[COMMITTEE PRINT]

94TH CONGRESS
2d Session
SENATE

# NURSING HOME CARE IN THE UNITED STATES: FAILURE IN PUBLIC POLICY

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## Supporting Paper No. 7

## THE ROLE OF NURSING HOMES IN CARING FOR DISCHARGED MENTAL PATIENTS (AND THE BIRTH OF A FOR-PROFIT BOARDING HOME INDUSTRY)

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PREPARED BY THE

SUBCOMMITTEE ON LONG-TERM CARE

OF THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

MARCH 1976

Printed for the use of the Special Committee on Aging

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## PREFACE

WASHINGTON, D.C., *November 19, 1974.*

Federal support of long-term care for the elderly has, within a decade, climbed from millions to billion of dollars.

What is the Nation receiving for this money?

This report explores that, and related questions.

It concludes that public policy has failed to produce satisfactory institutional care—or alternatives—for chronically ill older Americans.

Furthermore, this document—and other documents to follow—declares that today's entire population of the elderly, *and their offspring,* suffer severe emotional damage because of dread and despair associated with nursing home care in the United States today.

This policy, or lack thereof, may not be solely responsible for producing such anxiety. Deep-rooted attitudes toward aging and death also play major roles.

But the actions of the Congress and of States, as expressed through the Medicare and Medicaid programs, have in many ways intensified old problems and have created new ones.

Efforts have been made to deal with the most severe of those problems. Laws have been passed; national commitments have been made; declarations of high purpose have been uttered at national conferences and by representatives of the nursing home industry.

*But for all of that, long-term care for older Americans stands today as the most troubled, and troublesome, component of our entire health care system.*

It is costly and growing costlier.

It is increasing in numbers, already providing more beds than there are beds in general hospitals.

And there is every reason to believe that many more beds will be needed because the population of old persons in this Nation continues to grow faster than any other age group.

Nursing home care is associated with scandal and abuse, even though the best of its leaders have helped develop vitally needed new methods of care and concern for the elderly, and even though—day in and day out—underpaid, but compassionate, aides in many homes attempt to provide a touch of humanity and tender care to patients who, though mute or confused and helpless, nevertheless feel and appreciate kindness and skill.

This industry, which has grown very rapidly in just a few decades—and most markedly since 1965, when Medicare and Medicaid were enacted—could now take one of three courses:

It could continue to grow as it has in the past, spurred on by sheer need, but marred by scandal, negativism, and murkiness about its fundamental mission.

It could be mandated to transform itself from a predominantly proprietary industry into a nonprofit system, or into one which takes on the attributes of a quasi-public utility.

Or it could—with the informed help of Government and the general public—move to overcome present difficulties, to improve standards of performance, and to fit itself more successfully into a comprehensive health care system in which institutionalization is kept to essential minimums.

Whatever course is taken, it is certain that the demand for improvement will become more and more insistent.

Within the Congress, that demand has been clearly expressed in recent years. But often congressional enactments have been thwarted by reluctant administration, or simply have been ignored. Now, facing the prospect of early action upon a national health program of all age groups, the Congress must certainly consider long-term care a major part of the total package. Wisely used, the momentum for a total health care package could be used to insure better nursing home care.

Within the administration, there has been drift and unresponsiveness to congressional mandate since 1965. There are signs, however, that rising costs and rising public concern have aroused certain members of the executive branch to see the need for long-term care reform more clearly than before. Their actions and initiatives are welcome, but it is essential that the Department of Health, Education, and Welfare take far more effective, well-paced action than it has thus far.

Everywhere, the demand for reform is intensifying. People know that a nursing home could be in everyone's future.

They ask why placement in such a home should be the occasion for despair and desperation, when it should be simply a sensible accommodation to need.

The Subcommittee on Long-Term Care of the Senate Special Committee on Aging continually has asked the same question.

Care for older persons in need of long-term attention should be one of the most tender and effective services a society can offer to its people. It will be needed more and more as the number of elders increases and as the number of very old among them rises even faster.

What is needed now? As already indicated, the forthcoming debate over a national health program will offer opportunity for building good long-term care into a comprehensive program for all Americans.

But the issues related to the care of the chronically ill are far from simple. Tangled and sometimes obscure, technical questions related to such matters as reimbursement, establishment of standards, enforcement, and recordkeeping, often attract the attention of policymakers, to the exclusion of other questions, such as:

Could nursing homes be avoided for some, if other services were available?

What assurance is there that the right number of nursing homes are being built where they are most needed?

What measures can Government take to encourage providers themselves to take action to improve the quality of nursing home care?

What can be done to encourage citizen action and patient advocacy at the local level?

Such questions intrude even when the best of care is given. In other settings, however, scandal and calamity enter the picture, and dark new questions emerge.

The Subcommittee, in this report and succeeding Supporting Papers, recognizes the importance of the nursing home industry, and it pledges every effort to continue communication with representatives of the industry and with members of the executive branch.

For these reasons, the Subcommittee has devised an unusual format: After publication of the Introductory Report, a series of followup papers on individual issues will follow; then we will publish a compendium of statements invited from outside observers; after this will come our final report. In this way, the Subcommittee can deal with the many parts needed to view long-term care as a whole.

Testimony from many, many days of hearings and other research have been tapped for this report, which is extensive and heartfelt. Concern about people has been at the heart of this effort. The Subcommittee has, therefore, been especially dependent upon responsive staff effort. Mr. Val Halamandaris, associate counsel for the Senate Special Committee on Aging, deserves specific mention for his role in assuring that Subcommittee inquiries remained directed at their real target: to wit, people in need of good care. Mr. Halamandaris has had the primary responsibility for directing the Subcommittee's hearings; he is responsible for the excellent research on data and for writing this report. He is more than a skilled and attentive attorney; his investigatory skills are rooted in concern and, when necessary, outrage. He has made it possible for this Subcommittee to compile and offer more information and insights into the nursing home industry than the Congress has ever had before.

He has been helped considerably by other Committee personnel. Staff Director William Oriol has provided guidance and consultation leading to the design and special points of emphasis in this report. Committee Counsel David Affeldt has given generously of his legislative expertise, as well as painstaking attention to detail.

Particularly fortunate for the Subcommittee was the fact that a professional staff member, John Edie,* had special qualifications for making a substantial contribution to this effort. Mr. Edie, an attorney, formerly served as counsel to a program on aging in Minneapolis, Minn. When the Subcommittee went to that city for intensive hearings on scandalous shortcomings in nursing home care there, Mr. Edie testified and then continued his efforts on behalf of reform. In the preparation of this report, he has worked closely and at length with Mr. Halamandaris and his associates.

The Subcommittee also stands in debt to a select group in the nursing home industry and within the executive branch. Usually without much attention or encouragement, these public servants have stubbornly refused to compromise their goal of seeking high, but reasonable, standards of care.

With the publication of the Introductory Report, the Subcommittee began a final exploration of issues. We will publish responsible comments on findings expressed in this document and the Supporting

*As of October 1, 1975, John Edie left the Committee on Aging to accept the post of Deputy Director of the California Office on Aging.

Papers which precede and will follow. And we will, in our final report, make every effort to absorb new ideas or challenges to our findings. The care of chronically ill older Americans is too serious a topic for stubborn insistence upon fixed positions. Obviously, changes are needed. Obviously, those changes will occur only when public understanding and private conscience are stirred far more than is now the case.

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

# CONTENTS

## PART 3



## PART 4



## PART 5



## PART 6



## APPENDIXES

# NURSING HOME CARE IN THE UNITED STATES: FAILURE IN PUBLIC POLICY

## SUPPORTING PAPER NO. 7

## THE ROLE OF NURSING HOMES IN CARING FOR DISCHARGED MENTAL PATIENTS (AND THE BIRTH OF A FOR-PROFIT BOARDING HOME INDUSTRY)

### ABOUT THIS REPORT

To deal with the intricate circumstances and governmental actions associated with nursing home care in this Nation, the Subcommittee on Long-Term Care of the U.S. Senate Special Committee on Aging is issuing several documents under the general title of *Nursing Home Care in the United States: Failure in Public Policy.*

An Introductory Report, published in November 1974, declared that a coherent, constructive, and progressive policy on long-term care has not yet been shaped by the Congress and by the executive branch of this Nation.

Examining the role of Medicare and Medicaid in meeting the need for such care, the report found that both programs are deficient.

Further, it raised questions about current administration initiatives originally launched personally by President Nixon in 1971.

These shortcomings of public policy, declared the report, are made even more unfortunate by the clear and growing need for good quality care for persons in need of sustained care for chronic illness. It called for good institutions and, where appropriate, equally good alternatives, such as home health services.

(A more detailed summary of major findings from the Introductory Report appears later in this section of this report.)

Supporting Paper No. 7 examines the growing trend to dump thousands of former mental patients into nursing homes, and more recently, into boarding homes. The consequences which flow from the policy decision to empty State hospitals and to place exinmates on the welfare rolls are severe but are just beginning to be felt. Unless the Congress and the States act immediately, they will be confronted with a major crisis reminiscent of the earliest and unhappiest experiences with nursing homes in the 1950's.

### THE FACTUAL UNDERPINNING OF THIS STUDY

Seventeen years of fact-gathering preceded publication of this report. In 1959, the Senate Committee on Labor and Public Welfare established a Subcommittee on Problems of the Aged and Aging. Findings from subcommittee reports and hearings have been evaluated.

That subcommittee acknowledged in 1960, as this report acknowledges in 1976, that nursing homes providing excellent care with a wide range of supportive services are in the minority.

With the establishment of the U.S. Senate Special Committee on Aging in 1961, additional hearings were conducted. The most recent phase began in 1969 with hearings on "Trends in Long-Term Care." Since 1969, 29 hearings were held and some 3,500 pages of testimony were taken, as of March 1976.

These hearing transcripts have provided valuable information and expert opinions, as have several supplementary studies by the Subcommittee staff, the General Accounting Office, and private groups such as Ralph Nader's Study Group on Nursing Homes in 1971. The Library of Congress and other congressional committees, as well as professional organizations such as the American Health Care Association, have also been helpful. Finally, a great portion of the data is from the Department of Health, Education, and Welfare and other administrative or independent agencies, such as the Securities and Exchange Commission. The assistance of State officials proved especially helpful.

## ORGANIZATION OF THIS STUDY

This Supporting Paper will be followed by other Supporting Papers to be published at approximately monthly intervals over the next few months. Each will deal with a fairly specific issue, and each of these issues will be examined in the detail needed for understanding, not only by legislative and health specialists, but by laymen.

**A study of this magnitude would be incomplete without reaction by the nursing home industry and by representatives of the executive branch. Accordingly, national organizations and appropriate governmental units will be invited to submit statements within 2 months after publication of the final Supporting Paper. Finally, the Subcommittee will issue a concluding report intended to update earlier information and to analyze the situation at that time.**

**The format is unusual, perhaps unprecedented. But the nursing home industry is too vital a part of our health system and of the national scene for lesser treatment.**

## MAJOR POINTS OF THIS SUPPORTING PAPER

- **Some 2½ million elderly are going without the mental health services they need.**
- **Current programs designed to assist the mentally impaired elderly are ineffective and poorly administered.**
- **Responsibility for mental health programs is fragmented among dozens of Federal, State, and local agencies.**
- **Some patients continue to be housed in State mental hospitals for the singular reason that they have no place else to go.**
- **At the same time, thousands of individuals who need the intensive services which can only be offered at a State hospital have been precipitously discharged into smaller community based facilities.**
- **Nursing homes are one category of such community based facilities receiving large numbers of former patients. Unfortunately,**

nursing homes are poorly equipped to meet the needs of exinmates. There are generally no psychiatric services available; no plans to rehabilitate patients; there are not sufficient numbers of trained staff people to care for their needs; and a distinct absence of followup on the part of State hospitals to see that patients are appropriately placed. There are few recreation services, and a heavy and perhaps unwise use of tranquilizers to manage patients. Finally, the effect of mixing the physically infirm patients with the mentally impaired is often deleterious. "Normal" sick patients quite often manifest the behavioral patterns of the disturbed patients they see around them.

• Given these facts, experts such as Dr. Jack Weinberg and Dr. Robert Butler have concluded that in most cases the mentally impaired are better off in State mental institutions (as bad as they are) than in nursing homes. However, there is a growing effort on the part of many State and nursing home operators to learn how to manage exinmates; Vermont is an excellent example of what is possible when nursing homes work closely with officials of the State Department of Mental Health.

• If nursing homes are poorly prepared to meet the needs of the discharged mental patients, boarding homes are even less capable of doing so. More and more patients are being moved from State hospitals into such facilities which go by many names such as "foster care homes," "board and care homes," "domiciliary care facilities," "shelter care facilities," and "personal care homes." They may be greatly dissimilar in physical appearance. Most often, they are converted residences but they may also be new high-rise buildings or converted hotels, in some cases they may be converted mobile homes or renovated chicken coops. What they have in common is that they offer board and room but no nursing care and that most States do not license such facilities.

• Between 1969 and 1974, the number of inpatients in State mental hospitals dropped 44 percent, from 427,799 to 237,692 remaining on an average day at the end of 1974. At the same time, the ranks of the elderly inmates were reduced by 56 percent, from 135,322 to 59,685. (See State-by-State table on p. 719.) This sharp reduction in the number of inpatients was caused by four factors:

1. Humanitarian motives, the idea that mental hospitals are snakepits, and that patients are better off almost anywhere else.

2. The impact of recent court decisions, which have established that involuntarily committed patients have a constitutional right to treatment and that they must be released if such treatment is not forthcoming.

3. Cost. It costs the average State about $12,000 a year to care for a patient in a State mental hospital. Costs are much higher in some States. At St. Elizabeths Mental Hospital in Washington, D.C., the per patient per year cost is now $24,000.

4. The impact of the Supplementary Security Income (SSI) program. SSI is a 100-percent Federal welfare program for the aged. It pays $157 per recipient per month in most States. Some States, such as New York, supplement these welfare patients with their own money (New York adds $229 per month for a total SSI payment of $386).

All of these factors come together to push residents out of State hospitals and into boarding homes.

- Many States including California, New Mexico, Pennsylvania, Ohio, Michigan, New York, the District of Columbia, and Illinois are beginning to feel the effect of this mass dumping into boarding homes. The reports of poor care or no care, of poor food and unspeakable conditions are increasing daily. So many discharged patients have been deposited in the slums of major U.S. cities that instant "psychiatric ghettos" have been created including Chicago's Uptown and the Ontario Road NW., section of Washington, D.C.
- Through the enactment of SSI, the Congress created the beginnings of a for-profit boarding home industry just as it created the for-profit nursing home industry in 1935. In 1935, Congress enacted Social Security but barred payments to inmates in public institutions because of the widespread public reaction condemning conditions in public "poor houses" maintained by most States. However, funds were available to individuals living alone or with unrelated individuals in "boarding homes." Such boarding homes soon added nursing care and became known as nursing homes. In 1972, Congress barred the receipt of SSI funds by "inmates in public institutions" and required that SSI funds be reduced if SSI recipients were living with related individuals. Once again, however, SSI funds could be received in full by residents in boarding homes living with unrelated individuals.
- It is obvious that if Federal SSI funds are going to be used by the States to care for discharged mental patients, the Federal Government must step in and require that such facilities be licensed by the States and meet certain Federal minimum standards. The alternative would be to permit thousands of mentally impaired Americans to vegetate in unspeakable conditions.

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## MAJOR POINTS OF INTRODUCTORY REPORT

(Issued November 19, 1974)

Medicaid now pays about 50 percent of the Nation's more than $7.5 billion nursing home bill, and Medicare pays another 3 percent. Thus, about $1 of every $2 in nursing home revenues is publicly financed.*

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There are now more nursing home beds (1.2 million) in the United States today than general and surgical hospital beds (1 million).

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In 1972, for the first time, Medicaid expenditures for nursing home care exceeded payments for sugical and general hospitals: 34 percent to 31 percent.

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Medicaid is essential for growing numbers of elderly, particularly since Medicare nursing home benefits have been cut back sharply since 1969. Average Social Security benefits for a retired couple now amount to $310 a month compared to the average nursing home cost of $600. Medicaid (a welfare program) must be called upon to make up the difference.

**The growth of the industry has been impressive. Between 1960 and 1970, nursing home facilities increased by 140 percent, beds by 232 percent, patients by 210 percent, employees by 405 percent, and expenditures for care by 465 percent. Measured from 1960 through 1973, expenditures increased almost 1,400 percent.**

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**Despite the heavy Federal commitment to long-term care, a coherent policy on goals and methods has yet to be shaped. Thousands of seniors go without the care they need. Others are in facilities inappropriate to their needs. Perhaps most unfortunate, institutionalization could have been postponed or prevented for thousands of current nursing home residents if viable home health care and supportive services existed. Although such alternative forms of care may be more desirable from the standpoint of elderly patients—as well as substantially less expensive—the Department of HEW has given only token support for such programs.**

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**Despite the sizable commitment in Federal funds, HEW has been reluctant to issue forthright standards to provide patients with minimum protection. Congress, in 1972, mandated the merger of Medicare and Medicaid standards, with the retention of the highest standard in every case. However, HEW then watered down the prior standards. Most leading authorities concluded at Subcommittee hearings that the new standards are so vague as to defy enforcement.**

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**There is no direct Federal enforcement of these and previous Federal standards. Enforcement is left almost entirely to the States. A few do a good job, but most do not. In fact, the enforcement system has been characterized as scandalous, ineffective, and, in some cases, almost nonexistent.**

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**President Nixon's program for "nursing home reform" has had only minimal effect since it was first announced in 1971 and actions in 1974 fall far short of a serious effort to regulate the industry.**

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**The victims of Federal policy failures have been Americans who are desperately in need of help. The average age of nursing home patients is 82; 95 percent are over 65, and 70 percent are over 70; only 10 percent are married; almost 50 percent have no direct relationship with a close relative. Most can expect to be in a nursing home over 2 years. And most will die in the nursing home. These patients generally have four or more chronic or crippling disabilities.**

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*The Committee's Introductory Report, as released on November 19, 1974, incorporating the latest statistics from HEW, reported that total revenues for the nursing home industry in 1972 were $3.2 billion and $3.7 billion for 1973. Subsequent to publication of this report, the Social Security Administration released new estimates for 1974. Total expenditures are estimated at $7.5 billion. This change reflects spending for the Intermediate Care Program, which, until recently, was a cash grant program to old age assistance recipients. With its change to a vendor payments program such expenses are properly countable as nursing home expenditures. Consequently, changes were made in this report. Total payments in 1976 are estimated at about $8.5 billion.

Most national health insurance proposals largely ignore the long-term care needs of older Americans. Immediate action is required by the Congress and executive branch to improve past policies and programs which have been piecemeal, inappropriate, and short lived.

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## MAJOR POINTS OF SUPPORTING PAPER NO. 1

(Issued December 17, 1974)

## "THE LITANY OF NURSING HOME ABUSES AND AN EXAMINATION OF THE ROOTS OF CONTROVERSY"

The Subcommittee's Supporting Paper No. 1 reveals the following were the most important nursing home abuses:

- Negligence leading to death and injury;
- Unsanitary conditions;
- Poor food or poor preparation;
- Hazards to life or limb;
- Lack of dental care, eye care or podiatry;
- Misappropriation and theft;
- Inadequate control of drugs;
- Reprisals against those who complain;
- Assault on human dignity; and
- Profiteering and "cheating the system."

