urban and suburban ones. The major differences are that presumed lack of agencies in rural areas upon which P.C.O.'s can be built, much the same situation as confronts plans to extend MHO's to rural areas where doctors are in grossly short supply. However, rural areas frequently retain more rich friendship and family associations which can be drawn upon; and the P.C.O. concept as outlined above may well prove viable in rural as in urban areas.



## PART TWO

### MOBILIZING COMMUNITY RESOURCES TO PROVIDE ALTERNATIVES TO NURSING HOME CARE

A Model Developed by the Levinson Gerontological Policy Institute,  
Waltham, Massachusetts, October 1971

#### INTRODUCTION

##### NECESSITY FOR ALTERNATIVES TO INSTITUTIONAL LIVING\*

Studies of the characteristics and needs of the nursing home population in Massachusetts and elsewhere in the country indicate that 15-20 percent of such persons are absolutely misplaced in the institutional environment.<sup>1</sup> Their residence in such settings is directly associated with the absence of intermittent services and flexibly applied home care supports to daily living in the neighborhoods from which they came.<sup>2</sup>

One out of six Massachusetts elderly is a recipient of public welfare. Thirty thousand of these 103,000 are in licensed nursing homes, chronic hospitals, and public medical facilities as recipients of Medicaid. On the basis of systematic disability evaluations of nursing home patients, the Massachusetts Department of Public Health has disclosed that only 37 percent of the residents require full-time, skilled nursing care. Fourteen percent needed no institutional care whatsoever for medical reasons: another 26 percent required minimal "supervised living;" and 23 percent needed limited or periodic nursing care that might, for some, well be provided on a home visit basis. (Figure 1).

A complementary study of the use and misuse of nursing homes in the Buffalo, New York area indicated that 27 percent of that institutionalized population did not need this type of care. Most significantly, of nursing home residents in the 65-74 age group, 41 percent of former city residents were inappropriately placed as opposed to only 20 percent of those whose former homes had been out of city, or rural.<sup>3</sup>

**The national implications of this research are that the absence of supportive persons and services to the elderly and disabled living especially within highly urban environments forces decisions to institutionalize on doctors, social workers, families, and friends.**

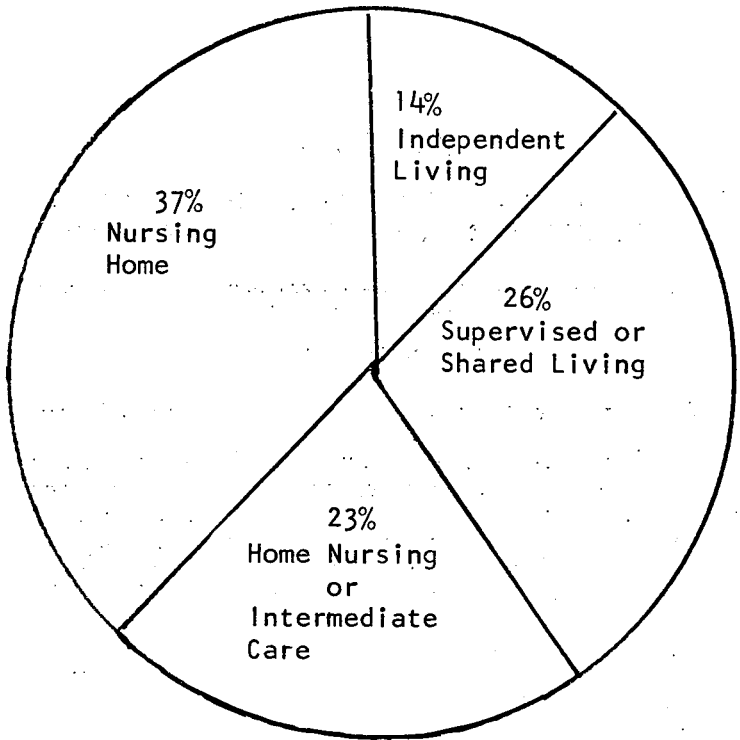
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\*Developed by institutional staff: Dr. Francis Caro, Dr. Sandra Howell, Mrs. Helen Kistin, assisted by Dr. Ruth Berger, Dr. Susan Pettiss, and Miss Elizabeth Harris.

<sup>1</sup>Pettigrew, A., and D. Kinlock, *Background Information for Long-Term Care Facilities Proposal*. Prepared for internal circulation, Massachusetts Department of Public Health, 1971.

<sup>2</sup>Trager, B., "Home Health Services and Health Insurance," *Medical Care*, vol. IX, No. 1 (January-February 1971), pp. 89-98.

<sup>3</sup>Davis, J. W. and M. J. Gibbs, "An Areawide Examination of Nursing Home Use, Misuse, and Nonuse," *American Journal of Public Health*, 61 (1971), pp. 1146-1155.



**FIGURE 1**

**Estimated Appropriate Placement of  
Current Institutionalized Elderly \***

\* Based upon data derived from Massachusetts Department of Public Health studies, 1969.

The persons now in institutions represent only a small fraction of the seriously disabled population in Massachusetts and in the United States. From the larger base is drawn the continuously growing institutional population. Inadequate efforts to deal with disability while individuals still live in their own homes represent a basic failure in prevention. This does not mean that no institutional care is ever needed—it often is—but lack of attention during the pre-institutional phase leads to an over-use or abuse of institutions, and results in a tendency to use the most costly, but not necessarily the most beneficial forms of care. Thus, the total population of the disabled—the source of difficulty—requires as much attention as the number currently in long-term or nursing institutions.

In addition to the currently institutionalized population, it is estimated that at least 16 percent (or 2.9 million) of the 19 million non-institutionalized elderly in the United States are unable to carry out

their daily activities as a result of chronic disease and disability.<sup>4</sup> Provision of organized community services and personal helpers for these senior citizens, in addition to the nearly 3 million younger disabled, is whimsical and meagre. Translated into Massachusetts figures, this means at least 100,000 disabled elderly and at least 75,000 younger persons living at home but unable to carry on their daily activities. Their management at home is dependent upon the durability and accessibility of helping relatives, neighbors, and friends. Little assistance is provided to prevent the ultimate bankruptcy of these natural supports.

## I. LIMITATIONS OF PARTIAL SOLUTIONS

### A. MEDICARE AND MEDICAID

It is becoming apparent that disproportional amounts of Medicare and Medicaid money is being spent to maintain elderly and disabled in institutions. The allocation of public monies toward institutional rather than neighborhood solutions to the plight of the elderly and disabled becomes apparent by contrasting the 32 percent of vendor payments which go to nursing homes with the 0.3 percent provided to Home Health Services under Title XIX alone.<sup>5</sup> Public expenditure to nursing homes, nationally, amounted to \$1.8 billion in 1970. In Massachusetts nearly \$100 million per year is being spent for nursing home care by the Department of Public Welfare. An increase of 137 percent in Medicaid dollars to nursing homes was reported for the whole country from 1965-1968,<sup>6</sup> and the supposed policy of increasing choice, by states with major welfare rolls, turns out to be the transfer of elderly acute and chronic hospital patients to nursing homes rather than to attempt alternative community placement.

It is widely reported that Medicare's attempts to provide a national network of Home Health Agencies has been relatively ineffective as an alternative to institutionalization. The excessively restrictive service benefits and the limitations on duration of stay for those elderly who qualify for home health services severely limits the usefulness of this portion of the program. Program and professional responsibility is for the episode of illness, rather than for the long-term support of the elderly individual in his home environment.

What has not been appropriately recognized is that this long-term support predominantly requires social-maintenance rather than specifically medical types of services. Home Health Aide personnel currently employed by Medicare-certified agencies are legislatively limited to medical care related tasks and are, therefore, not able to be responsive to the continuing multiple needs of the individual or his family unit.

<sup>4</sup> National Center for Health Statistics "Chronic Conditions and Activity Limitations," Vital and Health Statistics, Public Health Service Publication No. 1000, Series, 10, No. 17 (1965).