The inevitable conclusion is that such abuses are far from "isolated instances." They are widespread. Estimates of the number of substandard homes (that is, those in violation of one or more standards causing a life-threatening situation) vary from 30 to 80 percent. The Subcommittee estimates at least 50 percent are substandard with one or more life-threatening conditions.

These problems have their roots in contemporary attitudes toward the aging and aged. As Senator Frank E. Moss, chairman of the Subcommittee on Long-Term Care, has said:

> It is hell to be old in this country. The pressures of living in the age of materialism have produced a youth cult in America. Most of us are afraid of getting old. This is because we have made old age in this country a wasteland. It is T. S. Eliot's rats walking on broken glass. It's the nowhere in between this life and the great beyond. It is being robbed of your eyesight, your mobility, and even your human dignity.

Such problems also have their roots in the attitudes of the elderly toward institutionalization. Nursing home placement often is a bitter confirmation of the fears of a lifetime. Seniors fear change and uncertainty; they fear poor care and abuses; loss of health and mobility; and loss of liberty and human dignity. They also fear exhausting their savings and "going on welfare." To the average older American, nursing homes have become almost synonymous with death and protracted suffering before death.

However, these arguments cannot be used to excuse nursing home owners or operators or to condone poor care. Those closest to the action rightly must bear the greatest portion of responsibility.

To deal with the litany of abuses, action must be taken immediately by the Congress and the executive to: (1) Develop a national policy with respect to long-term care; (2) provide financial incentives in favor of good care; (3) involve physicians in the care of nursing home patients; (4) provide for the training of nursing home personnel; (5) promulgate effective standards; and (6) enforce such standards.

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## MAJOR POINTS OF SUPPORTING PAPER NO. 2

(Issued January 17, 1975)

## "DRUGS IN NURSING HOMES: MISUSE, HIGH COSTS, AND KICKBACKS"

The average nursing home patient takes from four to seven different drugs a day (many taken twice or three times daily). Each patient's drug bill comes to $300 a year as compared with $87 a year for senior citizens who are not institutionalized. In 1972, $300 million was spent for drugs, 10 percent of the Nation's total nursing home bill.

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Almost 40 percent of the drugs in nursing homes are central nervous system drugs, painkillers, sedatives, or tranquilizers.

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Tranquilizers themselves constitute almost 20 percent of total drugs—far and away the largest category of nursing home drugs.

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Drug distribution systems used by most nursing homes are inefficient and ineffective. An average home of 100 beds might have 850 different prescription bottles and 17,000 doses of medication on hand. Doctors are infrequent visitors to nursing homes. Nurses are few and overworked. All too often, the responsibility for administering medications falls to aides and orderlies with little experience or training.

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Not surprisingly, 20 to 40 percent of nursing home drugs are administered in error.

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Other serious consequences include: the theft and misuse of nursing home drugs; high incidence of adverse reactions; some disturbing evidence of drug addiction; and lack of adequate controls in the regulation of drug experimentation.

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Perhaps most disturbing is the ample evidence that nursing home patients are tranquilized to keep them quiet and to make them easier to take care of. Tragically, recent research suggests that those most

likely to be tranquilized sometimes may have the best chance for effective rehabilitation.

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Kickbacks are widespread. A kickback is the practice whereby pharmacists are forced to pay a certain percentage of the price of nursing home prescription drugs back to the nursing home operator for the privilege of providing those services.

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The atmosphere for abuse is particularly inviting when reimbursement systems under Federal and State programs allow the nursing home to act as the "middle man" between the pharmacy (which supplies the drugs) and the source of payment (private patient, Medicare, or Medicaid).

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Kickbacks can be in the form of cash, long-term credit arrangements, and gifts of trading stamps, color televisions, cars, boats, or prepaid vacations. Additionally, the pharmacist may be required to "rent" space in the nursing home, to furnish other supplies free of charge, or to place nursing home employees on his payroll.

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The average kickback is 25 percent of total prescription charges; over 60 percent of 4,400 pharmacists surveyed in California reported that they had either been approached for a kickback or had a positive belief that kickbacks were widespread; these same pharmacists projected $10 million in lost accounts for failure to agree to kickback proposals.

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In order to lower costs to meet kickback demands, pharmacists admitted numerous questionable, if not illegal, practices such as: billing welfare for nonexistent prescriptions, supplying outdated drugs or drugs of questionable value, billing for refills not dispensed, supplying generic drugs while billing for brand names, and supplying stolen drugs which they had purchased.

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Congressional action in 1972 to make kickbacks illegal has had little effect. HEW has yet to announce regulations to implement this law.

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## MAJOR POINTS OF SUPPORTING PAPER NO. 3

### (Issued March 3, 1975)

## "DOCTORS IN NURSING HOMES: THE SHUNNED RESPONSIBILITY"

Physicians have shunned their responsibility for nursing home patients. With the exception of a small minority, doctors are infrequent visitors to nursing homes.

Doctors avoid nursing homes for many reasons:

- There is a general shortage of physicians in the United States, estimates vary from 20,000 to 50,000.

- Increasing specialization has left smaller numbers of general practitioners, the physicians most likely to care for nursing home patients.
- Most U.S. medical schools do not emphasize geriatrics to any significant degree in their curricula. This is contrasted with Europe and Scandinavia where geriatrics has developed as a specialty.
- Current regulations for the 16,000 facilities participating in Medicare or Medicaid require comparatively infrequent visits by physicians. The some 7,200 long-term care facilities not participating in these programs have virtually no requirements.
- Medicare and Medicaid regulations constitute a disincentive to physician visits; rules constantly change, pay for nursing home visits is comparatively low, and both programs are bogged down in redtape and endless forms which must be completed.
- Doctors claim that they get too depressed in nursing homes, that nursing homes are unpleasant places to visit, that they are reminded of their own mortality.
- Physicians complain that there are few trained personnel in nursing homes that they can count on to carry out their orders.
- Physicians claim they prefer to spend their limited time tending to the younger members of society; they assert there is little they can do for the infirm elderly. Geriatricians ridicule this premise. Others have described this attitude as the "Marcus Welby Syndrome."

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The absence of the physician from the nursing home setting leads to poor patient care. It means placing a heavy burden on the nurses who are asked to perform many diagnostic and therapeutic activities for which they have little training. But there are few registered nurses (65,235) in the Nation's 23,000 nursing homes. These nurses are increasingly tied up with administrative duties such as ordering supplies and filling out Medicare and Medicaid forms. The end result is that unlicensed aides and orderlies with little or no training provide 80 to 90 percent of the care in nursing homes.

It is obvious that the physician's absence results in poor medical and to some degree in poor nursing care. Poor care has many dimensions, it means:

- No visits, infrequent, or perfunctory visits.
- The telephone has become a more important medical instrument in nursing homes than the stethoscope.
- No physical examinations, pro forma or infrequent examinations.
- Some patients receive insulin with no diagnosis of diabetes.
- Significant numbers of patients receive digitalis who have no diagnosis of heart disease.
- Large numbers of patients taking heart medication or drugs which might dangerously lower the blood pressure do not receive blood pressure readings even once a year.
- Some 20 to 50 percent of the medication in U.S. nursing homes are given in error.
- Less than 1 percent of all infectious diseases in the United States are reported—a special problem in nursing homes where patients have advanced age and lessened resistance. This fact was graphically proven in 1970 when 36 patients died in a Salmonella epidemic in a Baltimore, Md., nursing home.

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• Physicians do not view the bodies of patients who have died in nursing homes before signing death certificates.

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The need for physicians to exercise greater responsibility for the 1 million patients in U.S. nursing homes is abundantly clear from these and other facts. Until doctors take a greater interest the litany of nursing home abuses will continue, the majority of America's nursing homes will be substandard, and the quality of patient care will be unacceptable.

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## MAJOR POINTS OF SUPPORTING PAPER NO. 4

### (Issued April 24, 1975)

## "NURSES IN NURSING HOMES: THE HEAVY BURDEN (THE RELIANCE ON UNTRAINED AND UNLICENSED PERSONNEL)"

There are few nurses in the Nation's 23,000 nursing homes. Of the 815,000 employed registered nurses (RN's) in the Nation, only 65,235 can be found in U.S. long-term care facilities.

There are many reasons why this is true:

• There is a general nurse shortage. The U.S. Department of Labor estimates the need for 150,000 more RN's. Others claim it is simply a matter of maldistribution or that the 400,000 RN's presently out of the work force could be induced into service—given better wages and working conditions. Still others assert that if there is a shortage it is because nurses are required to spend their time with administrative duties and paperwork rather than with patients.

• Few nurses are required by law. At present the Federal standard requires only the 7,300 Skilled Nursing Facilities in the United States to have an RN as their highest nursing officer—and this only applies to the day shift. The 8,200 Intermediate Care Facilities are required to have only a licensed practical nurse in charge—again only during the day shift. The remaining 7,500 facilities need have no "licensed" nursing officer at all. To make matters worse, there are no requirements for ratios between nurses and patients in Federal regulations. By contrast the State of Connecticut requires one RN for every 30 patients on the day shift, one for every 45 on the afternoon and one for every 60 in the evening.

• Poor working conditions. RN's working in nursing homes do not have the support of physicians and trained personnel that they find in hospitals. Many nursing homes are poorly administered and there is a lack of authority vested in the nursing service department. A very real problem is the fact that nursing homes are isolated from other health care facilities.

• Nursing homes have a poor image. "Hospitals have their pick while nursing homes take what they can get," is a common statement among nursing home employees. An RN who goes to work in a nursing home will often be asked, "Why are you here? Where did you foul up?"

- Wages and fringe benefits are low. The consensus is that nursing homes do less well in compensating nurses than other health care entities. Many nursing homes also lag behind in fringe benefits, stimulating nursing personnel to seek work elsewhere.
- Nurses have little training in geriatrics and the needs of nursing home patients and are therefore unprepared to work in long-term care facilities. Of the over 1,000 schools of nursing surveyed by the Subcommittee, only 27 responded that they had a program wherein geriatrics was treated as a specialty.
- There are no graduate programs in geriatic or gerontological nursing. Federal Government programs likewise neglect geriatrics. In 1970 there were 144 programs for the training of nurses and health care personnel administered by 13 agencies. None of these programs emphasized geriatrics.
- It goes without saying that the few nurses working in nursing homes are grossly overworked. Because they are overworked or simply not present in significant number, the result is the reliance on aides and orderlies to provide 80 to 90 percent of the care in nursing homes.
- Only one-half of the 280,000 aides and orderlies are high school graduates. Most have no training. Most have no previous experience. They are grossly overworked and paid the minimum wage. It is little wonder that they show a turnover rate of 75 percent a year. Put simply, the absence of RN's and the reliance on untrained aides and orderlies result in poor care. Poor care runs the gamut from essential tests not being performed to negligence leading to death and injury.
- In Illinois, an investigator sought employment as a nursing home janitor. Within 20 minutes he was hired, not as a janitor, but as a nurse; he carried the keys to the medication and narcotics cabinet on his belt and distributed drugs to patients. His references were never checked. He never represented that he had any prior experience.
- In Minnesota, aides were instructed how to distribute drugs "in case of an emergency." The "emergency" began the next day; aides continued distributing drugs even though this constituted a violation of Federal regulations and Minnesota law.
- A recent national HEW study notes that some 37 percent of the patients taking cardiovascular drugs had not had a blood pressure reading for more than a year. More than 25 percent of this number who were receiving heart medication had no diagnosis of heart disease on their charts. Some 35 percent of those taking tranquilizers which might lower the blood pressure markedly had not had a pressure reading in more than a year.

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The solution for these problems lies in greater emphasis on geriatrics in schools of nursing and in government programs training health care personnel. Funds should also be provided for the in-service training of nursing home personnel.

This paper also contains a major report analyzing the role of nurses in long-term care facilities prepared by the Committee on Skilled Nursing of the American Nurses' Association. See highlights, part 2, pages 385–417.

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## MAJOR POINTS OF SUPPORTING PAPER NO. 5

(Issued August 30, 1975)

## "THE CONTINUING CHRONICLE OF NURSING HOME FIRES"

- Older Americans make up 10 percent of the population but 30 percent of the deaths by fire. They are involved in 59 percent of all clothing fires, having a 73-percent mortality rate in such fires as compared to 23 percent for younger persons.
- Nursing home patients present a particular problem because of several factors: (1) Their advanced age (average 82); (2) their failing health (average four disabilities); (3) their mental disabilities (55 percent are mentally impaired); (4) their reduced mobility (less than half can walk); (5) their sensory impairment (loss of hearing, vision, or smell); (6) their reduced tolerance to heat, smoke, and gases; and (7) their greater susceptibility to shock.
- Some patients resist rescue. They are reluctant to leave their room and few possessions. In other cases, those rescued have inexplicably run back into burning buildings.
- Despite much progress in recent years, nursing homes and related facilities still rank number one on the list of unsafe places to be from a fire safety point of view. Six patients die in nursing home fires for every one in a hospital fire.
- In 1973 there were 6,400 nursing home fires (17.5 each day of the year) causing $3.6 million in damage. An estimated 500 persons lost their lives in single-death fires. Fifty-one persons lost their lives in multiple-death fires (those killing three or more). These figures represent sharp increases from 1971, when there were 4,800 fires and 31 persons killed in multiple-death fires.
- Because nursing home patients often cannot take action to protect themselves in case of fire, they must rely upon the help of others. In most cases such help has not been available. There are few nursing personnel available (particularly at night), and most are untrained in rescue and firefighting techniques. Compounding the problem, many patients are under sedation or bound with restraints.
- Because the elderly cannot protect themselves and nursing home personnel often prove incapable of taking action to save them in case of fire, automatic detection, alarm, and extinguishment are recommended. Sprinkling systems, while far from a panacea, are, by and large, the difference between life and death.
- Over the years, 33 percent of all nursing home fires have been caused by smoking or matches; heating or electrical problems followed next with 18 and 15 percent, respectively. Eight percent were labeled "suspicious"—a suggestion that arson was the fire's cause. Fires most frequently began in patients' rooms (35 percent) and most often

took place from midnight to 6 a.m. (42 percent). Some 35 percent of all nursing home fires occur in wood-frame buildings; only 3 percent in fire-resistive buildings.

● Greater emphasis must be placed on the installation of fireproof furnishings. Too often fire-resistive buildings are constructed only to be filled with flammable carpets, curtains, vinyl upholstery, and the like. The Department of Commerce has yet to promulgate the fire safety standards with respect to carpets (for all age groups) that they promised at hearings on the Marietta fire. There is no emphasis on the hazard of smoke production or on the effect of toxic gases on humans. Recent research demonstrates that deadly gases such as phosgene and cyanide are released when various plastics, acrylics, and nylons are burned. Many such products are found in nursing homes.

● Some 7,200 of the Nation's 23,000 long-term care facilities (personal care and shelter care homes) do not participate in Federal programs, and therefore meet only such standards as are promulgated by the States. All too often, such standards are weak or nonexistent. There are even fewer standards for boarding homes and old hotels which, more and more, are absorbing the thousands of patients discharged yearly from State mental institutions. In some cases the States are placing Medicare and/or Medicaid patients in these facilities; the use of such "bootleg" nursing homes (so named because they are not certified under Federal requirements) is a violation of law.

● The 15,800 Skilled Nursing Facilities and Intermediate Care Facilities participating in Medicare and Medicaid must comply with the Life Safety Code of the National Fire Protection Association. This requirement was enacted in 1967 but far too many nursing homes fail to comply. In 1971 and again in 1975, U.S. General Accounting Office audits projected 50 and 72 percent (respectively) of the nursing homes in the United States had one or more serious violations of the code. The Department of Health, Education, and Welfare estimated 59 percent had deficiences in 1974 and notes two-thirds have "several" (four or more) deficiencies in 1975.

● Not only are standards not being enforced, there is a lack of uniformity in the interpretation and application of the code by State surveyors who inspect nursing homes applying the Federal fire safety standards. Only 22 percent of those doing fire inspections had backgrounds qualifying them to do so; 78 percent were nurses, sanitarians, and members of other professions, including State police or detectives. Some HEW regional offices are overzealous while others are complacent. As further evidence that State surveyors are not adequately performing their jobs, fully 87 percent of the deficiencies reported by the GAO earlier this year had not been discovered by State surveyors.

● HEW must take action to insure that Federal fire safety standards are enforced; 8 years is too long to wait. HEW must undertake measures to insure uniform enforcement of the code among the 50 States. One such measure might be the mandatory training of State surveyors. If such measures do not prove workable, then HEW should suggest the need for direct Federal inspection to the Congress.

## MAJOR POINTS OF SUPPORTING PAPER NO. 6

(Issued October 30, 1975)

## "WHAT CAN BE DONE IN NURSING HOMES: POSITIVE ASPECTS IN LONG-TERM CARE"

• During its 29 hearings between 1969 and 1976, the Subcommittee on Long-Term Care has conducted a careful search for positive and innovative programs which distinguish America's finest nursing homes. The Subcommittee learned that a good nursing home is a complex mix of factors. The first and foremost being a firm belief that the physical and mental problems of the elderly are, to a substantial degree, preventable, and that even when these problems are present they are, more often than not, reversible.

• Good nursing homes are a matter of motivation. Of paramount importance is the administrator's ability to stimulate his staff and to create an intangible kind of harmony and unity of purpose rooted in competence and compassion. Education for nursing home administrators in these techniques is essential to improved nursing home care.

• Many of the best nursing homes in the United States feature innovative approaches to therapy and rehabilitation. A variety of techniques are used to upgrade the mental and physical functioning of patients. Among these techniques are:

—Reality orientation, the basic aim of which is to put a mentally regressed patient into renewed contact with the world around him.
—Sensory training is a therapeutic program designed to reduce sensory deprivation.
—Remotivation essentially is an effort to find out what activities a patient enjoyed in earlier life (or which he would have enjoyed) and directing him to those same goals.

• Some homes boast improvements in the physical structure which facilitate better patient care and greater patient comfort. Innovations in this area run the gamut from "campuses" for senior citizens, which provide the broad range of health care services in one location, to the use of color and design to make nursing homes more appealing and better suited to the needs of the infirm aged.

• One of the most important series of positive and innovative programs relates to the education and utilization of employees. Nursing homes presently offer a variety of such techniques, including:

—Employee sensitivity training is the practice of requiring prospective employees to assume the role of patients for 24 hours before their employment. By this experience the employees are "sensitized" to the needs of the aged patients.
—Accident prevention programs reduce injury.
—In-service training programs and continuing education programs help employees to perform their jobs. Some schools of nursing have established programs whereby student nurses work in nursing homes as part of their training. Some homes use computers to monitor patient care and for staff education.
—A novel program in St. Paul, Minn., trains able-bodied senior citizens to work in nursing homes.

- Many of the best nursing homes in the Nation feature comprehensive activity programs. Activity programs range from residents' councils (self-government by patients) to senior citizens' olympic games. Activity programs generally are inexpensive but they can have a dramatic effect on the patient's sense of dignity and comfort in the nursing home environment.
- America's finest nursing homes inevitably find ways to aid the community in which they operate. They may provide outreach services for senior citizens in their surrounding area. Such services may include meals-on-wheels, transportation, recreation, entertainment, social and home health services.
- Still other nursing homes participate in peer review programs established by their State nursing home association. Some State associations have adopted a code of ethics encouraging good care and disciplining those members found continually in violation of standards.
- Good homes invariably enjoy the support of their local community. Informal "ombudsman" projects have been created in many States to help monitor the quality of nursing home care. Such projects also perform an educational function, assisting administrators who want to improve their overall operations. Formal ombudsman projects under the direction of the Administration on Aging are springing up in almost every State. The National Council of Senior Citizens has established a national ombudsman project.
- Some community groups are printing nursing home directories or issuing ratings to aid consumers in their choice of nursing homes. Some senior citizen groups have established a nursing home referral service. Others have organized volunteers to visit nursing homes and nursing home patients on a regular basis.
- Those who would like to become involved in the effort to bring about a better quality of nursing home care will benefit from the report: *Citizens Action Guide: Nursing Home Reform,** prepared by Elma Griesel and Linda Horn for the Gray Panthers of Philadelphia, Pa., April 1975.