<sup>5</sup> U.S. Department of Health, Education, and Welfare. Social and Rehabilitation Service. *Medicaid, and Other Medical Care Financed from Public Assistance Funds*. Selected Statistics, 1951-1969, NCSS Report B-6 (1951-1969). Washington, D.C.: Government Printing Office, 1970.

<sup>6</sup> U.S. Department of Health, Education, and Welfare. Social and Rehabilitation Service. *Number of Recipients and Amounts of Payments Under Medicaid, 1968*, NCSS Report B-4 (CY68).

## B. HOUSING

Public housing, nationally, had provided approximately 140,000 residential units especially for the elderly at the beginning of 1970.<sup>7</sup> It has become apparent, however, that this housing is for the "well elderly."<sup>8</sup> While housing authorities have not necessarily discouraged on-site services and have, in some cases, provided space, no active planning, coordinating or sustaining role has been assumed by housing authorities for the provision of needed services, personnel or facilities within their publicly funded shells.

**Modern housing has typically been built, in Massachusetts and other states, which, in its design, severely limits the development of personal care alternatives within a living unit. Efficiency apartments, which dominate these structures, make mutual help living arrangements between related and/or non-related adults virtually impossible. Further, the absence of personal care services, available in the neighborhood on an intermittent basis, exacerbates the difficult living conditions of the vast majority of aged who do not reside in public housing.**

## C. EXISTING COMMUNITY AGENCIES

Public and private health and welfare agencies which operate within local areas respond to individual crises with specific limitations on the services they can afford to provide. They are aware but ill-equipped to deal with the ongoing human needs which the elderly and disabled sustain in choosing to remain in their own homes. The historically defined roles of existing agencies do not allow for flexibility. Invited intrusions in life problems of a known neighborhood population of elderly and disabled is atypical and antithetical to established referral mechanisms. Agencies usually wait for the elderly to come to them, to avoid intrusion into their privacy; but the elderly are usually reluctant to approach an unknown social agency first.

## D. COORDINATION OF SERVICES

It has long been assumed that coordination of services will produce a more efficient system, relying on existing programs without requiring the creation of new ones. This approach assumes that the requisite programs do, in fact, exist to lend themselves to coordination. The foregoing analysis of Medicare, housing, and voluntary agencies has already outlined some of the flaws in this assumption. The fallacy is reinforced by a recent survey of homemaker and accredited home health agencies available in a survey month in eastern Massachusetts.<sup>9</sup>

**Forty-seven major home health and homemaker agencies were identified in public listing. On inspection, only fourteen of this number actually employ and provide home aides; the remainder**

<sup>7</sup> Robbins, I. S., "Background Paper on Housing for the 1971 White House Conference on Aging," chapter IV, p. 9 (1970).

<sup>8</sup> Lawton, M. Powell. Statement on Housing, Institutions, and Older People's Relationship to Their Environment. Prepared for the National Goals Research Staff, November 1969, pp. 19-20.

<sup>9</sup> Morris, Robert and Elizabeth Harris, "Home Health Services in Massachusetts, 1971: Their Role in Care of the Long-Term Sick," Working Paper, Levinson Gerontological Policy Institute, Brandeis University (July 1971).

**purchase such services through contract with these working fourteen. In a survey month, the total volume of delivered home health aides and home helps reached only 2.5 percent of the persons estimated to be in serious need of these services. A similar study in New York found about 10 percent actually served.**

This gap between supply and demand is even more pronounced in less populous and in rural areas. Coordination can contribute little to the solution of this problem until this gap is closed by an increase in the supply of alternative programs.

## **II. A PROPOSED PERSONAL CARE SERVICE SYSTEM: THE MASSACHUSETTS MODEL**

The absence of adequate existing alternatives to nursing home and institutional care has led the Massachusetts Department of Public Welfare, burdened by enormous vendor payments to institutions, to consider the development of a Personal Care Service System. A model of such a system, testable for the Department in a clearly defined community and for a designated population, has been proposed\* by The Levinson Gerontological Policy Institute, Brandeis University.

**Based upon a careful analysis of needs and resources, it appears to the Institute and the State Department of Public Welfare that public money could be more advantageously spent in the provision of maintenance and care services for the elderly and disabled in non-institutional neighborhood settings.**

Underwriting a personal care service system promises a reduction in the inappropriate use of both long-term care and acute care institutions, especially if it is made readily available to all who are found in need of such services. With the State Department of Public Welfare functioning in a planning and contracting capacity, a contract would be made with at least one local agency to provide a range of core services essential to maintain the disabled and the partially disabled elderly in their homes, complementing the natural helping relationships which already exist. Such a local Personal Care Organization (P.C.O.) would assume responsibility for the population at risk in its "catchment area," focusing, initially, upon the recipients of Old Age Assistance and Aid to Blind & Disabled. For each case deemed eligible, the Department of Welfare would reimburse the P.C.O. a flat sum each month in return for which the P.C.O. assumes full responsibility for providing or developing alternatives to institutional care wherever that seems desirable.

### **A. NATURE OF NEEDED SERVICES**

Practitioners and researchers in gerontology and long-term care concur that the most needed services to the aged and disabled at home are intermittent home helpers. The Levinson Gerontological Policy Institute surveyed the current utilization of available "homemaker-home health aide" personnel in the State of Massachusetts. Based upon a reasonably conservative estimate of the elderly population at risk in the state (i.e., that proportion unable to perform usual daily tasks),

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\*See appendix, p. 25, for late word on status of proposal.

only one in forty elderly in probable need of such services were receiving personal care assistance.<sup>10</sup>

The types of maintenance and support needs that could be met by a local Personal Care Organization include assistance with food shopping and meal preparation; mobility assistance within and outside of the home; transportation to health services or delivery of prescription drugs; assistance with laundry or home maintenance; dressing and personal care; guidance in financial, legal and relocation matters; counselling of client and family on available health and social services (including completion of written forms); and telephone availability in crisis. A recent Columbia University study of patients on home health services indicated that 85 percent of those over the age of 55 needed help to shop or cook.<sup>11</sup> As is apparent from this listing, a Personal Care Organization would consist, dominantly, of non-professionals supervised by appropriate professional staff, but offering a very diverse and flexibility delivered range of homely and personal tasks.

The location of better residential accommodation and providing minor structural improvement and adaptation of existing housing for the elderly and disabled population would be another package of tasks for a Personal Care Organization. Such service activities have been fragmentary and unsystematic to date, even in the Model Cities programs, although they could easily tap into the existing skills of the retired and the youth.

Current programs tend to emphasize the more complex and costly services, since they have been dependent upon physical, that is medical perceptions. A comprehensive personal care service can be established which will give proper weight to simpler home care tasks which are social and not medical in nature. Appropriate incentives can be introduced for the Personal Care Organization to use the simpler and more homely services wherever these will serve the needs of the disabled person.

## B. ESTIMATED COSTS PER CASE

Current assessments of the cost of providing a corps of personal care service personnel are based upon experiences in Massachusetts and elsewhere with "homemaker-health aide" categories. An aggregate cost for the state is dependent upon variables which have yet to be explored in the proposed pilot service. These include: the distribution of services by complexity and intensity or volume; the average per capita cost per day; case turnover and average case load; and cost of administration, supervision and overhead to provide an on-going staff of full-time and part-time personnel ready to serve a known population.

Massachusetts' local experience with "homemaker-home health aides" indicates the average current client receives ten hours per week of service at a per client cost of \$3.00-\$4.00 per hour, inclusive of administration. This range tends to be supported in other, albeit service-

<sup>10</sup> This statistic is based upon a survey conducted by Miss Elizabeth Harris and disability estimates made by Dr. Francis Caro, both of the Levin Gerontological Policy Institute staff.