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## MAJOR POINTS OF FORTHCOMING SUPPORTING PAPERS

### Supporting Paper No. 8

### "ACCESS TO NURSING HOMES BY U.S. MINORITIES"

Only 4 percent of the 1 million nursing home patients in the United States are members of minority groups, even though their health needs are proportionately greater. Part of the problem is caused by cost obstacles or lack of information about Medicaid. Discrimination is the greatest obstacle to greater utilization by blacks. But discrimination need not be overt; often relatives are made to feel that their parent or grandparent would not be made comfortable. In the case of Asian-Americans and Spanish-speaking Americans, language barriers often cause insurmountable difficulties. Cultural and other problems, including rural isolation, cause problems to American Indians.

*For a copy of this report, send $1.50 to Long-Term Care Action Project, 3700 Chestnut Street, Philadelphia, Pa., 19104 (telephone: 215-382-3546).

Members of minority groups at Subcommittee hearings have been sharply critical of the Nixon administration's nursing home "reforms." They protested the "arbitrary and punitive" closing of a few minority owned nursing homes that do exist and the absence of assistance to help upgrade standards.

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Supporting Paper No. 9

## "PROFITS AND THE NURSING HOME: INCENTIVES IN FAVOR OF POOR CARE"

Profits by nursing homes have occasioned serious and persistent controversy. Nursing home administrators say that Medicaid reimbursement rates are low and that they can hardly become the basis for profiteering. Critics say that the economics of nursing home operation, supported in such large measure by public funds, should be examined more closely and publicly than they now are.

On the basis of available evidence, including a Subcommittee survey made in 1973–74, the Subcommittee has found that the 106 publicly held corporations controlled 18 percent of the industry's beds and accounted for one-third of the industry's $3.2 billion in revenue (as of 1972). Between 1969 and 1972 these corporations experienced the following growth:

- 122.6 percent in total assets;
- 149.5 percent in gross revenues; and
- 116 percent in average net income.

One recent HEW study, however, shows marginal rates of return in a sample of 228 nursing homes. Thus, the issue is far from settled. But a joint study—conducted by the General Accounting Office and the Subcommittee—suggest significant increases in total assets, revenues, and profits for individual operators as well.

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*Two final documents will be issued as part of this study: A compendium of statements by national organizations and administration spokesmen, and a final report by the Subcommittee on Long-Term Care.*

94TH CONGRESS } SENATE { REPORT
2d Session } { No. 94——

# NURSING HOME CARE IN THE UNITED STATES: FAILURE IN PUBLIC POLICY

## SUPPORTING PAPER NO. 7

## THE ROLE OF NURSING HOMES IN CARING FOR DISCHARGED MENTAL PATIENTS (AND THE BIRTH OF A FOR-PROFIT BOARDING HOME INDUSTRY)

—Ordered to be printed

Mr. Moss, from the Special Committee on Aging, submitted the following

## REPORT

### INTRODUCTION

For the last four or five decades, America has lived with an uneasy paradox: thousands of individuals have languished in mental institutions solely because they had no place else to go while other thousands have walked the streets unable to obtain the mental health services they desperately need.

In 1963, when President John F. Kennedy declared that many mental hospitals in the United States were veritable "snakepits." American citizens, particularly the elderly, could be committed with comparative ease. Generally all that was required was an affidavit of a family member and a physician. Once committed to these institutions, the constitutional rights under the 5th, 8th, and 13th amendments evaporated. Generally, little sustained treatment was forthcoming and release was usually out of the question. The elderly, 10 percent of the population, accounted for more than a third of the half a million citizens in mental hospitals.

President Kennedy proposed, and the Congress authorized and established, 2,500 community mental health centers,[1] each intended to be an integral part of the community instead of a separate and isolated entity. Needs of individual persons would be readily assessed, and

[1] "The Need for the More Effective Management of Community Mental Health Centers Program." U.S. General Accounting Office, Aug. 27, 1974, pp. 1-3.

efforts could be made to provide services, and even in patients' own homes, where possible. Two year later, Congress passed the Medicare and Medicaid laws authorizing mental health services for the aged, blind, and disabled.

Some 10 years have passed since the enactment of Medicare and Medicaid, and yet today an estimated 2½ million elderly are going without the mental health services they require.[2] Part of the problem is that community mental health centers have failed to fulfill their potential. Only 443 of the proposed 2,500 centers have been constructed and are functioning today, and the number of elderly served is disproportionately low.[3] These two facts would seem to lead to the conclusion that mental hospitals are still serving large numbers of patients, but the fact is that the average daily census has been cut in half in the past 10 years.

**Some 427,799 individuals were housed in mental institutions in 1969 while only 237,692 remained at the end of 1974. A drop of 44 percent in just 5 years (and by an estimated 50 percent through 1975).[4]**

**An even sharper reduction—56 percent—has occurred among elderly patients. Today only 59,685 older Americans remain institutionalized in State mental hospitals.[5]**

Where have all the patients gone? This question dominates this report. The quest for "cost-savings" at the State level has played a part. So have recent Court decisions upholding a Constitutional right to treatment by those involuntarily committed and mandating release from custody for those who do not receive treatment. The net effect is that thousands of patients have been transferred to nursing homes, boarding homes, and smaller community based facilities.

**This raises still other questions:**

**—Are nursing homes and less medically-oriented facilities appropriate places for discharged mental patients?**

**—What kind of care and services do such patients require?**

**—How adequately do nursing homes and boarding homes perform this function?**

Serious questions arise as to the ability of nursing homes to cope with former mental patients. This is particularly true when they are asked to care for comparatively young and actively ambulatory patients. The demands of these patients (and of the mentally retarded now being moved into nursing homes) can present insurmountable problems for nursing homes, which had traditionally too few employees with too little training and a turnover rate of something like 75 percent a year. Mingling the mentally ill with the physically ill requires careful management which often has not been available. Generally, the results have been to the disadvantage of both the infirm elderly and to those with mental disabilities.

**But perhaps even more serious than the placement of former mental patients in nursing homes is their wholesale and precipitous transfer**

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[2] Testimony of Senator Edmund S. Muskie before the Subcommittee on Health, Senate Committee on Labor and Public Welfare, May 1, 1974.

[3] "Mental Health and the Elderly," joint hearings by the Subcommittee on Long-Term Care and the Subcommittee on Health of the Elderly, Senate Committee on Aging, September 29, 1975. See, in particular, testimony of Nancy Perlman, director of program development department of the American Federation of State, County, and Municipal Employees.

[4] Committee questionnaire. See table 2, p. 719.

[5] *Ibid.*

**to boarding homes, shelter care facilities, foster care homes, or domiciliary care facilities—for the most part, converted residences which provide board and room with no nursing or psychiatric services. With some few exceptions, the most that is offered is minimum supervision during daylight hours. In most States such facilities are unlicensed and they are required to meet no Federal standards despite the fact that the source of funds is the Supplementary Security Income program (SSI) enacted by the Congress in 1972.**[6]

The report examines these issues in detail with reference to several States. Two States, Illinois and New York, were selected for in-depth analysis. Recommendations are offered with the hope of making it possible for all Americans to have the mental health services they need; to restrict commitment to State hospitals to those with obvious need; to help community mental health centers to reach their potential and to enable nursing homes to better cope with their new responsibility.

**Action must be taken immediately to stop proliferation of a for-profit boarding home industry and the relegation of thousands of Americans to boarding homes—often the least suitable, the least qualified, the least regulated, and not always the least expensive answer to their needs.**

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[6] Title XVI of the Social Security Act.

# PART 1

## MENTAL HEALTH CARE OF THE AGED: THE NEED

In 1972, the last year for which comprehensive figures are available, the United States spent about $3 billion on mental health care.[7] This amount represents about 4 percent of the Nation's total expenditures for health in that year. These Federal dollars were distributed through a wide array of programs, as can be seen from table 1 (page 707). Unfortunately, these programs have largely overlooked mental health needs of older Americans.

The degree and dimensions of this failure was documented by the Senate Special Committee on Aging in its 1971 report, *Mental Health Care and the Elderly: Shortcomings in Public Policy*, which declared:

> Public policy in the mental health care of the aged is confused, riddled with contradictions and shortsighted limitations, and is in need of intensive scrutiny geared to immediate and long-term action.[8]

**In the 4 years since, the need for a clear and comprehensive policy with respect to the mentally impaired aged has become all the more acute. Similarly, the needs of the elderly have become more visible.**

According to the best estimates, between 14 and 25 percent of our 22 million older Americans suffer from some degree of mental impairment.[9] A noted authority, the late Margaret Blenkner, wrote that about 8 percent of our seniors are impaired to the point of needing protective (psychiatric) services.[10]

The American Psychological Association has its own estimates. According to the association, 3 million elderly require mental health services, but a bare 20 percent of this number have their needs met through existing resources.[11] This statistic is buttressed by other sources, including Senator Frank E. Moss [12] (Chairman of this Subcommittee) and Senator Edmund S. Muskie, Chairman of the Subcommittee on Health of the Elderly, Senate Committee on Aging. Senator Muskie said:

> [W]e must reflect upon the fact that perhaps 2½ million elderly who require mental health services are going without the care they need.[13]

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[7] May 25, 1973, letter to Hon. Edmund S. Muskie from Harold F. Eberle, congressional liaison, the White House.

[8] *Mental Health Care and the Elderly: Shortcomings in Public Policy*, Report by the Senate Committee on Aging, November 1971, p. 3.

[9] P. 8 report cited in footnote 8.

[10] Prevention or Protection? Aspects of Social Welfare Services for the Mentally Impaired Aged, December 1, 1967.

[11] P. 5, reference cited in footnote 8.

[12] Speech by Hon. Frank E. Moss before the Utah Department of Social Services May 29, 1975.

[13] Reference cited in footnote 2.

TABLE 1.—*Estimate of 1972 obligations for mental health services, including financing*

[Millions of dollars]

| | |
|---|---|
| Health, Education, and Welfare: | |
| Health Services and Mental Health Administration: | |
| National Institute of Mental Health | 326.7 |
| St. Elizabeth's Hospital | 24.0 |
| Medical facilities construction | 2.8 |
| Patient care and special health services | 4.1 |
| Maternal and child health | 13.0 |
| Indian health | 4.2 |
| Comprehensive health planning | 1.0 |
| 314(d) formula grants | 13.4 |
| Appalachian health | 3.6 |
| Social Security Administration | 900.0 |
| Social and Rehabilitation Services: | |
| Medical Services Administration (Medicaid) | 563.0 |
| Rehabilitation Services Administration | 162.9 |
| Community Services Administration | 141.5 |
| Veterans' Administration | 464.7 |
| Office of Economic Opportunity | 17.4 |
| ACTION | 17.9 |
| Housing and Urban Development | 6.8 |
| Defense (includes CHAMPUS): | |
| Army | 65.3 |
| Navy and Marines | 34.0 |
| Air Force | 24.7 |
| Transportation: Highway safety | 26.7 |
| Justice: | |
| Law Enforcement Assistance Administration | 16.6 |
| Bureau of Prisons | 3.7 |
| Civil Service Commission: Federal employees health program | 51.0 |
| Other (Interior, Commerce, Labor, State, Panama Canal, miscellaneous agencies) | 4.8 |
| Total | 2,893.8 |

Source: The White House.

What explanation can be offered for this stark failure to address the mental health needs of the elderly? Several reasons can be suggested.

## A. THE "SENILITY" BARRIER

Historically, there has been a great deal of misunderstanding concerning the emotional problems of senior citizens. Myths continue to abound, such as: "Senility is a natural stage for the aged" and "Emotional disorders of the elderly do not respond to treatment."

Clearly, the words "senility" and "mental illness" have medical, legal and programmatic meanings. There has been little agreement as to definition.

How do you tell the difference between these two conditions? Are these two distinctions important, and how do we care for patients exhibiting these symptoms? Where should they properly be housed? What kind of therapeutic environment works best?

Dr. Karl Menninger, chairman of the board of trustees of the Menninger Foundation, Topeka, Kans., put it this way in his testimony before the Subcommittee:

> Now, as to the first question, the difference between senility and psychosis. I do not think that either one of these "things" exist, or at least they do not exist in the clear form in which the words are used.

Let us take senility, for example. I am sure that this word does not mean merely the condition of somebody who is older than most people. Some people become quite worn out at a relatively young age, and some reach 90 with considerable vigor. The word "senility" is rather vague, but I assume that what is meant in this discussion is the general reduction in functioning ability sufficient to make a person dependent upon someone else for ordinary needs.

Grandfather gets slow and uncertain, or he gets inattentive as to where he throws his matches; he appears somewhat disheveled at times, or unduly irritable. These sometimes add up to definite evidence of change, disorganization; a kind of deterioration is ascribed to age, and is called senility.

## A Matter of Interpretation

I read into the question the inference that if this condition can be called the "psychosis," then the State will take care of this man in the State hospital; it is the State's responsibility. So long as it is merely frailty and weakness of the flesh, so to speak, then it is still the family's responsibility. This often becomes a question of how much of a nuisance the older person is considered to be. Unfortunately, my profession has contributed, I think, to a great injustice here by employing the word very loosely. Personally, I am not convinced there is any such clearly definable condition as psychosis. But, it is in such common usage that you may reply, "Well, everybody knows what psychosis means; it means just crazy." But, I ask, just what does crazy mean?

Well, crazy means insane. Here again, insane is a word defined by the State legislatures, not by us doctors. It is another of these words which really have no sound medical meaning.

The practical meaning is that someone has become a considerable nuisance to the people in his environment.

If he is considerably irritating and annoying, and difficult, and provoking to the people around him, his "senility" is apt to be called his "psychosis." These are both social diagnoses, and not medical diagnoses, and I think this results in a great deal of injustice, because name-calling diagnosis is usually an administrative, political act.

It is all a question of one's interpretation of the nuisance factor. There are, to be sure, some aspects of being a nuisance which are alarming. If an elderly individual has a propensity for setting fire to everything inflammable in the house, I can see how somebody would like to attribute this to a mental illness, and not merely to mental decay. But most of the symptoms of what we used to call "senile dementia" are of the nature of impaired perception, memory, and movement.[14]

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[14] "Trends in Long-Term Care," hearing by the Subcommittee on Long-Term Care, part 15, Chicago, Ill., Sept. 15, 1971, p. 1513.

Dr. Charles Kramer, president of the Kramer Foundation and clinical director of the Plum Grove Nursing Home and assistant professor of psychiatry at the University of Illinois, told the Subcommittee that the distinction between senility, psychosis, and chronic brain syndrome becomes meaningless. You have to deal with the individual at the behavior level," he said.[15]

Finally, renowned psychiatrist and author Dr. Robert Butler offered his perspective, writing in the September 1975 edition of the *American Journal of Psychiatry:*

> All too many psychiatrists use the term "senility" indiscriminately, applying it to anyone over 60 with a problem. Having invoked this magic word, they need not undertake the kind of careful diagnostic assessment that is necessary to determine a proper course of treatment. Indeed, in most cases, when the label "senility" is applied, no course of treatment is started.
>
> Senility is not, properly speaking, a medical diagnosis but is instead a wastebasket term for a range of symptoms that include (minimally) some memory impairment or forgetfulness, difficulty in attention and concentration, decline in general intellectual grasp and ability, and decreased emotional responsiveness to others. Studies at the National Institutes of Health and elsewhere have shown that this condition is not an inevitable consequence of age per se. Rather, it is a cerebrovascular disease, destruction of central nervous system cells, or an emotional state such as severe depression. For example, the depression of an older person may be inner preoccupation and constriction manifesting itself as disturbed concentration, forgetfulness, and withdrawal. The term "senility" should be discarded altogether in favor of "emotional and mental disorders in old age." This issue involves more than semantics. Viewing disorders in the way I have suggested would encourage a more careful diagnosis and treatment plan, as well as a broader perspective on the everyday problems and disorders of old age.

## B. SHORTCOMINGS IN MEDICARE AND MEDICAID

Both the Medicare and Medicaid programs provide some degree of assistance to the aged in need of mental health care. Obviously, these services are far from adequate.

### 1. MEDICARE

Part A, Medicare's Hospital Insurance Plan, provides benefits toward the cost of inpatient care in a participating psychiatric or general hospital. However, inpatient care in a psychiatric hospital is limited to 190 days during a person's lifetime, as opposed to inpatient care for other illness, which has no lifetime limitation. Moreover, an elderly patient who is admitted to a psychiatric hosptial for the first time, if he is beginning a new benefit period, can be reimbursed

[15] Reference cited in footnote 14, p. 1445.

under Medicare for up to 150 days (90 plus 60 lifetime reserve days) in that benefit period. But, in order to obtain reimbursement for the remaining 40 days of inpatient care, he must leave the hospital for 60 consecutive days, and then re-enter the hospital when his new "benefit period" begins.

The "lifetime" restriction of 190 days does not apply to the psychiatric units of general hospitals, where Medicare benefits are the same for patients suffering from mental illness as for those with other illnesses.

If a person becomes a patient in a participating psychiatric hospital sometime before his 65th birthday, for example 30 days preceding his 65th birthday, and remains there or is transferred to a general hospital psychiatric unit, that period of time (30 days) is deducted from his maximum 150 days allowable during his first benefit period, thereby leaving a maximum of only 120 days reimbursable in that benefit period. The patient may still be covered for 70 more days of inpatient psychiatric care, after a lapse of 60 consecutive days outside the hospital, because inpatient days in a psychiatric hospital prior to age 65 are not included in the 190 days lifetime limitation. Furthermore, the deduction for days spent in a psychiatric hospital before age 65 is not applicable when the patient is admitted to a general hospital for diagnosis or treatment of injuries or illnesses that are not primarily psychiatric in nature.

### Supplementary Medical Insurance; Part B

Part B of Medicare pays 80 percent of the reasonable charges for covered physicians' and other medical services, after a $60 deductible has been met by the patient in each calendar year. However, in the case of mental illness, if an individual is not an inpatient of either a psychiatric or general hospital, he is considered an "outpatient," whether the treatment is provided in a physician's office, the patient's home, a nursing home, or outpatient clinic of a hospital. Reimbursement of such outpatient care cannot exceed 50 percent of the expenses for treatment, or $250 in each calendar year, whichever is less. Reimbursement to physicians who provide such "outpatient" care, is limited to $250 a year; no such limitation on reimbursements is set for other illnesses under Part B. The $250 reimbursement limitation does not apply when physicians' services are rendered for medical or psychiatric treatment when the patient is an inpatient, regardless of whether the patient's 150 days benefit period, or 190 days lifetime limit in inpatient psychiatric hospitalization have expired. As noted in a recent report "This circumstance, in view of the restrictions on reimbursement for psychiatric treatment of patients outside the hospital, would seem to encourage hospitalization in the case of needed extended psychiatric services which could perhaps be provided as well or better in an outpatient clinic at less cost to the program."