<sup>11</sup> Van Dyke, F. and V. Brown, "Home Health Services Study," Columbia University School of Public Health and Administrative Medicine. Unpublished report submitted to Associated Hospital Service of New York, Health Research Council of the City of New York, and Social Security Administration, U.S. Department of Health, Education, and Welfare (April, 1971).

limited, programs around the country. A complete personal care system is necessary to find out whether this is a realistic average; or whether many can be helped with less time, to offset the needs of a few for much more service.

### C. SOURCE OF FINANCIAL SUPPORT

Appraisal of existing budgetary allocations by the Massachusetts Departments of Public Welfare and Public Health indicates the potential availability of adequate funds to maintain an on-going, if initially selective, program. However, the earmarked character of much public money and the statutory limitations on alternate use of these moneys is, at this point, a substantial stumbling block in the development of a deliverable personal care service system. The capacity of State agencies to influence Federal and State legislatures and, administratively, to effect transfer of costs and savings between hitherto separately funded programs is a continuing problem.

**Despite these obstructions, a significant part of current expenditures for institutional care, now paid by Medicaid and by assistance funds, can be shifted to support a part of the present welfare population in their own homes. Such a shift will provide the stable financial foundation for a personal care system.**

In Massachusetts, direct monthly payments to "skilled" nursing home vendors amounted to \$395 per patient in fiscal 1970. The average annual cost per case ranged from \$3850 in nursing homes to \$4900 in chronic hospitals; a substantial portion of this is attributable to overhead, plant maintenance and non-professional personal care services. The estimated average monthly cost for maintaining a welfare client in a skilled nursing home is \$512 per month. By contrast, the maximum basic budget available to Old Age Assistance recipients is approximately \$230 per month in Massachusetts. The margin of \$280 between nursing home and basic relief costs should be more than sufficient to support the organization of an improved range of services needed to maintain welfare recipients in non-institutional community settings.

### D. ESTIMATES OF POPULATION TO BE COVERED

Firm estimates of the population which might be covered by the proposed program are difficult to establish with present data, since the point of eligibility can be varied by legislative and administrative policy. However, usable working estimates can be derived from studies already cited. One target population could be the 40 percent of those 30,000 Medicaid recipients now in nursing homes, chronic hospitals, and public medical facilities, who, in the words of the Massachusetts Department of Public Health survey, either need no institutional care for medical reasons or who require minimal supervised living—a total of 12,000 persons in a given month. Some of these are too demoralized from long institutional life, or are too confused for a normal residence, having lost all family and friendship supports long ago; but the proportion who are thus limited is unknown at this writing. Ten thousand represents a more realistic minimum figure.

At the next higher estimate level, one could add perhaps another 6,000 new admissions or applicants for admission to nursing homes each year, who do not require such care for medical reasons but who will be admitted if present programs are not altered. These cases represent the best opportunity for preventive intervention in the institutionalizing cycle.

At the highest estimate level, one would have to add all those elderly who have severe functional handicaps due to physical disability—perhaps 100,000 aged in Massachusetts. However, many of these have substantial family supports, or require only such minimal help as can be given by neighbors. In projecting a workable program, this population must be studied in the context of a working personal care-home care system to ascertain how many require and would use a P.C.O. and how many could afford to pay for its services out of personal or family income.

#### E. CRITERIA FOR SELECTION OF CLIENT POPULATION

Concern for the problem of defining the appropriate recipient for personal care services suggests the need to review criteria used in establishing disability by such programs as the Veterans Administration. That agency's experience with an "Aid and Attendants" program for homebound veterans sets a precedent for the Massachusetts proposal and may provide organizational and administrative experience. Assessment of functional capacity with respect to activities of daily living and behavior that is instrumental to health and social maintenance is particularly complicated in the case of the elderly. Many have ongoing and multiple chronic diseases and disabilities which only partially or periodically impair function. A personal care service must be sufficiently flexible to take on a case at first contact even though the service requirements may change later, since the elderly are particularly loath to deal with red tape. Equally, a procedure needs to be devised for periodic review of needs for addition or elimination of services. Consideration needs to be given both to the types of decisions and the locus of the decisionmaking in the proposed Personal Care Organization.