Obviously, Medicare's 190-day lifetime limitation on treatment in mental hospitals is of particular concern. Similarly, the outpatient must pay 50 percent of the cost of doctor's service and there is an annual limit on outpatient care of $250. This $250, says former Group for the Advancement of Psychiatry (GAP) chairman, Dr. Robert

Butler, could be completely depleted by only five to eight 1-hour-long visits to a psychiatrist who charges moderate fees. A GAP report sums up:

> This system not only affords inadequate coverage but promotes hospitalization rather than care in the community, often contrary to sound psychiatric practice. These limitations in coverage must be brought into line with those respecting physical illness.[16]

GAP also points out that liberalization of present restrictions on mental illness under Medicare has been called for by the Health Insurance Benefits Advisory Council (HIBAC) of the Social Security Administration and by the American Medical Association. Specifically, HIBAC calls for Medicare coverage in community mental health centers.[17]

## 2. MEDICAID

Title XIX of the Social Security Act provides Federal funds intended to help States meet the costs of elderly patients in State mental hospitals when Medicare benefits are exhausted or when they are ineligible for Medicare. The following requirements must be met by the States in order to receive such funds:

a. A joint working agreement between the State agency responsible for the State mental hospitals and the single State agency responsible for the title XIX program.

b. A special staff in the single State agency to oversee the program.

c. Provision of evidence of maintenance of State effort in the funding of mental health services.

d. Show progress toward the development of comprehensive mental health programs through periodic reports.

e. Provision of initial and subsequent periodic medical, social, and psychiatric evaluations of each patient participating in the program.

f. Provision and development of alternatives to inpatient hospital care.

g. Patients included in the program must meet the State eligibility requirement for medical assistance.

Despite heavy expenditures in Federal funds for Medicaid patients, GAP charges that the money spent has not resulted in higher medical standards for elderly patients in State and county mental institutions. "In most States," GAP points out, "moneys designated by law for the improvement of the care of elderly mental patients in State hospitals go into the State general revenue fund and are seldom seen by the hospitals." Labeling the utilization of funds as a "tragic situation," GAP notes that in low-income areas that disabilities frequently accumulate and illnesses remain untreated, resulting in substantial costs in terms of human suffering and socioeconomic losses.

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[16] P. 19, reference cited in footnote 8.

[17] *Mental Health Care and the Elderly: Shortcomings in Public Policy*, Report by the Senate Special Committee on Aging; November 1971, footnote 36, p. 20.

Additionally, the report discusses difficulties in implementing the spirit of Medicaid standards. Numerous States, for example, have failed to meet the requirement that each older patient must have an "individual plan" of treatment. Approximately half of the States, it is estimated, have failed to meet other important requirements, such as the employment of a full-time social worker experienced in mental health and a part-time psychiatrist to administer and organize the program.

## C. SHORTCOMINGS IN COMMUNITY MENTAL HEALTH PROGRAMS

At least five "essential services to keep patients close to their families and friends and end the over-reliance upon large mental institutions" were to be performed at the 2,500 community mental health centers requested by President Kennedy in 1963: 24-hour inpatient services, outpatient services, partial hospitalization, services such as day or night care and week-end care, around-the-clock emergency services, and consultation and education services to community agencies and professional personnel. To date, only 443 of these centers are in operation, although something over $1 billion has been spent on the construction and operation since 1963.

Perhaps the most significant criticism made of the centers was issued by the U.S. General Accounting Office in its August 27, 1974, report. Among the unsolved problems cited:

—Need to establish more appropriate catchment areas.
—Need to improve the centers' capability to operate without continued Federal financial assistance.
—Need to improve program monitoring and evaluation.
—Need to coordinate center activities with those of other community agencies.
—Need to improve the use of construction funds.[18]

The primary concern from spokesmen for older Americans is that centers reach comparatively few elderly. One report estimates that the elderly constitute only 4 percent of the admissions to community mental health centers.[19] In addition, there have been charges of age discrimination. One social worker reported being told by officials of a Washington, D.C., center that they would accept no one over 60.[20] From the elderly's point of view, the centers have not accomplished their purpose: Making it possible for them to receive treatment in their own localities.

### SPECIAL NEEDS OF THE ELDERLY: TWO CASE HISTORIES

As described above, perhaps 2½ million older Americans are in the community, in their own homes and elsewhere, who are going without the mental health services that they need. On the other side of the

[18] P. v, reference cited in footnote 1.
[19] P. 21, reference cited in footnote 8.
[20] P. 22, reference cited in footnote 8.

coin, there are a great number of individuals like Kenneth Donaldson who remain in State asylums, against their will, who could and should be released. There are even greater numbers of people like Bill Dixon who are caught in a revolving door which takes them from wretched conditions in State hospitals to even worse conditions in community boarding facilities, and back again to the hospitals.

### Kenneth Donaldson

Mr. Donaldson's story serves as a reminder that there are still many elderly in institutions who do not belong there. He had been involuntarily committed to a Florida mental institution for 15 years until his release in 1971. He petitioned the courts some 20 times before he finally won his freedom. He told the Subcommittee his story:

> After my experience of 15 years, just being alive is something, and I think it is the most important statement that I will make, to just be sitting here this morning.
>
> I lost hundreds of friends who died from abuse. My experience is unique only in the fact that I lived to tell the story, and largely, that is because of my belief in Christian Science, medication was not forced on me.
>
> Medication that they gave in these hospitals, at least in the hospital I was in, tears a person up, and I had hundreds of friends that died there—that did not live through the experience.
>
> The treatment consists almost entirely of tranquilizer drugs. They usually will give two of them, and the two together is even worse than just double.
>
> An average doctor's call will last less than 2 minutes. The doctor will ask three questions. He will ask what ward you are on; do you take any medication; are you working anyplace. And that will be all—the end of the interview.
>
> *Some patients went as much as 4 years, that I know of, without seeing a doctor, and some of them were on medication all that time.* (Emphasis added.)
>
> My experience over the years is that most of those locked up with me—there were 6,800 in the hospital when I went there, there were 1,300 of us under one doctor for a period of 2 years.
>
> There was one doctor for 1,300 men. He was licensed by the State of Florida only as an obstetrician.
>
> The saddest thing is seeing people die in front of your eyes—not only old men, but old men of course go quicker than the younger ones. They would give up hope after about 2 years. People deteriorate physically when they are in confinement—even the young people. But many of the older people just gave up, and they were not fit really to return to society . . .
>
> What do we want now for these older people? Most of us in those institutions, who have come out, do not want to see Federal money perpetuate such a thing.[21]

[21] In hearings identified in footnote 3.

Asked to expand his statement with respect to the use of tranquilizers, Mr. Donaldson added:

> I have not had time to read everything in the field, but doctors have found out that if one tranquilizer will not do it, two will knock a person out, that is why they give them two, and the idea is to keep them so tranquilized that they cause no housekeeping problems.
>
> There is nothing scientific to it beyond that. I say these people do not need any medical treatment.
>
> That is my observation, and over 15 years, I know I probably have brushed shoulders with 10,000 people on the various wards, coming and going, and I actually know of three that were schizophrenic during that time, who really needed some kind of care, who were afraid to go out in the free world. But the rest of them were no different than you and I are, except that they have been beaten down. That is all.[22]

Senators were visibly moved by Mr. Donaldson's presentation. Senator Pete V. Domenici commented:

> I have not heard, in my 2 years and 9 months in the Senate, of a more serious indictment of our system than I have heard here. I do not think you intended it to be that, but rather to lay it out as it is.[23]

In Mr. Donaldson's landmark Supreme Court decision, the Court ruled:

> A State cannot constitutionally confine without more (presumably, without treatment) a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members and friends.[24]

### Bill Dixon

Mr. Dixon is the plaintiff in the case *Dixon* v. *Weinberger* (1974). His case was brought to the Subcommittee's attention by the spokesmen for the Mental Health Law Project. Ms. Gail Marker, M.S.W. of the project, told his story:

> Mr. Dixon is a 65-year-old involuntary patient at St. Elizabeths Hospital who is confined to a wheelchair. Like Mr. Donaldson, he is a gentle, intelligent, sensitive man. He has been hospitalized for 23 years.
>
> In 1952 he was transferred to St. Elizabeths from a general hospital because he was confused, disoriented, and depressed.
>
> From 1964 to 1972, he spent most of his life in foster homes in the District of Columbia. During those 8 years he was periodically returned to St. Elizabeths for treatment of problems relating to his physical condition.
>
> When he was returned to the hospital in October 1972, he expressed a strong interest in going to another foster home as soon as possible, but was concerned that it be a "good" home.

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[22] In hearings identified in footnote 3.
[23] *Ibid.*
[24] 422 U.S. 563, 45 L. Edition 2nd 396.

In his last placement, he had spent most of his time sitting alone in his room. He felt isolated and shunned. He was confined to the second floor of the home—a clearly dangerous situation, since he was in a wheelchair.

We first met Mr. Dixon about 3 years ago on a ward at St. Elizabeths. He had been referred to us by the Public Defender Service at the hospital.

He told us that he desired to leave the hospital and we agreed to represent him in these efforts. In checking his hospital records and talking with the staff, we learned that Mr. Dixon had been repeatedly recommended for outplacement by his doctors in a suitable foster home which could accommodate wheelchair patients.

In May 1974, 3 months after the lawsuit of *Dixon* v. *Weinberger* was filed, Mr. Dixon was placed in a room and board facility in Washington, D.C.

### Conditions in the Boarding Home

On July 5, 1975, we visited him at this facility. Ms. Susan Opdyke, a social worker from the public defender service at the hospital, accompanied us. The conditions we found at this facility or which Mr. Dixon told us about, were unconscionable.

Mr. Dixon's sleeping room was about halfway below ground level. There were two exit doors in his room—both were closed. The only windows in the room—which were located at or slightly above ground level—were also closed and had a glass plate in front of them, making them difficult if not impossible for Mr. Dixon to open.

They appeared to be painted shut. There was no fan or air-conditioner in the room and although it was only 10 a.m., the room was already hot and stuffy.

Mr. Dixon did not have a phone in his room, nor was there any phone on his floor. There was no buzzer. We do not know how he would have contacted anyone if there were a fire or other emergency.

In fact, we tried to call Mr. Dixon at this outplacement on July 3, 1975, and were told by the operator that it was not a working number.

At the time of our visit, Mr. Dixon had not been served any breakfast, although he had been out of bed since 7 a.m. He stated that mealtimes were usually irregular and that sometimes he would get so hungry waiting for lunch he would ask a roomer to buy him sandwich meat and bread.

He could remember having only one glass of milk during his whole stay at the facility, which lasted 6 weeks, and virtually no fresh fruit.

Consequently, on the same afternoon of our visit, Ms. Opdyke contacted the hospital staff described the conditions we had found and strongly urged that Mr. Dixon be promptly returned to the hospital. He was returned that evening.

The hospital social worker who arranged the placement accompanied Mr. Dixon to the facility. To the best of Mr. Dixon's recollection, she never visited him again at the facility, despite his telling her that he did not like the facility and that he wanted to go back to the hospital until a better place could be found. Only one other person from the hospital visited Mr. Dixon during his entire 6-week stay, and he came only once.

### Return to the Hospital—Again

When he saw Mr. Dixon several days later on his hospital ward, he expressed mixed emotions about coming back to the hospital—he recognized that the conditions in the outplacement were deplorable, but also realized that he had been free of the mental hospital.

Mr. Dixon is still on this same hospital ward today, waiting to be outplaced.

In his 1974 psychiatric evaluation he is described by his doctor as "alert, coherent, cooperative, personable. He is seen to exhibit significant inertia, but his usual apathy and inertia are seen to be quite understandable for a man who has been waiting over 16 months for community placement."

According to an assessment by the hospital superintendent, there is a "significant risk of emotional and/or psychological deterioration" because Mr. Dixon cannot be placed in the required alternative facility and his stay in the hospital is prolonged.

It presently costs about $24,000 a year to keep Mr. Dixon in St. Elizabeths Hospital. It is hard to imagine that he could not receive the services he requires for a great deal less. Since Mr. Dixon does not have psychiatric or medical problems which require active intervention, these needs could be probably best met on an as-needed basis, although he should be examined once a year to insure his condition does not deteriorate.[25]

Ms. Marker added:

> **Mr. Dixon's situation is not unique. Hundreds of thousands of patients in this country are placed in the same dilemma—they must either live in a mental hospital or in a substandard community-based facility.**
>
> **They have no choice—provisions have not been made for a system of adequate mental health care services. But it does not have to be this way.**[26] (Emphasis added.)

## SUMMARY

**In summary, the needs of the elderly are complex and varied. Thousands of individuals are in their own homes and need help. At the same time there are thousands like Mr. Dixon who are confined and who should be released. Happily the numbers of Donaldsons**

[25] Testimony of Gail Marker in hearings identified in footnote 3.
[26] *Ibid.*

and Dixons in institutions have been sharply reduced. Unhappily, some of these individuals were not ready to leave their protected environment. In many cases, little screening was done to determine who were proper candidates for discharge. Many States engaged in "wholesale dumping" of the elderly into nursing homes, boarding homes, foster care facilities, shelter care facilities, or dilapidated hotels. Such facilities have generally been unprepared to care for their needs and paradoxically, the elderly often find themselves worse off in such facilities than they were in the mental institution. Part II describes this trend.

# PART 2

# THE EXODUS FROM STATE MENTAL HOSPITALS

A 1970 report by the Group for the Advancement of Psychiatry (GAP) said: "The effort to solve long-standing problems of chronic hospitalization has now resulted in a swing of the pendulum to rapid and premature discharges from the mental hospital." [27]

Spokesmen for the elderly—such as the National Council of Senior Citizens, executive director, William R. Hutton—have also voiced their concern about "the 'dumping' of aged mental patients from State institutions into commercial nursing homes." [28] This section of this Supporting Paper documents that there have been sharp reductions in the number of patients in mental hospitals (particularly the elderly) in almost every State. It discusses the reasons for such massive transfers, ranging from humanitarian motives to the impact of recent court decisions, and perhaps, most important of all, potential cost savings and the replacement of State dollars with Federal dollars.

## A. THE NUMBERS

In 1967 there were 573 psychiatric hospitals in the United States with 545,913 beds (an average of 2.8 beds per thousand of U.S. population). In 1972, there were 76 fewer State asylums. The number of beds had dropped to 372,603 (1.8 per thousand) and the number of institutions to 497.[29]

Statistics with respect to the numbers of inpatients in State hospitals indicate a similar pattern.

Some 427,799 individuals were housed in State mental hospitals on an average day in 1969, while only 237,692 remained at the end of 1974. The average daily census of the hospitals had been reduced 44 percent in just 5 years.[30]

Figures relating to the elderly are even more dramatic. Over the same 5-year period, there has been a 56-percent drop in the number of older Americans in State institutions on any given day. The numbers: 135,322 aged inmates in 1969, and only 59,685 remaining at the end of 1974.[31]

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[27] P. 12, reference cited in footnote 8.
[28] P. 911, reference cited in footnote 14, part 11, Washington, D.C., Dec. 10, 1975.
[29] Health Resource Statistics, 1973–74, U.S. Department of Health, Education, and Welfare, National Center for Health Statistics, p. 386.
[30] Committee questionnaire sent in 1973, 1974, and 1975, to State Departments of Mental Health from Senator Frank E. Moss.
[31] *Ibid.*

Statistics from a few individual States are revealing:

| | 1969 inpatients over 65 | 1974 | Percent reduction |
|---|---|---|---|
| Alabama | 2,646 | 639 | 76 |
| California | 4,129 | 573 | 86 |
| Illinois | 7,263 | 1,744 | 76 |
| Massachusetts | 8,000 | 1,050 | 87 |
| Wisconsin | 4,616 | 96 | 98 |

These figures are illustrative of a national trend. Complete State-by-State details can be found in the following table:

TABLE 2.—NUMBER OF IN-PATIENTS IN STATE MENTAL HOSPITALS, 1969, 1973, AND 1974, AND NUMBER OVER AGE 65 BY STATE

| State | Total in-patients | | | Percentage of decrease (or increase) | | Total in-patients over age 65 | | |
|---|---|---|---|---|---|---|---|---|
| | 1969 | 1973 | 1974 | 1969–74 | 1973–74 | 1969 | 1973 | 1974 |
| Alabama | 7,601 | 3,810 | 3,067 | −60 | −20.0 | 2,646 | 1,197 | 639 |
| Alaska | 674 | 831 | 148 | −78 | −83.0 | 27 | 11 | 0 |
| Arizona | 1,141 | 659 | 655 | −43 | −1.0 | 384 | 179 | 116 |
| Arkansas | 1,460 | 1,247 | 474 | −68 | −62.0 | 311 | 416 | 491 |
| California | 16,116 | 7,011 | 6,476 | −60 | −8.0 | 4,129 | 997 | 573 |
| Colorado | 10,317 | 11,952 | 5,652 | −45 | −53.0 | 1,250 | 1,379 | 614 |
| Connecticut | 6,068 | 3,892 | 3,597 | −41 | −8.0 | 1,611 | 601 | 568 |
| Delaware | 1,140 | 944 | 966 | −15 | +2.3 | 408 | 380 | 410 |
| District of Columbia | 5,111 | 2,994 | 2,708 | −47 | −10.0 | 2,058 | 1,161 | 1,077 |
| Florida | 9,562 | 8,170 | 6,385 | −33 | −22.0 | 3,952 | 3,241 | 1,966 |
| Georgia | 7,653 | 6,480 | 7,446 | −3 | +15.0 | 2,207 | 1,678 | 1,040 |
| Hawaii | 581 | 250 | 297 | −49 | +18.0 | 182 | 52 | 92 |
| Idaho | 527 | 232 | 207 | −61 | −11.0 | 300 | 100 | 46 |
| Illinois | 28,233 | 15,703 | 14,179 | −50 | −10.0 | 7,263 | 2,065 | 1,744 |
| Indiana | 16,703 | 12,866 | 7,735 | −54 | −40.0 | 4,209 | 2,783 | 1,248 |
| Iowa | 2,230 | 2,954 | 991 | −56 | −66.0 | 1,742 | 431 | 132 |
| Kansas | 5,592 | 5,961 | 1,298 | −77 | −78.0 | 1,175 | 982 | 114 |
| Kentucky | 3,479 | 1,199 | 1,956 | −44 | +63.0 | 873 | 412 | 390 |
| Louisiana | 4,676 | 3,327 | 2,851 | −39 | −14.0 | 553 | 349 | 255 |
| Maine | 2,726 | 1,249 | 1,480 | −46 | +18.0 | 1,072 | 463 | 442 |
| Maryland | 7,161 | 5,950 | 4,968 | −31 | −17.0 | 2,387 | 1,983 | 1,469 |
| Massachusetts | 21,000 | 7,500 | 11,688 | −44 | +55.0 | 8,000 | 2,300 | 1,050 |
| Michigan | 12,293 | 6,865 | 5,922 | −52 | −14.0 | 2,890 | 1,358 | 1,119 |
| Minnesota | 3,792 | 2,710 | 5,584 | +47 | +106.0 | 785 | 574 | 478 |
| Mississippi | 5,955 | 5,627 | 4,107 | −31 | −27.0 | 2,567 | 2,272 | 865 |
| Missouri | 7,496 | 5,210 | 4,054 | −46 | −22.0 | 2,587 | 1,439 | 807 |
| Montana | 1,376 | 1,104 | 1,057 | −23 | −4.0 | 500 | 453 | 139 |
| Nebraska | 1,685 | 765 | 2,815 | +67 | +267.0 | 382 | 70 | 208 |
| Nevada | 439 | 367 | 264 | −40 | −28.0 | 78 | 77 | 19 |
| New Hampshire | 2,074 | 1,446 | 1,306 | −37 | −10.0 | 966 | 672 | 472 |
| New Jersey | 22,857 | 21,616 | 10,695 | −53 | −51.0 | 6,563 | 4,981 | 3,680 |
| New Mexico | 700 | 400 | 337 | −52 | −16.0 | 168 | 61 | 86 |
| New York | 70,765 | 44,042 | 39,770 | −44 | −10.0 | 28,400 | 19,642 | 17,681 |
| North Carolina | 22,507 | 20,010 | 4,829 | −79 | −76.0 | 3,824 | 4,188 | 1,347 |
| North Dakota | 1,208 | 644 | 642 | −47 | −.5 | 360 | 200 | 146 |
| Ohio | 16,934 | 16,726 | 9,793 | −42 | −42.0 | 4,752 | 3,155 | 2,850 |
| Oklahoma | 3,854 | 2,702 | 2,281 | −41 | −16.0 | 713 | 552 | 507 |
| Oregon | 3,360 | 3,340 | 3,491 | +4 | +4.5 | 710 | 730 | 219 |
| Pennsylvania | 27,536 | 18,235 | 16,307 | −41 | −11.0 | 8,360 | 5,811 | 5,597 |
| Puerto Rico | (1) | 1,154 | 995 | (1) | −14.0 | (1) | 129 | 166 |
| Rhode Island | 1,881 | 1,845 | 3,456 | +84 | +87.0 | 610 | 687 | 660 |
| South Carolina | 5,805 | 5,484 | 4,330 | −25 | −20.0 | 1,872 | 2,161 | 1,224 |
| South Dakota | 1,229 | 860 | 690 | −44 | −20.0 | 711 | 425 | 194 |
| Tennessee | 6,713 | 4,584 | 4,562 | −32 | −.95 | 1,807 | 1,353 | 1,357 |
| Texas | 14,253 | 9,048 | 8,588 | −40 | −5.0 | 5,464 | 2,876 | 1,447 |
| Utah | 1,284 | 823 | 897 | −30 | +9.0 | 209 | 80 | 96 |
| Vermont | 1,079 | 582 | 475 | −56 | −18.0 | 455 | 182 | 110 |
| Virginia | 11,338 | 7,740 | 6,072 | −46 | −22.0 | 4,100 | 2,700 | 2,614 |
| Washington | 4,252 | 3,738 | 4,286 | +1 | +14.5 | 722 | 430 | 349 |
| West Virginia | 3,950 | 3,507 | 2,869 | −27 | −18.0 | 1,194 | 1,206 | 782 |
| Wisconsin | 10,908 | 7,574 | 1,691 | −84 | −78.0 | 4,616 | 3,222 | 96 |
| Wyoming | 435 | 304 | 303 | −33 | | 160 | 95 | 60 |
| Total | 427,799 | 304,233 | 237,691 | | | 135,322 | 84,959 | 59,685 |

[1] 1969 figures for Puerto Rico not available.

Source: Committee questionnaire.

| Year | Total inpatients | Percentage of reduction | | Total over age 65 | Percentage of reduction | | Percentage of inpatients over age 65 |
|---|---|---|---|---|---|---|---|
| | | 1969 base | 1973–74 | | 1969 base | 1973–74 | |
| 1969 | 427,799 | | | 135,322 | | | 32 |
| 1973 | 304,233 | 29 | | 84,959 | 37 | | 28 |
| 1974 | 237,692 | 44 | 22 | 59,685 | 56 | 30 | 25 |

Why has there been such tremendous pressure to push patients out of State mental hospitals?

## B. IMPETUS FOR THE EXODUS

Projected cost-savings play a large role in mass discharge programs. So do the desire to replace scarce State dollars with Federal dollars from the new Supplementary Security Income program (SSI); the impact of recent "right to treatment" Court decisions, the development of new drugs and the evolution of treatment programs, pressure from the proprietary nursing home (and boarding home) industry, as well as humanitarian motives inherent in the conviction that mental hospitals are unhealthy environments for people.

### 1. HUMANITARIANISM

The literature in the field of mental health is replete with the evidence suggesting that mental institutions are hazardous to health. High incidences of mortality and morbidity are associated with placement or entry into State hospitals. Loss of liberty can interact with the loss of community orientation, often producing emotional and/or psychological deterioration. Among the saddest examples that come to light from time to time are persons committed apparently for the singular reason that no one could understand their native language. Similarly, several studies have indicated that many supposedly mentally ill patients were really physically ill. For example, strokes or toxic confusions can mimic psychotic symptoms.[32] Such symptoms may also be side effects from taking large doses of psychoactive drugs (e.g., tranquilizers) over a long period of time.[33] In fact, one study reports that 16 percent of the patients in one State hospital geriatric ward had side effects from tranquilizers. The study concludes that at least 20 percent of all admissions to geriatric wards "are precipitated by the adverse effects of psychoactive drugs." [34]

In short, most Americans will agree that institutionalization should be the absolute last resort. Wherever and whenever possible, individuals should be maintained in independence in their own homes. This is the very essence of human dignity.

[32] "Protective Services for the Elderly: Commitment Guardianship, and Alternatives," 13 William and Mary Law Review, p. 595, by John J. Regan.

[33] "Drug Issues in Geropsychiatry" edited by William E. Fann, M.D. and George L. Maddox, Ph. D., proceedings of the Conference on Psychopharmachology and Management of the Elderly Patient held at Duke University in June of 1973, p. 19. For related discussion see Supporting Paper No. 2, "Drugs in Nursing Homes: Misuse, High Costs, and Kickbacks."

[34] *Ibid.*

## 2. DRUGS AND NEW TREATMENT TECHNIQUES

In the past 20 years, scientists have created most of the so-called wonder drugs which have changed our lives so dramatically.[35] Antibiotics have been developed to help control infections, new drugs ease the pain of arthritis—and seemingly every pain and malady with which man is affected. In terms of treatment of the mentally ill or impaired, the development of psychoactive drugs has proved to be a major breakthrough.

Properly managed, such medication can have positive results in helping to control violent patients. Other drugs are helpful in relieving tension or anxiety or to increase the flow of blood to the brain. The result has been to make it possible to release patients which heretofore would have been necessary to retain in the institution.

Moreover, new therapeutic techniques have been developed, making it possible in many cases to release patients. One such development is called "reality orientation": This is the term for the program developed by Dr. James Folsom, director, VA Hospital, Tuscaloosa, Ala. The basic aim is to put a regressed patient into renewed contact with the world around him. The program can be conducted in a class or through informal interaction. Orientation is begun at the most basic level. If a patient does not know his own name, he is taught.

If he does not know where he is from, he is told. Then, the patient is taught the day, the week, the month, the year, his age, et cetera. Typically, patients may exhibit confusion for many weeks. Yet, once a patient is able to grasp any bit of information such as his name, the name of his spouse, his birthday, he begins to recall and use ever-increasing amounts of previously known material.[36]

Another technique is called "sensory training." It is aimed at the consequences of the complete dependence found in many State hospitals. When patients sit staring into space, receiving total care with nothing to do but breathe, swallow, and excrete, dependence develops to the point where they no longer care. Sensory training supplements reality orientation and attempts to stimulate the patient. It is particularly useful for patients manifesting psychomotor retardation and poor discrimination between, and response to, environmental stimuli. The therapist gathers patients in a small group. They are asked to identify objects by smell, taste, hearing, touch, and sight.[37]

## 3. THE IMPACT OF RECENT COURT DECISIONS

Decisions by State and Federal courts have played a major part in decisions made by States to transfer large numbers of patients from State hospitals into nursing homes and other facilities. First and foremost is the Supreme Court's decision in the *Donaldson* case. (See p. 713 for earlier discussion.)

### DONALDSON *v.* O'CONNOR

Mr. Paul R. Friedman, managing attorney for the Mental Health Law Project, prepared a summary of the *Donaldson* decision under

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[35] Seventy percent of the drugs now on the market were unavailable 20 years ago. See Supporting Paper No. 2, p. 245.

[36] See Supporting Paper No. 6, "What Can Be Done in Nursing Homes: Positive Aspects in Long-Term Care."

[37] *Modern Nursing Home*, June 1972, p. 40.

the title: "The Supreme Court Unlocks the Doors." Portions of this insightful analysis are reprinted below: [38]

> On June 26, 1975 a unanimous United States Supreme Court opened for judicial scrutiny the locked doors of the back wards of many shameful institutions which we euphemistically call "mental hospitals."
>
> While the actual holding in *O'Connor* v. *Donaldson* is very narrow, its significance is great indeed and its ramifications are only beginning to be felt. *Donaldson* is one of the very few cases in its almost two-hundred-year history in which the Supreme Court has addressed the constitutional rights of civilly committed mental patients. At its most basic level, the opinion says that the members of our highest court care about the plight of the mentally handicapped and recognize that the United States Constitution protects this under-represented minority just as it protects other citizens.
>
> WHAT DOES THE OPINION SAY?
>
> The narrow legal holding of *Donaldson* is that *"a state cannot constitutionally confine without more* [presumably, without treatment] *a non-dangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members and friends."*
>
> Writing for the unanimous court, Justice Stewart rejected the notion that mental patients might be exiled by a community which finds their presence upsetting: *"May the state fence in the harmlessly mentally ill solely to save its citizens from exposure to those whose ways are different? One might as well ask if the state, to avoid public unease, could incarcerate all who are physically unattractive or socially eccentric. Mere public intolerance or animosity cannot constitutionally justify the deprivation of physical liberty."*
>
> The court held further that *"mental illness alone"* cannot serve as a basis for *"simple custodial confinement."* May someone be confined because he or she would be better off in an institutition? *"That the state has a proper interest in providing care and assistance to the unfortunate goes without saying. But the mere presence of mental illness does not disqualify a person from preferring his home to the comforts of an institution."*
>
> WHAT ELSE DOES IT IMPLY?
>
> While the *Donaldson* case was decided narrowly, the opinion is rich in ancillary holdings and implications. The court noted that adequacy of treatment *is* a justiciable question, that states are under a continuing obligation to review periodically the justifications for individual commitments and that mental-health personnel *can* be held personally liable for bad-faith violations of a patient's constitutional right to liberty. Moreover it suggests that dangerousness should be defined narrowly, that the "least-restrictive alternative" principle protects patients against unnecessary

[38] P. 11, September 1975 Newsletter of the Mental Health Law Project.

institutionalization and even that the term "mental illness" may be unconstitutionally vague.

### WHAT MUST STATES DO NOW?

In the wake of the *Donaldson* decision, states will have to take several immediate steps. They must re-evaluate all of their involuntarily hospitalized patients to identify non-dangerous individuals who are being held against their will in custodial confinement. They will have to establish procedures to review periodically the status of all patients in the system. They would also be well advised to re-evaluate the standards and procedures for commitment under their state laws, since the *Donaldson* opinion indicates that many may be unconstitutionally vague and are likely to be reviewed by the Supreme Court in the not too distant future.

### SOUDER *v.* BRENNAN

This class action was brought on behalf of three mentally ill and mentally retarded working residents of State institutions. One of the plaintiffs had been committed for 33 years and had worked 29 days every month (usually 9½ or more hours per day) during the entire term of his stay. He was paid about $10 a month. The Court ruled that when the State institution receives any consequential economic benefit from the employment of patients, it must pay these patients the appropriate competitive rate.

In the Courts words, the Secretary of Labor was ordered "to implement reasonable efforts applying the minimum wage and overtime compensation provisions of the Fair Labor Standards Act to patient-workers on non-Federal institutions for the residential care of the mentally ill." [39]

The cost to replace patient labor with regular employees would be substantial: Pennsylvania projects a cost of some $12.8 million to replace 10,000 patient workers, Ohio computes $13 million, and Minnesota a conservative $1.6 million to hire 397 people to do the work of 2,143 patients.

In a related development the U.S. Department of Justice is itself suing the State of Maryland in a test case designed to bring about active treatment or release. The suit charges involuntary servitude unsanitary conditions, lack of privacy, and violation of the eighth amendment's bar against cruel and unusual punishment.

## 4. COST SAVINGS

This is undoubtedly the primary reason for removal of thousands of patients from State hospitals into nursing homes and other facilities. The average national cost of keeping a patient in a State mental institution is presently estimated at about $1,000 a month or $12,000 a year, such costs can be a great deal higher. For example, Gardner State Hospital in Massachusetts estimates a cost of $16,000 a year.[41] In St. Elizabeths Hospital, Washington, D.C., the average cost per patient is now $24,000 a year.[42]

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[39] *Ibid*, p. 6.

[41] "The Transfer of State Hospital Resources to Community Programs," Hospitals and Community Psychiatry by Dr. Malcolm Sills, September 1975, p. 580.

[42] Testimony of Gail Marker, op. cit., footnote 3.

It should be clear that given the strain on many State budgets, tremendous pressure has been brought to bear to move patients into nursing homes, boarding homes, and old hotels. The advantage to the State is even greater than it appears. Typically, States must assume 100 percent of their mental hospital costs. If patients can be released and added to the States welfare rolls (including Medicaid) the Federal Government will then pay at least half of the cost. If the State releases the patients unconditionally and maintains the fiction that they are simply indigent elderly, the Federal Government will pay 100 percent of the cost through the new Supplementary Security Income program described below.

In short, potential cost savings—some say "economic expediency"—have accelerated transfer of thousands of elderly into nursing homes and boarding homes. This practice is defended by some as "returning patients to the community." Other observers characterize this phrase as a euphemism and decry the efforts to substitute Federal for State dollars.

## 5. SUPPLEMENTARY SECURITY INCOME

In 1972 the Senate Finance Committee found that many States had been using old age assistance funds under titles I, IV, X, and XVI, of the Social Security Act to support individuals with mental disabilities in shelter care facilities, rest homes, and boarding homes. A few States license such facilities which offer only minimum supervision (not nursing care) but most do not. The concern of the Finance Committee was that the States were using the old age assistance funds as a means to sidestep compliance with Federal minimum nursing home standards.[43]

Thus, States could make use of the facilities in their States which could not meet Federal requirements. (See Supporting Paper No. 5, *The Continuing Chronicle of Nursing Home Fires.*) The key to the "dodge" is that the States maintained the fiction that the individuals in question were independent. Old age assistance checks, of course, were cash payments addressed to qualifying individual payees instead of "vendor payment" which would list the nursing home as payee. In fact, the individual would endorse his check over to the facility owner (often, endorsement was accomplished by the owner marking an "X" on the back of the check).

Recent fires in Honesdale, Pa.,[44] and Rosecrans, Wis.,[45] brought this practice out into the open. In Honesdale, the State of Pennsylvania was found to be using old age assistance (title I) funds to support individuals in what the State called a "skilled nursing home." In reality the facility was little more than a boarding home. A similar pattern emerged in Wisconsin where 10 elderly patients died. Seven of the home's residents were supported by old age assistance funds; three of the patients needed "skilled nursing care" as determined by a State nurse the day before the fire. In 1973 the attorney general of Missouri issued a statement that there were some 755 unlicensed facilities in his State housing more than 10,000 patients.[46]

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[43] See *Nursing Home Care in the United States: Failure in Public Policy, Introductory Report*, p. 54 and following for detailed discussion.
[44] Oct. 19, 1971.
[45] Apr. 4, 1972.
[46] Jan. 16, 1973, editorial in the St. Louis *Globe Democrat.*

To head off this practice, Congress enacted section 249(D) of Public Law 92-603 which precludes Federal matching under titles I, X, XIV, and XVI, if a State is providing medical or remedial care in an institution certified under title XIX (Medicaid). What this means is that if a patient needs skilled nursing care or intermediate (nursing) care, States must be provided such assistance under the Medicaid program or not at all. By the same token, Medicaid funds are available only to patients appropriately placed in facilities meeting Medicaid skilled nursing or intermediate care standards.

Another congressional initiative was the replacement of the old age assistance program (which had been part Federal and part State money) with an entirely Federal program called Supplementary Security Income. This program placed a Federal minimum floor of $130 a month (now $157 a month) under the incomes of the blind, disabled, and aged poor. States which had higher old age assistance payments were required to supplement the $130 figure so that no recipient would have his benefits cut. Significantly, SSI funds were prohibited to individuals housed in institutions. The single exception is that the poor aged in nursing homes are eligible for $25-a-month personal spending allowance. Once again SSI is a cash grant program, not a vendor payment program. Another anomaly of the SSI program is that if individuals live with a related person, their SSI is reduced by one-third. This clearly creates a disincentive for the poor aged to live with relatives; it has also contributed to the birth of a for-profit boarding home industry.

At present, two trends are evident with respect to SSI. The first is that thousands of patients have been released from hospitals and enrolled in SSI. In theory, SSI recipients can use the cash grant for any purpose they wish. They may elect to pay any portion for housing and to select their own quarters. But in reality, the States more often than not place people in specified boarding homes. These facilities usually offer nothing more than board and room, closely approximating what individuals are paid under SSI. In most States that means $157 a month.

In the second instance, a few States have recognized that they have some greater responsibility for the patients. They require licensing and meeting of certain minimum standards with respect to fire safety, periodic medical and psychiatric evaluation, activities and food services. Generally, the States add some of their own money to the $157 in Federal SSI payments so that the boarding home or shelter care operator may be receiving some $300 to $400 a month to care for patients.

In both cases, these trends run counter to SSI law but at least in the second example there is some recognition on the part of the State of its continuing responsibility. There are efforts to protect patients with reasonable standards and to provide reasonable payment for needed services.

New York and Illinois have been using SSI funds in this second manner. Domiciliary Care Facilities and Shelter Care Facilities are the names these States give their boarding homes which care for large numbers of former mental patients.

Even though the facilities in the above two States are licensed, there is some supervision by the respective departments of social welfare and departments of health. However, the Social Security Administration recently pointed out that the use of these funds in the manner described above is technically illegal. This action resulted in the introduction of S. 1555 by Senator Moss. The bill would allow any State to use SSI funds to care for their mentally impaired and disabled, provided: (1) The State license such facilities, (2) the facilities meet certain Federal minimum standards, (3) the State provides not less than $100 a month in State moneys to supplement the $157 in Federal SSI payments, and (4) the States provide rehabilitation and habilitative services.[47]

As will be noted below, good food, good care, recreation and habilitative services are virtually nonexistent in many boarding homes. Facilities licensed by the States even in New York or Illinois continue to present serious problems but they are preferable to the unlicensed and unregulated old hotels and boarding homes which have become the depositories of so many mentally impaired aged.

## 6. PRESSURE FROM FOR-PROFIT NURSING HOME AND BOARDING HOME INTERESTS

Another factor whose impact is significant but difficult to totally assess, is the pressure brought to bear by spokesmen for proprietary nursing home and, more commonly, boarding home operators. There have been a number of reported instances where nursing home operators have offered bids for the patients to be discharged. In his testimony at the 1971 Subcommittee hearings, Dr. Jack Weinberg, clinical director of the Illinois State Psychiatric Association, told of being given the job of moving more than 7,000 aged from State hospitals into "the community." He accepted the job briefly but quickly resigned when he learned that discharges were to be made wholesale and that careful screening and evaluation on a patient-by-patient basis was not going to be permitted. Nevertheless during his brief tenure he was offered a stipend of $100 a head by a nursing home operator for every mental patient he transferred to a particular Illinois facility.[48] He rejected the offer.