An openness to sources of referral and provision of services implies a new approach to administrative controls, one which concentrates on desired results but which is not overly rigid as to details. Such questions as: who decides on the range and amount of services to be provided, frequency of review, and the nature of reviewing mechanisms need to be addressed.

At the start, medical personnel, especially those in hospitals and in health maintenance organizations, will play a key part in deciding what patients could remain in or could be discharged to their own homes. The Personal Care Organization will have its own criteria as to the range of difficulty it can handle. The Department of Public Welfare staff must decide that the referred case is eligible for public support (i.e., is an assistance eligible case).

From this point on, the Personal Care Organization would be free to do whatever is necessary, in its judgment, to help the patient/client maintain himself in his home for as long as he wished. Full use of



course, would have to be made, as it is today, of medical and rehabilitation services, but the Personal Care Organization would work, within the money assigned to each referred case, trying whatever seems necessary and not restricted by arbitrary limitations on what specific services will or will not be paid for.

A disability rating scheme is thought to be feasible for the population here at risk. Early considerations of the distribution of disability among the aging and disabled suggests that the largest proportion of potential clients would generally be only slightly disabled. Finer selection criteria, which incorporate environmental as well as personal-physical limitations to function, will evolve as the Department of Public Welfare works with the Personal Care Organization and with health professionals. For example, a chronically ill client whose domicile is over three miles from the nearest store might be considered to have an environmental disability qualifying him for periodic transport or delivery services. Similarly, a hemiplegic or arthritic client whose apartment is on a third floor could qualify for different and perhaps more frequent ambulation assistance than a comparably afflicted client whose residence has immediate access to the street.

This proposal is designed to complement the appropriate role of nursing homes, access to which by the very disabled will be enhanced. The focus is on appropriate use of institutions and the creation of real choice for the elderly and the disabled as to where they will live.

#### F. PROJECTED PROGRAM COSTS

Program cost estimates, as distinguished from case costs, can only be roughly estimated for reasons noted above—variability in eligibility criteria, uncertainty about variations in volume of services which can accomplish chosen results, etc.

If one accepts recent Massachusetts experience, the following estimates can be made, assuming that per case costs of home health agencies are reliable and that estimates of the nursing home population who can live in their own homes are accurate.

**Estimate Level 1:** For 10,000 persons now in nursing homes who are presumed capable of living elsewhere; \$19,200,000.00 per year. Against this can be offset an estimated \$40,000,000 probably spent in 1971 by Massachusetts for nursing home care for this population.

**Estimate Level 2:** Add the 6,000 persons reasonably likely to seek admission to institutions for conditions no more severe than those noted in Estimate 1. (Some of these, of course, will replace persons who die or who are discharged from nursing institutions; while others represent new additions to the nursing home population): \$11,520,000 plus \$19,200,000 listed for Estimate 1—a total of \$30,720,000. Note that this figure is still over nine million dollars below the estimated expenditures for the unnecessarily institutionalized in 1971.

These calculations must be seen as indicative only of the potential in the new program. The costs and their distribution among the under 65 as well as among the over 65 who are disabled need to be firmed

up in an operating program, as must the average case costs. However, these estimates are believed to be conservative, and permit true alternatives to develop within the limits of current expenditures and appropriations.

#### G. AGENCY LINKAGES

Implicit in the proposal for a Personal Care Organization system is the requirement that it provide the linkages to services (e.g., medical care) which are not included in its own portfolio. Perhaps the greatest inadequacy of the present multiple agency system in the United States is the inability or unwillingness of a single agency to act as ombudsman for the multiple needs of its clients or patients. A form of capitation system is here being proposed which would hold the Personal Care Organization accountable for a specified population to help them remain at home if they chose to.

This organization, once it accepts a referred case, is held accountable, by its contract with the Department of Public Welfare, for taking *whatever action is called for* to keep its client well at home. Such actions include: flexible use of its own staff, which are paid for under the contract; procuring medical or rehabilitation services from other agencies; etc. The sum paid the Personal Care Organization is expected to be adequate to cover a variety of such tasks.