## SUMMARY

In summary, many factors come together to force the mentally impaired out of State hospitals into nursing homes, boarding homes, old hotels—and sometimes into the streets. The desire to save State dollars is clearly the most important reason. The enactment of the SSI program presents the opportunity of substituting Federal for State dollars. Assuming a State is paying $10,000 to $20,000 a year per patient in its State hospitals and that the patient can be placed in boarding homes for $1,884 a year ($157 per month) in Federal SSI funds, the net impact on the State budget is a gain of thousands of dollars per patient per year! This is not to downplay the impact of recent Court decisions. The case law has presented the States with the option of providing care and treatment for their involuntarily

[47] S. 1555 was introduced by Senator Moss on Apr. 29, 1975, and is now pending before the Senate Finance Committee.

[48] Reference cited in footnote 14, part 13, Chicago, Ill., Apr. 3, 1971, p. 1222.

committed patients or turning them loose. Most States have chosen the latter option. The degree to which this is true can be seen by reviewing table 2 (page 719). But these States are only buying time because of the inexorable march of litigation spearheaded by the Mental Health Law Project, and the American Civil Liberties Union. Recent actions brought by these groups would extend the right to treatment to nursing homes, boarding homes, and community based facilities of all kinds.[49]

[49] See testimony of Benjamin W. Heineman, reference cited in footnote 3.

# PART 3

## WHERE HAVE ALL THE PATIENTS GONE?

In a recent speech, Senator Frank E. Moss described significant dangers for the elderly from the rapid and accelerating discharge of former mental patients into nursing homes and boarding homes. These dangers include:

- Patients often are being discharged wholesale and indiscriminately. There is virtually no screening procedure to decide who are proper candidates for discharge.
- There is no followup to determine if patients are properly placed in their new facilities.
- Nursing homes, boarding homes, or shelter care facilities are ill-equipped to handle these patients. It is not only that there are no psychiatric services available and no plans to rehabilitate patients because dangers are also present when discharged mental patients are mixed with those who are physically ill; the effect is to reduce all patients in the home to the lowest common denominator. Put another way, individuals tend to reflect their environment, and the "normal" elderly soon manifest the behavioral patterns of the disturbed patients they see around them.
- There are few, if any, recreational services or activity programs in the smaller community-based facilities.
- While most States have standards for nursing homes, few have any standards for boarding homes. Consequently, abominable conditions exist in some homes where patients are now being supported by Federal Supplementary Security Income.
- There is a heavy, and perhaps unwise, use of drugs to help manage patients and make up for the fact that these facilities are badly understaffed.
- Many States have given complete and final discharges to individuals placing them together in certain areas of our cities which have become instant "geriatric or psychiatric ghettos." For example, 13,000 patients were discharged from Illinois State hospitals into an area called "Uptown" in Chicago. In Washington, D.C., hundreds of patients will be found near Ontario Road, NW.[50]

Part 3 of this Supporting Paper examines placement of patients and the quality of life for them in these alternative settings. Section A examines how well nursing homes handle these patients. Section B discusses other facilities which do not provide nursing care under the general heading "The Boarding Home Crisis." The stark conclusion is that in most cases patients are better off in State institutions.

[50] Op. cit., footnote 12.

## A. THE NURSING HOMES AND MENTALLY DISTURBED PATIENTS

Most experts would agree that the ideal setting for the mentally impaired is a small community based facility of some type. Dr. Karl Menninger endorsed this recommendation provided that such facilities offer the kinds of programs, services, and therapy that patients require.[51] Nursing homes seem to fit this role very well. They have traditionally cared for the physically ill elderly, but the majority of their patients have some degree of mental impairment. Unfortunately most experts agree that most nursing homes, even "Skilled Nursing Facilities," do not have the staff or training to provide the therapeutic environment that patients need. Because transfers from State hospitals continue and because boarding homes and old hotels are hopelessly inadequate, it is apparent that nursing homes will increasingly be asked to bear the burden of caring for the mentally retarded or impaired. The basic premise of this Supporting Paper is that nursing homes will need help if they are to play this demanding role effectively.

### TENNESSEE: AN EXAMPLE OF THE STATE'S DILEMMA

In 1969, the 86th General Assembly of the State of Tennessee passed House Joint Resolution No. 35 noting that 25 percent of the residents in State mental institutions were over 65 and that their primary need was for nursing, not psychiatric care. The resolution expressed the State's dilemma: "A network of State operated or State supported nursing homes for the aged mentally ill might be the only solution unless private enterprise with its encouragement from State, local, and Federal governments is able to develop the facilities relating to overcrowding." [52]

The legislature resolved to study the facts and report to the 87th general assembly.

In its report, the legislature concluded that 65 percent of the State's almost 2,000 aged in State mental hospitals did not need to be there. It was stated that patients in mental hospitals were not dissimilar to those in nursing homes. It was further estimated that there were 11,000 additional people in the community (not in institutions), with mental problems requiring immediate attention. The need was fixed for 12,000 additional beds.

Rather than recommending the State construct a network of State nursing homes, it was decided to remove the obstacles that prohibited existing proprietary nursing homes from expanding to meet this need. The primary obstacle was a regulation that Tennessee nursing homes "could not admit patients suffering from insanity or abnormal mental conditions that clearly disturb other patients." It was recommended that this regulation be changed and that family or foster care homes be created. This would allow the placement of not more than two individuals with a private family. Moreover, it was recommended that a special rate be offered to nursing home administrators agreeing to

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[51] Op. cit., footnote 15.

[52] "Study on Nursing Homes for the Aged Mentally Ill, 1970," Final Report of the Legislative Council Committee, State of Tennessee.

take patients with psychiatric symptoms and that evaluation and screening procedures be established to review prospective patients and the need or desirability of admitting them to State mental hospitals in the future.[53]

This plan has been implemented. In 1969 there were 6,713 patients in Tennessee mental hospitals on any given day. At the end of 1974 there were 4,562 patients—a reduction of 32 percent. This is below the national average of 44 percent reduction in these same 5 years. Similarly, the decrease in the numbers of elderly has been much lower than the national average. There were 1,807 elderly in the State's hospitals in 1969 and 25 percent less, 1,357, at the end of 1974. Nationally, there has been an average 56 percent reduction in the number of aged inpatients.

## NEW JERSEY: MORE THAN ONE ROAD TO TRANSITION

Programs for gradual discharge of State hospital patients were begun in New Jersey, and special emphasis has been placed upon developing a variety of transitional settings for special needs of individual patients.

The State Department of Institutions and Agencies has worked, for example, with two community mental health centers and a hospital to develop care facilities for patients discharged from Greystone Park Psychiatric Hospital.*

One of the projects is Project Haven,** developed in cooperation with the Central Bergen Community Mental Health Center (Paramus, N.J.). This center is in a suburban area where inexpensive housing is so scarce that some Bergen residents discharged earlier from Greystone had been placed in foster homes of Morris County, 20 to 40 miles away. Over the years, the center had developed several forms of transitional accommodations, but the proposed Project Haven was to offer far more comprehensive service than had been available before. Of the 100 placement opportunities, 40 were to be in transitional residences, 10 in contracted nursing homes, and 50 living by themselves or with families.

Supportive services were to be provided. As the project description said:

> It is understood that there will be a ready patient flow between all the facilities and the programs offered by us, and it is anticipated that an individual patient may attend any and all of these service programs in sequence or simultaneously. *The important point is that we will gear the services to fit the need of the individual patient at any one given time.* (Emphasis added.)

As of March 1976, Project Haven was reported to be ahead of schedule, having placed 100 persons. Approximately 45 percent of the patients are over age 50; one is 92 years old.

Funds for the project are provided under title XX (formerly title VI) of the Social Security Act.

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[53] *Ibid.*

*For additional details, see appendix 2, p. 780.

**Information on Project Haven provided by Center Project Description (see appendix 1, p. 775) and in conversation with Central Bergen Community Mental Health Director Aristide H. Esser, M.D.

## ALABAMA: TWO SOURCES OF FUNDING

The December 1975 issue of *Alabama Social Welfare* reports that a contract in excess of $1.5 million had been signed by the State Pensions and Security Commissioner and the Mental Health Commissioner to fund transitional homes for the mentally ill.

The article provides these additional details:

> The contract calls for statewide coverage. The five existing transitional homes can continue present services due to contract monies and ten new homes can be established. Each of these 15 group homes will serve persons from designated counties. An estimated total of 432 eligible persons will benefit, following signing of subcontracts with the individual homes.
>
> The services come under title XX of the Federal Social Security Act. Those eligible will include persons being discharged from mental hospitals or who would otherwise require continued hospitalization. Such persons, however, must meet income requirements of title XX or be recipients of Supplemental Security Income under Social Security or Aid to Dependent Children through the Department of Pensions and Security.
>
> Each home will provide room and board, social, recreational, medical, educational, vocational, and rehabilitative services with psychiatric and consultative services available through the local mental health centers.
>
> Of the $1,503,333 in monies, three-fourths of the total is provided by Pensions and Security through title XX, with the State's share (the remainder) furnished by Mental Health.

As these examples indicate, some States apparently have begun to move slowly and innovatively. In most States, this has not been the case.

## WHAT KIND OF PATIENTS DO NURSING HOMES CARE FOR?

In Tennessee and elsewhere, mental patients transferred to nursing homes exhibit a wide range of abnormal behavior. Dr. Bernard A. Stotsky, writing in *Nursing Homes*, suggests that disturbed patients fall into five categories:

> 1. *The depressed patient.* He is in a depressed mood, withdrawn, retiring, quiet, and cooperative but in a passive way; apathetic, displays a lowered response to people and to activities, underactive, slowed in movements, speech, and thought, is overly preoccupied with bodily functions and physical complaints, and sometimes follows strict rituals in daily routine. These patients sleep poorly, awaken early in the morning, have trouble getting going, and eat poorly.

2. *The passively uncooperative patient.* He is quiet, sullen, negativistic, and stubborn, avoids people, refuses to follow routine, wanders off and gets lost, and may refuse to eat. In extreme situations, such patients become rigid, immobile, mute, and withdraw completely from all activity and contact. Unless actively treated, they may die.

3. *The disturbed, aggressive patient.* This is the "hot potato," threatening and assaultive to others, destructive of property, overactive, who frequently paces up and down, is verbally aggressive, unpredictable in behavior, and may manifest disturbed sexual behavior. He is aggressively uncooperative; his speech is frequently loud and boisterous; he feels watched and threatened by others, and often responds to voices which threaten or accuse but may sometimes extol.

4. *The agitated patient.* He is tense, jittery, anxious, handwringing, sometimes is self-mutilating or destructive to his own possessions and clothes, is inappropriately preoccupied with bodily functions (feeling of rotting or wasting away), and has feeling of being doomed. He may threaten or attempt to hurt himself. Such a patient is in terror, often cannot sleep, rest, or eat. He is afraid of being left alone, becomes confused and disoriented, and needs constant reassurance. Unless treated vigorously, such a patient may push himself to exhaustion and die.

5. *The deteriorated patient.* He is confused, disoriented, and suffers severe intellectual impairment; often he is incontinent and is unable to bathe, feed, or dress. He may ambulate with difficulty; his personal hygiene is poor; his behavior is characterized by unusual mannerisms and facial expressions, silliness, unpredictable giggling or crying; his speech is irrelevant and, at times, incomprehensible. This patient may get into other patients' beds out of confusion and may show reversal of sleep pattern. He may show aggressive, negativistic, depressed, or agitated behavior also, but the hallmark of his condition is the intellectual and emotional deterioration. Many of these patients do not survive for long, though, with modern medical methods of treatment, a surprising number survive for extended periods.[54]

## HOW WELL DO NURSING HOMES MANAGE PATIENTS WITH MENTAL DISABILITIES?

With some exceptions, as noted below, the answer is "poorly." There are many reasons for this conclusion. It is a direct result of the limited numbers of personnel in nursing homes generally. There are 5.3 nursing home employees for every 10 patients. The great majority of the employees are aides and orderlies, most of whom have no prior experience or training, some literally hired off the street and most paid the minimum wage. There is a turnover rate of 75 percent a year among such employees. At the same time there are comparatively few registered nurses in nursing homes (about 65,000 for 23,000

[54] *Nursing Homes*, February 1967.

homes). Few of these nurses have psychiatric training, spending more than 50 percent of their time with administrative duties.[55] They show a turnover rate of 71 percent a year.

The February 1967 edition of *Nursing Homes* featured an article on "The Care of the Mentally Ill" in which all of the above facts were noted and confirmed. Speaking of the problems nursing homes have in caring for the mentally impaired elderly the article notes:

> Some of the deficiencies encountered in the homes were (1) lack of staff tolerance and understanding for the mentally ill patient, (2) need for activities for the confined patient, (3) poor social adjustment by relatives and patient, (4) limited information regarding patients referred to the facility, (5) difficulties in adjustment to medication, (6) reluctance of the private physician to familiarize himself with tranquilizing drugs, and (7) procedures used by the public assistance department for obtaining drugs.[56]

Other spokesmen such as Dr. Joseph Zubin and Dr. Paul H. Hoch protest the overuse of the unfortunate term "senility" (see earlier discussion pp. 707) with respect to the aged sent to nursing homes. They contend that the liberal use of this term as a diagnosis tells the untrained nursing home personnel that the patient is "hopeless" and that they need not provide any treatment at all. They comment:

> The fact that these disorders may very properly be called "senile psychoses" due to cerebral arteriosclerosis or senile deterioration, or better, chronic brain syndrome, is evaded by attributing them to "senility" and by the use of other euphemisms. In this way the medical-psychiatric nature of many disorders is obscured and attempts to deal with the problems of their management result in an administrative, social and economic tangle to which physicians often may inadvertently contribute.[57]

Dr. George Warner, then director of the Bureau of Long-Term Care, New York State Department of Health, made a similar comment in an interview in *Patient Care* magazine:

> From the viewpoint of the regulatory agencies, the group of patients who are least satisfactorily managed and present the toughest challenge to physicians and staff are those in the junk-can diagnosis known as "mental impairment," but who, in fact, exhibit various detailed, possibly treatable symptoms of senility and related mental problems.
>
> Here again, we find that a lack of close attention and leadership by the physician results in the "management" of these patients via overutilization of the depressant/stimulant drugs, physical restraints, or both.[58]

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[55] See Supporting Paper No. 4, "Nurses in Nursing Homes: The Heavy Burden (The Reliance on Untrained and Unlicensed Personnel)."
[56] Op. cit., footnote 54.
[57] Hearings by the Subcommittee on Long-Term Care, 1964, pp. 251 and 252, "The Psychopathology of Aging."
[58] *Patient Care* magazine, Mar. 30, 1972, p. 59.

A number of the criticisms of nursing homes relate to the unfair burden placed on the existing nursing staff already overburdened with the demands of the physically ill elderly. Dr. Leonard Gottesman, then of the University of Michigan Division on Gerontology and now with the Philadelphia Geriatrics Center, said:

> In many States the response to severe overcrowding of mental hospitals is to send the patients directly to nursing homes. There is a vigorous effort being made to return large numbers of mentally ill geriatric patients from mental hospitals to community facilities, thus shifting part of the patients' support to the Federal Old-Age Assistance Program. However, the trend is potentially dangerous because there are no real plans for improved patient care in community nursing homes. Most State hospitals are releasing or referring geriatric patients to local facilities without knowing what effect these new settings will have on the patients' mental health and well-being.
>
> Care of the seniles poses a great challenge and there is much we need to know about separation or integration, about diet, staffing, etc. It seems to me that there is a critical point beyond which it is impossible to absorb seniles in the general population of a home. By this I mean that from the studies I have made in a home with 50 residents, six or eight confused seem to be absorbed or tolerated by the group. This does not deny that there are problems—the visible symbol of failure, wandering, soiling—but there are always some residents and staff who are altruistic and will look after the less fortunate. Beyond that number it seems to be defeating. The disproportionate amount of staff time required to look after the confused subtracts from the time available for the others.[59]

Dr. Charles Kramer expands this theme, pointing out that physicians are infrequent visitors to nursing homes and that this is particularly true of psychiatrists:

> Most of my psychiatrist friends shy away from this field. That means that a girl with only a high school education may be dealing every day with serious psychological problems, with serious interpersonal relationship problems, and she is expected to manage, not only these, but severe physical disability in patients as well.
>
> I have worked in almost every kind of institution, and the patients in nursing homes and extended care facilities are as debilitated and disabled and multiple handicapped as any that I have run into. The only other place that is true would be in geriatric wards in State hospitals, where patients have a combination of physical and psychological impairments.[60]

Another dimension of this problem is the effect of mixing patients with mental and physical disabilities. Experts have noted that when the mentally impaired are placed in a facility housing competent but

[59] Monograph in Committee files.
[60] Op. cit., footnote 15.

infirm elderly, the effect is to reduce the patient population to the lowest common denominator. Dr. Lionel Z. Cosin, internationally known British expert on geriatrics, explained it this way:

> Very often the confused elderly pick up their confusion, their first symptoms of violence and agitation, from the anxious, occasionally violent environment.[61]

In February 1970, Dr. Melvin White, director of the University of Utah's Rocky Mountain Gerontology Center, told the Subcommittee:

> I question very seriously if patients who are being placed in nursing homes primarily for psychiatric treatment require the same type of home, the same facilities as those who are primarily there for extensive medical treatment. Perhaps we tend to place psychiatric patients in homes that are large and some of the personalized care aspects are missing that they need for their particular type of treatment.[62]

After examining all these factors over a long period, the late Margaret Blenkner commented a few years ago:

> Nursing homes have little to do with the mental health needs of the aged now and I hope will have even less in the future.

She continues:

> Nursing homes are, by and large, less capable of meeting the mental health needs of their residents than the institutions from which many of the mentally ill in them have been transferred (Goldfarb, 1961, 1962; Gottesman, 1964; Rhetts & Stotsky, 1965). A not inconsiderable share of the mental health problems of nursing home residents arise out of their being there. Old people cling tenaciously to home and familiar surroundings, and there is probably a primitive wisdom in their doing so. Several studies (Camargo & Preston, 1945; Whittier & Williams, 1956; Lieberman, 1961, 1965; Aleksandrowicz, 1961; Ferrari, 1962; Aldrich & Mendkoff, 1963; Blenkner, Jahn, & Wasser, 1964; Miller, 1964; Prock, 1965) have indicated that relocation of the old may be hazardous, especially if it is not of their own choosing; men and animals, as well as plants, are subject to transplantation shock. It is entirely possible that in our zeal to protect the elderly we may sometimes overprotect—at the cost of their very survival.[63]

## NURSING HOMES: THE EXPERIENCE OF THE STATES

Testimony presented at hearings of the Subcommittee on Long-Term Care provide additional examples of experiences in States which provide aid in evaluating nursing home performance with the mentally impaired.

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[61] "Trends in Long-Term Care," part 14, Washington, D.C., June 15, 1971, pp. 1389–91.
[62] "Trends in Long-Term Care," part 7, Salt Lake City, Utah, Feb. 13, 1970, p. 601.
[63] Monograph, "The Place of Nursing Homes Among Community Resources, 1965."