#### H. ALTERNATIVES IN ADMINISTRATION

The Massachusetts pilot program for a Personal Care Organization is to be administered through the Secretary of Human Services and his State Department of Public Welfare, since it controls a major allocation of funds for the population under consideration. It is believed to be essential that State level planning and control be required to assure maintenance of equal standards and the guarantee of ongoing support to local communities. Once established, this program will be available to other than relief recipients: those with modest incomes able to pay part or full cost for these services.

The choice of the appropriate agency to transform itself into a Personal Care Organization is a matter of community history and style. In one locale, a Visiting Nurse Association may, with guidelines and consultation, be quite ready, able, and acceptable to develop and adapt its program. In another locale, a community action group or senior citizens organization may already be providing the nuclear services needed for its population of elderly and disabled residents. A family service agency, a health maintenance organization, even a proprietary organization (such as Homemakers, Inc., of The Upjohn Company) could equally well develop into a P.C.O. In any event, room should be made for a wider policy voice from senior citizen organizations. They can provide advisory resources, members for policy positions, and can act as ombudsmen.

#### I. MANPOWER REQUIREMENTS AND IMPLICATIONS

Whatever the service agency of choice, a new flexibility with regard to personnel selection and use is imperative for a program such as is proposed. Just because the areas of greatest service need and greatest underemployment coincide in the most urban settings, new opportuni-

ties for full- and part-time employment could well be one of the social and economic by-products of a Personal Care system for the elderly and disabled. An urban area with one to three million residents could well generate several hundred, and even several thousand part-time or full-time jobs. These jobs range from those requiring little skill and limited special training, to jobs which require certain organizational, administrative, or technical skills. This range provides for career growth and personal improvement for those seeking it. It also can assure stable employment for those who supplement family income by part- or full-time work.

These jobs differ from the conventional maid service—daily housecleaning performed by an hourly or daily maid. The jobs are related to a definable physical condition; their content is determined by professional personnel—medical and supervisory; performance is subject to quality control by supervising staff and by opportunity for consumer opinion expression. Above all, these positions carry with them the dignity and compensation of regularized employment: a respected status, regular pay, regular hours of work, fringe benefits of insurance, vacation, etc.

Employment of the elderly themselves, application of construction skills by youth, and the reimbursement of present occasional helpers who are neighbors, friends and relatives would provide a new dignity to human caretaking tasks.

### III. ROLE OF FEDERAL GOVERNMENT

The Federal government is already embarked on a major overhauling of provisions for medical care and for welfare services, some of which are now financed by state or local governments, some by private individuals, and the balance by Federal grants. In the search for a better model for both health and welfare, the requirements of the disabled occupy a strategic position.

The role of the Federal government, in taking advantage of this strategic position, is a blend of policy guidance, financial support, and research to fill in vital knowledge gaps. It can clearly articulate a policy of choice in alternatives to institutional care; it can provide incentives which will help a personal care system come into being; it can support experiments which will test our alternate populations which are to be covered, alternate service modules, and alternate control systems.

In the development of models for a Personal Care service system, it will be necessary to commit specific funds for demonstration and evaluation purposes. Equally vital is a relaxation of constraints over the use of funds from hitherto rigidly separated programs. For example, a more free use can be made of funds presently allocated to Medicaid and Old Age Assistance, but only if administrative staff is free to use—and to account for—both sets of funds on behalf of alternate living arrangements for the sick elderly. Under present accounting procedures, obstacles exist which interfere with a free choice to move sick persons into or out of nursing homes.

Given the economic and social implications of a system which could minimize both the short and long-term use of institutions,

**the Federal government, perhaps via the Social Security Administration or the Social and Rehabilitation Service, should provide the monetary incentives to States, both to design personal care systems and to support evaluation of such programs. A particular need will be for start-up money to allow for States and localities to shift present dollar allocations, retrain requisite personnel and reorder past program emphasis.**

Specific areas of programming which will need to be evaluated in connection with a personal care system have to do with: (a) the staging of inclusions of population segments at risk or of expanding feasible and needed services; (b) alternate methods of linking existing programs (e.g., rehabilitation, medical services, and housing); (c) substitutions of personnel and services which reduce program costs (e.g., provision of housing repair and relocation service, family and neighborhood care-training programs, etc.); (d) alternative reallocations of local and State funds to maximize service flexibility; and (e) mechanisms for control of utilization and cost.