## California

A recent story in the *Los Angeles Times* reported that 32 patients had died within a very short time after the State of California began its program to transfer patients from Skilled Nursing Facilities to Intermediate Care Facilities. The transfers from higher to lower (and thus less expensive) levels of nursing home care were undertaken against the wishes of the families and, in some cases, against their physicians' advice. In all cases, the State made the determination that the patients were not sick enough to need 24-hour nursing services.[64]

## Illinois

The Illinois Legislative Investigating Commission in June 1975 released a report on the deaths of seven patients at the Illinois Extended Care Center, a for-profit nursing home in Rockford, Ill. The commission asserts that five of the seven deaths were "avoidable," charging that negligence on the part of the nursing staff was a major factor in the deaths. "Insufficient staff observation and treatment, unacceptable and unprofessional attitudes, general irresponsible nursing performances were the rule rather than the exception." [65]

In 1971, the Subcommittee subpoenaed the records of the Melbourne Nursing Home, which housed great numbers of discharged mental patients in Chicago. The owner, Mr. Daniel Slader, admitted under oath that he made $185,000 profit in 1 year while spending 54 cents per day for food.[66] These same hearings dealt with care at the Carver Nursing Home, which also housed discharged mental patients. On May 5, 1972, a fire in this facility of "suspicious" origin claimed the lives of 10 of the home's 41 patients.[67]

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[64] *Los Angeles Times*, July 5, 1972, reprinted in "Trends in Long-Term Care," Part 20, p. 2523.
[65] "Seven Patient Deaths at Illinois Extended Care Center," a report to the Illinois General Assembly by the Illinois Legislative Investigating Commission, June 1975, p. 203 and following.
[66] P. 1259, hearing cited in reference 14, Part 13, Chicago, Ill., Apr. 3, 1971.
[67] See p. 461, Supporting Paper No. 5, "The Continuing Chronicle of Nursing Home Fires."

—Chicago Tribune Photo.

Patient sits unattended at Melbourne Nursing Center, Chicago, Ill.

—Chicago Tribune Photo.

Former mental patient tied to a chair in Chicago nursing home.

In October of 1975, the Illinois Legislative Investigating Commission conducted hearings on the deaths of 14 patients in the All Season's Nursing Home of Waukegan, Ill. William P. White, committee counsel, testified that 13 of the deaths were "pneumonia related" and indicated inadequate care. The 14th patient choked to death on a piece of food that became lodged in his throat. White further charged that on September 20, 1973, Earl L. Rosenbaum, the home's administrator, had an employee stand up the body of a dead patient to fit into a service elevator and take it out the back door to avoid notice by inspecting public health officials. He charged that Rosenbaum then had the head nurse hide the patient's records in her car. Rosenbaum was called to testify but invoked his fifth amendment rights.[68]

Other witnesses at the hearings, including past and present employees and doctors, testified under oath that at least one patient was raped and that another had become pregnant while staying at the home.

White also charged that the partners of the All Seasons Home—Norman Ruttenberg, Hyman M. Naiman, and Dan Lipman—claimed a $331,000 loss in 1973, but each collected dividends of $28,500 and salaries of $13,000 in that year.[69]

## Minnesota

Subcommittee hearings in Minnesota produced testimony relating to several mentally alert individuals who quickly broke down when

[68] *Chicago Tribune*, Oct. 16, 17, also *Chicago Daily News*, Oct. 16, 1975.
[69] *Ibid.*

the nursing home administrator placed them in a room with the most difficult and mentally impaired patients. One such patient jumped to her death from the third floor of a nursing home because the home gave her a roommate that drank out of the toilet and ran around with her dress over her head.[70]

## NEBRASKA

In testimony before the Subcommittee, Nancy Perlman, director of program development of the American Federation of State, County, and Municipal Employees, stated:

> In Nebraska institutions, nursing home owners, in the most inhumane and indecent way, were bidding on patients depending on how little trouble they would cause. And, if they get patients who are troublesome or difficult to care for, the owners return them to the state hospitals as soon as they can.
>
> On a Thursday approximately 1 year ago, a patient at Hastings State Hospital was transferred to a nursing home 100 miles away. This patient had refused to eat and had been fed through a tube for some time. The same patient was returned to the hospital on Saturday because the nursing home had removed the tube and couldn't get the patient to eat. Asked why they didn't replace the tube, the home said they didn't have anyone on staff who knew how. They did have an LPN but she did not know how to do the procedure.
>
> If any proof is needed that residents are being released before there are appropriate alternative services, it is illustrated by these statistics from Nebraska—12 patients have been released and readmitted a total of 127 times, and one patient has been readmitted 27 times.[71]

## UTAH

On September 15, 1971, a 91-year-old former mental patient admitted pouring a flammable liquid on the floor of the Lil' Haven Nursing Home and igniting it with a match. The result: 6 out of the 19 patients in the facility perished.[72]

## WISCONSIN

Allan Hahn, a social worker with the Milwaukee County Welfare Department, has reported:

> At a nursing home that I was assigned to last year, a mentally ill elderly man was allowed to wander repeatedly onto nearby highways and roads until one night he wandered out into a blizzard and froze to death. His body was found, I think, nine days later.[73]

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[70] "Trends in Long-Term Care," parts 19 A and B, St. Paul, Minn., Nov. 29, 1971, pp. 2218 and 2291.
[71] Hearings cited in footnote 3.
[72] "Trends in Long-Term Care," part 16, Washington, D.C., Sept. 29, 1971.
[73] "Out of Their Beds and Into the Streets," a report by the American Federation of State, County, and Municipal Employees. Feb. 1975. Written by Henry Santiestevan, p. 32.

He added that a survey of one nursing home revealed:

> . . . approximately forty pages of violations, yet this home is still certified to receive the mentally retarded. Recently, at this home, someone cut initials into the buttocks of a patient who is 80 years old and senile. And they still continue to operate and receive funds.[74]

Jim Dalland, another Milwaukee social worker, said:

> We've sent patients to nursing homes who shouldn't go * * *. They should be in mental institutions * * *. There's been a real problem in terms of actual care received in these nursing homes which are acting as mental institutions. They generally have very poorly trained people, they are understaffed, they frequently violate the state standards * * *.[75]

Dalland offered the example of the 18-year-old young woman who had been prematurely released from a county mental institution and placed in a long-term care facility:

> "This girl had spent maybe ten years in that county institution, and had made a lot of progress," Dalland said. "She had had almost hourly outbursts which were quite damaging to herself and others * * * (but) had come to the point where she was able to function well in the institution * * *."
>
> "Well, due to the pressure (on county facilities) to place kids, they looked around for TS–3 (maximum level of care) certified nursing homes. There weren't any vacancies, so instead of holding her, they changed her rating down about four steps * * *. She was put in a residential facility intended for people who function well."
>
> A few days later, the young woman was falsely accused "in an extremely hostile way" of having taken some money that was missed by another patient.
>
> "She ripped her face apart," Dalland said. "It was just horrible. We had to send a county ambulance over to get her. She had mutilated herself because the nursing home couldn't follow simple instructions not to confront her, never scold her, never threaten her."
>
> "Now as far as I know she is still institutionalized at a county facility * * *. Now she's disfigured."[76]

Ruth Brown, a long-term mental health worker in Milwaukee institutions, stated that nursing homes "handpick" the patients they want from mental institutions:

> "They come in and look at the patient," she said, "and, if they are too fat and look like they're not easy to care for, they'll reject them * * *. We feel that, if they're going to take patients and try to rehabilitate them, as they claim, they should take a look at the medical record to see if they have the facilities or personnel in their nursing home to deal with them * * *."[77]

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[74] *Ibid.*
[75] *Ibid.*
[76] *Ibid*, p. 33.
[77] *Ibid.*

Don Miner, a union representative at Milwaukee institutions, charged conflict of interest in the county practice of contracting out former mental patients to nursing homes:

> We found that a lot of the good patients, the ones that really didn't require much care, were being shipped out from the county facilities. We found them over at the St. Mary on the Hill Nursing Home. We also found out that the doctor in charge of all the psychiatric services for Milwaukee County was involved with St. Mary's.[78]

In addition, a number of Wisconsin residents have expressed concern about the release of former mental patients from Mendota State Hospital to the Mt. Carmel Nursing Home. The home was cited by the State Justice Department for 136 violations and faced a possible $136,000 fine.

### Vermont: A Positive Example

In contrast to the examples cited above is an excellent program underway in Vermont. There the State Department of Mental Health and the Vermont Nursing Home Association have entered into an agreement to care for patients "who had obtained maximum benefit from their hospitalization but required continued nursing care." Despite initial apprehension on the part of both mental health officials and nursing home operators the program is apparently working successfully.

In a sample survey of 25 patients (previously housed in mental hospitals) 16 were found to be functioning better in the nursing home than at the time of their discharge from the State hospital; 6 were functioning the same, and 3 had deteriorated. Based on this success a proposal was submitted to the National Institute for Mental Health which approved a contract in early 1974.

A report prepared by Paul H. Brodeur, ACSW, community program specialist, Department of Mental Health, notes:

> In sum, the experience of the Department of Mental Health with the nursing homes of the State over the past five years has for the most part been positive.
>
> First, we have found that the quality of care rendered to former hospital patients released into nursing homes has been good.
>
> Second, most of the problems experienced by other states in the deinstitutionalization programs have not been experienced to date in Vermont. This has perhaps best been avoided by developing close working relationships between the hospital, local mental health agencies, and the nursing homes and other alternate care facilities to insure that patients released into such facilities receive good followup and quick intervention prior to the development of crisis. This is and has been a clear priority for the Department.
>
> Third, there has been a serious attempt on the part of the mental health agencies, the hospital, and alternate care facilities to provide services which focus on improving the

[78] *Ibid.*

quality of life that patients experience once they have been released into the community.

Fourth, there has been a genuine interest on the part of nursing homes in providing high quality care and in working closely with the Mental Health Department. The efforts expended by the nursing home and the mental health agencies in developing and implementing their training programs despite the pitifully small amount of money available for the support of this effort, is ample witness to that effort and interest.

It is hoped that further support can be developed for the provision of additional training services and programs between the mental health agencies and the local nursing homes. It is evident that a variety of community care programs are necessary, that nursing homes play a definite role in the provision of these community based services, but at the same time efforts must be developed to insure that adequate attention is paid to the psychosocial aspects of care in nursing homes.[79]

Brodeur described several important considerations which helped to make this program work: (1) There was an effort to prepare patients at the hospital that were to be transferred. This involved resocialization programs, community visits, opportunities to visit nursing homes, etc.; (2) good followup services were provided so that crises that developed subsequent to nursing home placement could be dealt with quickly and efficiently in order to avoid a relapse of the need for institutionalization; (3) many of programs that had been developed at the State hospital to aid elderly patients were brought in to nursing homes. Overall, the major cause for the program's success was the "close working relationships between the mental health agencies and nursing homes." [80]

In his testimony before the Subcommittee, Dr. Karl Menninger provided an example of the kind of dramatic recovery that is possible when even the severely impaired, psychotic and "hopeless" elderly patients are approached with sensitive and highly motivated treatment.

He told about 88 aged patients classified as hopelessly "senile" and psychotic in a geriatric ward of the Topeka State Hospital. Many had been there for more than 10 years; one had been there for 58 years.

Dr. Menninger assigned a young doctor to the ward, along with "a therapeutic team of cheerful young nurses, aides, social workers, and psychiatric residents." With this team, "Each patient became a focus of attention. The ward was transformed from being a museum of dying human specimens into a hospital home in the best sense."

The new program included music, television, canaries as pets, new lighting fixtures, birthday parties, and other activities and physical improvements.

Dr. Menninger reported these results:

> By the end of the year, only nine of these 88 patients were still bedfast. Only six of them were still incontinent. Five had died. Twelve had gone on to live with their families. Six had

[79] "Brief Overview of Aspects of the Relationship Between Nursing Homes in Vermont and the Department of Mental Health," written by Paul H. Brodeur, community programs consultant, Department of Mental Health, Nov. 27, 1974, in Committee files.

[80] *Ibid.*

> gone to live by themselves, and four had found comfortable nursing home provisions outside the hospital. Four of the original 88 were now gainfully employed and self supporting.[81]

Dr. Menninger attributed much of the improvement "to the spirit of the place." He advised nursing homes to give special attention to each patient, making them feel wanted, needed, and important.

Dr. Kramer also told of the "remarkable changes" in behavior that are possible when the elderly are exposed to a warm, positive, and therapeutic environment.[82]

Dr. Muriel Oberleder offered similar thoughts, advising nursing homes not to assume that the infirm elderly cannot be helped. In fact, a prerequisite to treatment she states is a positive belief that the problems of the elderly, whether physical or mental, are to a large extent treatable and reversible. She states:

> More and more these days, those of us who work with the mentally impaired aged try to focus upon that which is arrestable, treatable and reversible. This is not easy, of course. Many people think it's impossible. Negative, hopeless attitudes toward old age are very deeply entrenched and they are very difficult to break down. Almost any mental problem which appears in older age is invariably considered to be associated with irreversible biological causes. The expectation of inevitable deterioration usually discourages creative treatment planning. The psychological or the behavioral factors which may be reversible are rarely considered. We simply don't entertain the idea of recovery when an old person breaks down mentally. Instead, we usually allow the impairment to harden. And yet, experience has shown us that mental breakdown in the aging is more often not transitory, and is associated with some discernible, usually external stress, or with some physical condition other than brain deterioration. And often, if the stress that caused the breakdown is corrected, functioning returns to the elderly person.[83]

This pilot program in Vermont indicates what can be done if nursing homes and mental health professionals work together to insure proper care and treatment for the needy patient. Unfortunately, this success story is by far the exception rather than the rule. For the many reasons discussed above, nursing homes generally do not provide adequate therapeutic environments for discharged mental patients. But for all their shortcomings nursing homes are greatly preferable to the alternative of placement in a boarding home, old hotel, or similar facility.

## B. THE BOARDING HOME CRISIS

The enactment of the SSI program not only fueled the discharge of tremendous numbers of patients from State hospitals, it also created a for-profit boarding home industry to receive them. As has already

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[81] "Trends in Long-Term Care," part 15, Chicago, Ill., Sept. 14, 1971, p. 1513.
[82] *Ibid*, pp. 1445–46.
[83] Speech for the American Association of Homes for the Aged, Washington, D.C., November 1970.

been explained, SSI payments are prohibited to patients in public institutions. The law also specifies that if an SSI recipient is living at home with related persons, the $157 monthly SSI check must be reduced by one-third. The clear result is to provide a disincentive to continue living with relatives and since access to public "institutions" is foreclosed, the only option available to SSI recipients is a low-rent boarding home.

In virtually every State of the Union, old hotels or large homes have been purchased by those who would provide services to the needy aged in exchange for their SSI checks. There has even been some new construction to take advantage of this program, principally in the more affluent States which are required to supplement SSI.

The facilities, known as boarding homes, offer only board and room. That means two or three meals a day and a bed to sleep in at night. New York, New Mexico, and California are exceptions to the general rule in that they license such facilities. With licensure comes the requirement of minimum supervision perhaps as much as 8 hours a day, 5 days a week.

To minimize confusion the point that should be made is that the facilities referred to in this report as "boarding homes" go by many names. They are called Domiciliary Care Facilities in New York, Shelter Care Facilities in Illinois, Foster Care Homes in the District of Columbia. Once again, they provide only board and room, occasionally minimum supervision but no nursing care. Little wonder that such facilities have become the number one worry of State inspectors and consumer spokesmen in almost every State.

The following is a litany of the abuses in boarding homes in several States which are representative of what happens in such facilities all across the Nation.

## California

California was one of the first States in the Union to begin the shift from State hospitals into community-based facilities. This trend can be illustrated by the fact that there were 34,955 people in State hospitals in that State in 1963 but only 6,476 at the end of 1974. The trend is even more marked with respect to the aged.[84]

Some 12,000 individuals age 65 or over were in California mental institutions in 1959; at the end of 1974, only 573 elderly remained.[85]

An accelerated program began in 1966. Gov. Ronald Reagan closed three hospitals down and in 1973 announced his plan to close all hospitals for the mentally ill (other than for criminal offenders) by 1977.[86] The 1969 Lanterman-Petris-Short Act proved to be of great assistance in this proposed plan. It required that all patients be thoroughly screened at the county level before admission to a State hospital. County screening teams consist of a physician, psychiatrist, and social worker who must determine the individual's competency and assess the possibility of meeting his needs in some way short of institutionalization.

The legislation was well motivated; it was an attempt to eliminate "precipitous or capricious institutionalization." However, the practical effect has been to keep patients out of hospitals whether they need services or not.[87]

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[84] See table 2, p.719 .
[85] *Ibid.*
[86] "Where Have All the Patients Gone?" *Human Behavior*, October 1973, by Janet Chase.
[87] See p. 18, a reference cited in footnote 3.

Following passage of this act and subsequent deinstitutionalization, police in Los Angeles County and elsewhere reported the heavy increase of arrests for bizarre behavior such a trespassing, exhibitionism, loitering, or wandering on the freeway which they attributed to discharged mental patients. There were numerous instances of violent crimes (murders, rapes, and so forth) committed by former patients.[88]

Meanwhile the number of for-profit boarding homes was expanding to fill the vacuum created by the massive transfers. For example, Beverly Enterprises, Inc., a chain of nursing homes, built 38 board and care facilities in California.

These events plus a 1971 fire in Taft, Calif., in which seven perished, resulted in increased public concern. Accordingly, in late 1972, a select senate committee of the California Legislature was appointed to look into the question of the massive transfers and their effect on the community.[89]

In 1973, a conference on "Access to Nursing Homes: Care of the Spanish-Speaking Aged in the Southwest" was conducted in California by the National Council of LaRaza with a grant from the Department of Health, Education, and Welfare. At that conference, board and care operators protested varying rates of payment which ranged from $157 a month to $300 a month or more. The implication of the conference report is that Medicaid funds (called Medi-Cal in California) are being used to house patients in board and care facilities. Technically, this would be a violation of the law. (See earlier discussion, p. 724.) In addition, operators at that conference were unsure of existing standards applicable to their type of facilities. Reportedly, there are no formal or specific admission requirements for patients who wish to enter board and care homes. No guidelines exist for determining how much care the patient or resident needs. Ability to pay was reported as the most important consideration prerequisite to admission.

The report of this conference adds:

> According to the operators, they are not required to have any special training to run a board and care home. In applying for a license, some questions as to previous experience are asked, but they do not seem to have any bearing on the final decision. One operator pointed out that some training was promised for operators, but neither the nature nor the extent was mentioned, and it has not been proposed again. Another operator mentioned that she had to take a physical examination (including X-ray for tuberculosis), but no other operators mentioned being requested to take such an examination.[90]

On March 15, 1974, the select committee released a report which was highly critical of the wholesale transfers into board and care homes which were ill-prepared to care for the needs of the discharged patients. The Committee stated that community mental health programs "were clearly not meeting the needs of discharged hospital

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[88] See p. 24, a reference cited in footnote 73.
[89] See Supporting Paper No. 5, "The Continuing Chronicle of Nursing Home Fires," p. 520.
[90] *Ibid.*

patients and others in residential settings. * * * Ghettos have been created in urban communities where a large number of chronically ill patients are living in substandard housing." [91]

The legislature passed a bill prohibiting hospital closures without its express approval. The bill was vetoed. It was passed again by the legislature—reportedly the first time the legislature had overriden a Reagan veto.[92]

In June of 1975, California terminated funding for an outpatient day care program for the "gravely disabled" which was called Thunderseed. It provided many board and care residents with their only meaningful opportunity for recreation and therapeutic treatment. Without Thunderseed the extent of the "treatment" received by patients was a weekly visit from a physician to insure that they took their medicine.