### SUMMARY

A Personal Care Service system is proposed for the purpose of maximizing residential choice for the elderly and disabled. The objectives of such a service would be to decrease inappropriate institutionalization and to optimize the capacity of the elderly and disabled to function in the housing and neighborhoods of their preference.

The mechanisms by which such a service would be delivered is seen to be a single, localized organization, accountable to a state-level agency and responsible for a specifiable population within an explicit geographic area.

Services to be dispensed would be defined in terms of the intermittent functional needs of residents and incentives would be provided to encourage flexibility of methods and innovative solutions. Maximum use of existing natural helping relationships and services within a community would be encouraged.

## APPENDIX

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### PERSONAL CARE SERVICE SYSTEM PROPOSAL

COMMONWEALTH OF MASSACHUSETTS,  
DEPARTMENT OF PUBLIC WELFARE,  
*Boston, Mass., September 10, 1971.*

DR. ROBERT MORRIS,  
*Levinson Gerontological Policy Institute,  
Brandeis University, Waltham, Mass.*

DEAR DR. MORRIS: This is to follow up on our recent discussions in respect to the proposal "An alternative to institutional care for the elderly and disabled".

The Department intends to follow through and implement this proposal to the extent feasible. We have mutually agreed that the Worcester Regional Office of the Department of Public Welfare would be an appropriate locus. In the next few weeks Dr. Caro plans to visit Worcester to assess next steps. The appropriate person to contact there is Mr. Gerald F. Nugent, telephone 791-6208.

Sincerely,

JAMES J. CALLAHAN, JR., Ph. D.,  
*Assistant Commissioner for Medical Assistance.*

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COMMONWEALTH OF MASSACHUSETTS,  
REGIONAL OFFICE, DEPARTMENT OF PUBLIC WELFARE,  
*Worcester, Mass., October 7, 1971.*

DR. ROBERT MORRIS, Ph. D.,  
*Levinson Gerontological Policy Institute, Florence Heller Graduate  
School for Advanced Studies in Social Welfare, Brandeis University,  
Waltham, Mass.*

DEAR DR. MORRIS: I have reviewed your proposal regarding alternatives to institutional care for elderly and disabled persons. I feel that this is an exciting project and one that would benefit the Department of Public Welfare as well as the older and disabled citizens.

I feel that Worcester would make an excellent demonstration city and as you probably realize, 16 or 17% of our population falls into the over age 65 category and our Welfare Service Office has at least 1,200 nursing home cases.

It is my opinion that such a demonstration project would not only save the Commonwealth money but would also release the backlog we now have waiting for nursing home care.

Very truly yours,

GERALD F. NUGENT, ACSW,  
*Regional Administrator*

AGE CENTER OF WORCESTER AREAS, INC.,  
Worcester, Mass., October 8, 1971.

Dr. JAMES CALLAHAN,  
*Assistant Commissioner, Massachusetts Department of Public Wel-  
fare, Boston, Mass.*

DEAR DR. CALLAHAN: A few days ago Dr. Robert Morris and Dr. Francis C. Caro of Brandeis University explored with me our interest in the demonstration of a "personal care" program. I understand that the core purpose of this would be to provide alternatives to institutional care for elderly patients receiving Medicaid.

I wish it to be noted, as a matter of record, that this proposal is in keeping with the objectives of the Age Center— "to explore and test new techniques and methods for meeting the needs of the elderly". Also, our Board and Staff are confident that under the guidance of the Heller School faculty at Brandeis, we would have the capability to initiate and administer this type of service.

We are looking forward to its early inception.

Sincerely,

SOL S. BOSKIND, ACSW,  
*Executive Director.*

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