A suit was brought by the San Francisco Neighborhood Legal Aid Foundation on behalf of about 100 former involuntarily committed patients who were released en masse from State hospitals. The suit asked for the reinstatement of the Thunderseed program. Alternatively, the plaintiffs charged that the failure of the State to provide aftercare to the patients in view of their previous involuntary commitment or, at a minimum, to protect them from further harm is a violation of their State and Federal constitutional right to treatment. Happily, the State voluntarily reinstated this program, making continuation of law suit unnecessary.[93]

## District of Columbia

Boarding homes have been a subject of continuing controversy in the District of Columbia. In his 1970 testimony before the Subcommittee, Dr. Robert Butler stated:

> It is worth citing aspects of the situation in the District because they are probably illustrative of problems elsewhere. Foster care does not mean foster family care as utilized in the placement of children. "Community" placement is a euphemism in the District for boarding house placement often in impoverished and crime-ridden neighborhoods. Indeed, "boarding housing" in turn, is often a euphemism for a flop house. Malnutrition was discovered. Some patients had been assaulted in those "homes" as well as while walking unattended on the streets. Often the assaults were not reported to the police. One patient had been bludgeoned to death. Some patients received inadequate medical coverage. Thus, diabetes might go uncontrolled. Racial segregation was practiced.
>
> Only $125 per month was paid by the D.C. Department of Public Welfare for each patient. It was difficult to conceive that the same or greater care was available at $4 per day than at the $18 per day cost at St. Elizabeths Hospital. The foster care operators had to extract their own profit from

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[91] See p. 26, a reference cited in footnote 73.
[92] *Ibid.*
[93] June 1975 Newsletter of the Mental Health Law Project.

this sum as well. There were some 180 to 200 such "foster care homes" with from 2 to 40 patients. Operators were given only six hours of training.[94]

In 1971 the Health and Welfare Committee of the District of Columbia conducted hearings on the problems in the District of Columbia's small community based facilities. Testifying before the Committee, Mr. Robert Heil, then director of professional services of the American Nursing Home Association, said:

> The pity of these circumstances in personal care homes is that they have patients requiring considerable professional care. Personal care homes obviously are not equipped nor staffed to provide such care. These patients are placed in personal care homes, it is said, because there is a shortage of facilities which *are* able to care properly for them. The shortage of beds presumably is the rationale used for official acceptance of inadequate care of patients whose needs dictate provision of better care. May I point out that so long as these sub-standard homes are allowed to continue in being, virtually no standards exist. There is little incentive for improvement and creation of new facilities so long as sub-standard operations are condoned.[95]

In December of that year a fire claimed the lives of two residents of one of Washington's foster care homes, and this led to hearings on proposed standards for such facilities.[96] Homes with four or fewer patients are not required to meet *any* licensure requirements by the District of Columbia.

In February of 1973 a new scandal erupted after a District of Columbia fire inspector was refused entry into a foster care home in which there had been a recent blaze. Armed with an administrative search warrant, District of Columbia officials found about 40 elderly patients locked behind closed doors in conditions described as dingy, vermin-infested, and overcrowded.[97] A month later the American Civil Liberties Union of the National Capital Area released a highly critical report of conditions concerning a board and care facility known as Taylor House. The ACLU charged St. Elizabeths Hospital with allowing patients to be exposed to "intimidation, verbal abuse, job exploitation, and substandard diet." In its 25-page report it noted the following conditions:

- During a four-day test period, diets were inadequate in quality and quantity and the breakfasts compared unfavorably to those served at Lorton Reformatory.
- Some patients were found to be doing heavy manual work at wages ranging from $2.50 to $10 a week.
- Persons live in enforced idleness and isolation; their physical and mental needs are ignored, and no therapy or recreation is provided.

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[94] "Trends in Long-Term Care," Part 11, pp. 905-906. Washington, D.C. Also p. 951.
[95] Testimony in Committee files.
[96] *Washington Evening Star*, Dec. 15, 1971, p. A-1.
[97] *Washington Post*, Feb. 16, 1973, p. A-1.

- Management subjects patients to verbal abuse, referring to them as "the dregs of humanity," and "the scum of the earth," and exercises total control over their lives.[98]

Despite investigations by the D.C. City Council a September 1974 article in *Washingtonian* magazine contends that other than changing the name (from Taylor House to Fendall House) little has been done to improve conditions at this facility. Fendall House is considered a boarding home for self directed patients said one St. Elizabeth's official. It houses about 80 patients from St. Elizabeths on convalescent leave and about 30 on independent status placed in the facility by the Department of Human Resources, a branch of D.C. government. The *Washingtonian* reports:

> Fendall House is a converted apartment house. In what used to be one-bedroom apartment units there are now five patients: two live in the living room, two in the bedroom, and one in the kitchen with a bed parallel to the old counter and sink. All pay $150 per month for their quarters and board.
>
> There is little or no supervision. Patients are left on their own while the Taylors and their manager, a Mr. Holmes, tend to other family businesses: two foster care homes in the same neighborhood, two more rooming houses for mental patients, "Diane's" restaurant, and a pizza carry out on Good Hope Road, Southeast.
>
> "Perfectly acceptable," Mr. Hester said. "These patients are self-directed and need little supervision."
>
> "Self-directed patients" I met there included a man who believed that all of the staff, including Mr. Taylor, who was banned from the home last year for harassment of the patients, were practicing witchcraft and "messing up" his mind, a woman wandering the halls with a handbag, sweater (it was 96 degrees that day), and a black wig on backwards; a tall gaunt man without shirt, shoes, or socks who was babbling in the hallway; and a man wearing a football helmet and all his worldly possessions attached to his jacket with baby diaper pins who came in to pay Mr. Holmes $250 in cash for the apartment he rented from the Taylors.[99]

No one knows exactly how many of these facilities there are in the District of Columbia. Part of the confusion is caused by the jurisdictional problems between St. Elizabeths whose employees work for the Federal Government (Federal funds make up two-thirds of the payments to the hospital) and the D.C. Department of Human Resources. No citywide identification is required. So-called foster care homes with four or less patients need not meet any licensure requirements.

The Subcommittee staff made an effort to learn how many such facilities there are in the District of Columbia in the summer of 1975. The staff obtained a computer printout of all homes (addresses) to which payments were sent by the D.C. government. A great number of the addresses did not appear on the official list supplied by St. Elizabeths or by the Department of Human Resources. In an interview with Arthur Scarpelli, who is in charge of the community place-

[98] A reference to *Washingtonian* magazine, September 1974, by Jeff Gillenkirk, p. 164.
[99] Testimony cited in footnote 3.

ment program at the hospital, the staff confirmed that there are two discharge programs at St. Elizabeths, one formal and one informal. Mr. Scarpelli takes credit for about 212 participating homes with about 700 patients. He states that he screens prospective operators to make sure that they are literate and of good character. He adds that they must complete a 6-hour orientation session conducted by the hospital staff. He invited investigation of the conditions in the facilities participating in his program.

After visiting several facilities, the Subcommittee found minor problems in the homes on Scarpelli's list, but they were far less serious than problems and conditions that were apparent at the "unofficial" foster care homes. It was evident that large numbers of patients were placed directly in the community without being funneled through Scarpelli's placement program.

The Mental Health Law Project has also identified problems with Washington, D.C., foster care homes and they joined the Subcommittee staff in calling for immediate licensing of such facilities. Actually regulations were passed by the D.C. City Council requiring licensure in 1974, but the proposals were vetoed by Mayor Walter Washington who cited the escalating costs to the city—which would result from licensure—and a resulting severe shortage of facilities in which to house patients. Representatives of MHLP cite the following as major problems in the District of Columbia:

(*a*) Inadequate training of home operators.

(*b*) Misplacement of patients in personal care or boarding homes who need more skilled care and services.

(*c*) No standards for foster care homes.

(*d*) No centralized St. Elizabeths placement service for patients who need different kinds of facilities or programs.

(*e*) No requirement of a physician's certificate for admission to skilled nursing homes.

(*f*) No agreed-upon definition of who goes into different levels of care.

(*g*) Most important, a lack of facilities and money to buy slots in those that exist. (There are no publicly-run facilities except D.C. Village.)[100]

## New Mexico

Alarmed by articles in the press concerning New Mexico boarding homes, Senator Pete V. Domenici in 1974 requested an investigation by the staff of the Subcommittee. The investigation revealed:

> Poor food, negligence leading to death or injury, deliberate physical punishment inflicted by operators upon their residents, poor care (for example: allowing patients to sit in their own urine, binding them to the toilet with sheets, not cutting toenails to the point where they curl up under the feet, making walking impossible), cutting back on food, electricity, water and heat to save money, and housing people in makeshift facilities, such as a former chicken coop or a rundown mobile home.[101]

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[100] *Washington Post*, May 25, 1973, p. C-1.

[101] "Barriers to Health Care for Older Americans," hearing by the Subcommittee on Health for the Elderly, Senate Committee on Aging, Part 12, Santa Fe, N. Mex., May 25, 1974, pp. 1241-43.

The report also notes that boarding home rates in New Mexico were keyed to Supplementary Security Income payments. However, "in a few cases, the residents have small social security or other pension checks which pay their own way. In still fewer cases, the relatives subsidize the resident's stay. Rates increase with ability to pay; some residents pay as high as $385 a month." [102]

The report continues:

> A significant problem exists with respect to SSI checks and other government annuity checks. Such checks are delivered to the boarding home with the resident named as payee. The resident endorses such checks over to the operator who then cashes them. There is presently no firm policy which limits how much of such checks a boarding home operator can keep. Some operators keep the entire $140. Others return $20 a month spending money to the resident for his personal use to buy cigarettes or have their hair done or whatever. In some cases, residents receive $200 in Social Security and never see it again after endorsing these checks. In some cases, they never see the checks at all—the endorsement is an "X" on the back of the check signed by the operator himself.[103]

The report emphasizes that New Mexico is better off than most States because it does license board and care homes. Since standards were on the books since 1972, the principal problem seemed to be enforcement. The investigation disclosed that there were only 3 inspectors for over 2,000 health care facilities in that State, including all the State's hospitals, nursing homes, and boarding homes.[104]

The report and witnesses at subsequent New Mexico hearings on the subject spoke of the need for accountability. Adelina Ortiz de Hill, assistant professor of behavioral sciences, New Mexico Highlands University, Las Vegas, N. Mex., told of visiting boarding homes in New Mexico, Kansas, and California, and finding "isolation of the elderly," "a deprived environment," and "overcrowding." She testified:

> As an example, I used my own home and got a friend of mine who is an engineer to figure out how much I would make, with overhead, and this includes utilities and everything else, and my house happens to be a little better than average. I pay $175 a month, including the utilities, for my home, which is 1,600 square feet. I could have 18 people in there, and I figured in my overhead, with feeding expenses of $600, which is quite a generous estimate, my income would be $2,160 a month, and I subtract $600 from that, and I am making $1,100 a month.
>
> Senator DOMENICI. Could you do that without any help?
>
> Mrs. HILL. Without any help. They use the residents to do the work. In fact, the sheriff told me that a woman had reported to him that she had been beaten. The reason given was that she was not carrying her own weight. They do some of the cooking, cleaning, and ironing. I do not object to their

[102] *Ibid.*
[103] *Ibid.*
[104] *Ibid.*

having any activity, but I know I would not be doing it alone, and even then, $1,500; I work pretty hard now.

Senator DOMENICI. What is the range of occupancy based upon the information you have?

Mrs. HILL. On my information, that would be a bed with at least 3 feet on either side, which is fairly typical of many boarding homes, with little personal space for storing.

You have a carton box under your bed, where some other patient might steal some of your things.[105]

Following the Committee's hearings in New Mexico, that State took action to improve the quality of life in its boarding homes by training more inspectors, but the roots of the problem continue to exist.

## OHIO

The situation in Ohio is much the same as it has been described in the other States mentioned above. There has been a 42-percent drop in the number of inpatients from State hospitals since 1969. In that year the *Cleveland Press* reported the beginnings of the transfer program charging:

"Ohio is relieving its congested State mental hospitals by placing elderly patients in private homes for $3.30 a day. As a result," the *Press* concluded, "many are jammed together in substandard homes where they are skimpily fed and left to shift for themselves." [106]

The problem came to light when the Cleveland State Hospital dispatched its own bus to reclaim 22 of its "discharged" patients from an illegally converted tenement just before the city housing inspector acted to close the home's third floor because of serious fire safety violations.

The *Press* asserted that the facilities housing the former mental patients were not nursing homes but what the State called "family care homes." The *Press* noted such facilities were often overcrowded, inadequate, unsanitary, and unsafe. In the specific instance noted above, 23 patients were housed in the facility. Although the State Department of Mental Health required a responsible person to be on duty at all times, reporters arrived to find one of the mental patients left in charge. This 64-year-old man who had been in the State hospital for more than 20 years was also the cook. The owner budgeted 63 cents per person per day for food.[107]

The principal change today is that SSI rather than State funds is the source of payments and instead of $3.30 a day, operators receive $5.23 ($157 a month standard SSI payment) to care for the abandoned elderly.

## PENNSYLVANIA

Pennsylvania is another State with significant problems in the operation of its board and care facilities. As noted earlier, tragic fires revealed that Pennsylvania was using old-age assistance payments plus a State supplement to care for patients in boarding homes. This was done, officials claim, because of a shortage of facilities in some areas

[105] *Ibid*, pp. 1186-87.
[106] *Cleveland Press*, Oct. 23, 1969, p. 1, by Paul Lilley.
[107] *Ibid.*

and a knowledge that the available facilities would not meet Medicaid/Medicare standards for Skilled Nursing or Intermediate Care Facilities.

What is principally at stake is compliance with the Life Safety Code of the National Fire Protection Association. Many homes could not meet that standard a few years ago and are less capable of doing so today. Accordingly, these facilities are now being used to house large numbers of former mental patients. The conditions in these facilities has become a matter of great concern. A number of stories have appeared in the Pennsylvania newspapers questioning the State's policy. Nancy Perlman testified:

> Pennsylvania is just now reeling from a series of investigative news stories documenting malnutrition, insect infestation and dehydration among former State mental patients confined to board and care homes. Although there are some 600 such homes in the City of Philadelphia alone, the State stopped licensing and inspecting them in 1967.[108]

## SUMMARY

**Where have all the patients gone? The question cannot totally be answered. This is true because the policy of deinstitutionalization has accomplished its purpose and most mental patients are out of sight if not totally out of mind.**

Some fortunate few have been returned to their own families or placed with foster families. Small numbers of others have found assistance from Community Mental Health Centers. However, most of the patients have been placed in for-profit nursing homes or boarding homes which are generally ill-equipped to meet their needs.

In the case of nursing homes, severe problems exist because of the limited numbers of nursing personnel, particularly registered nurses, and the general lack of training or experience of these employees in handling psychiatric patients. As noted, the admission of a few mental patients to a nursing home (whose traditional orientation has been chronic physical disease) can be most disruptive. It places a heavy burden on the already overworked nursing staff. In spite of these shortcomings, it is clear that nursing homes are increasingly making an effort to care for the mentally impaired. There is evidence some homes handle such patients very well. This is a hopeful sign. It is evident that with some assistance in terms of training and followup from State hospitals, nursing homes may be able to provide an acceptable alternative to hospital placement.

In some cases mental patients have been placed in the slums of our major cities in such numbers that their presence could scarcely remain unnoticed. This is the case in Uptown, an area of Chicago, where residents now speak of the "geriatric ghetto," a reference to the some 13,000 former mental patients that have been placed in this area of the city. The Ontario Road section of Washington, D.C., provides another example. In these areas where they are visible because of sheer numbers and in more common cases where they have vanished into the ghettos of our major cities, former mental patients will be found living in for-profit boarding homes.

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[108] Testimony cited in footnote 3.

**Throughout America a for-profit boarding home industry is expanding to meet the need—to provide a roof for the unwanted thousands caught in a bureaucratic revolving door which sends them from mental hospitals to nowhere and back again several times a year. Boarding homes come in various shapes and sizes. They include a converted hotel in New York City, a new six-story high-rise in Long Beach, N.Y., a converted mansion in Cleveland, a converted nursing home in Pennsylvania, and perhaps even a mobile home or converted chicken coop in Texas or New Mexico. There is a variety of labels to match the shapes of the facilities. They may be called boarding homes, foster care homes, shelter care homes, domiciliary care facilities, or halfway houses.**

Boarding homes of whatever size and whatever they may be called have several things in common. First, they are owned privately by for-profit operators (few are nonprofit or government-owned facilities). Second, they offer little in the way of services or recreation or therapy. Third, the food they offer is generally inadequate in quantity and quality and they often present significant fire safety hazards. Fourth they are not required to meet any Federal or (with few exceptions) State standards. Fifth, unlike nursing homes which have few and untrained personnel, boarding homes often have no personnel whatsoever

**The inevitable conclusion is that, at best, the quality of life in boarding homes is marginal; at worst, it is a cruel and intolerable exploitation of helpless human beings, ranking with prisons and concentration camps as a prime example of man's inhumanity to man.**

# PART 4

# AN IN-DEPTH ANALYSIS: TWO CASE STUDIES

In order to more extensively examine the effect of transferring mental patients from State hospitals into boarding homes, the Subcommittee selected two States, Illinois and New York, for an in-depth analysis. The experiences of these large States may be suggestive of the problems which will be encountered in other States.

## A. ILLINOIS: AN ANALYSIS

In March of 1969 legislation was proposed before the Illinois State Legislature, popularly known as the Copeland bills. The bills proposed removing the elderly from the State's definition of mental illness; requiring the State to make an immediate evaluation of all patients admitted prior to July 1, 1964, to determine the possibility of their receiving care outside the hospital; establishing screening procedures to keep new admissions down; and vesting authority in the Department of Mental Health to place discharged individuals "in a suitable family home or such other facility as the Department may consider desirable. . . ." [109]

In May 1969 the Governor, Richard B. Ogilvie, gave the bills his enthusiastic support and announced the State's intention to move 7,000 senior citizens out of mental institutions into nursing homes and shelter care facilities within a year and a half. These bills were signed into law in September 1969 and a press release from the Governor's office declared:

> 10,000 Elderly Patients To Leave State Mental Hospitals
>
> Legislation to permit the transfer of over 10,000 elderly patients from state mental hospitals into private nursing homes and sheltered care facilities has been signed by Gov. Richard B. Ogilvie. The House Bills—992-995—specify that elderly persons whose mental processes are impaired only by advanced age will no longer be committed to mental institutions, and establish machinery to determine whether patients presently in mental hospitals might be better served in private nursing or sheltered care facilities.
>
> In signing the bills, the Governor said:
>
> "The approval of these bills today marks the culmination of a long and determined effort by many dedicated people to restore a sense of dignity to thousands of forgotten senior citizens in mental institutions throughout Illinois.

[109] "Trends in Long-Term Care," Part 13, Chicago, Ill., Apr. 30, 1971.

"The passage of House Bills 992 through 995 is truly a major legislative achievement which ranks among the most humanitarian acts of the 76th General Assembly.

"More than 10,000 elderly citizens today live in mental hospitals—not because they are mentally ill, but simply because they have nowhere else to go. Under existing conditions, there is no place for them to live out their lives in freedom and dignity.

"Last May, I said it was our goal to move 7,000 of these senior citizens out of the mental institutions and into nursing homes and shelter care facilities within a year and a half. I am confident we will meet that goal."

Despite assurances from the State that the patients would receive followup care and help in their return to the community, Chicago officials were critical. In July, Robert Ahrens, director of the division of senior citizens in Chicago, wrote to the editor of the *Chicago Tribune:*

> The chief reason for placement of elderly in state mental hospitals has been that adequate alternative community facilities were not available. They are still not available. The problem will not be resolved, nor is it fair to the elderly simply to move them around and have "many small warehouses take the place of the large one."[110]

Thorough documentation for this criticism was presented to the State in a study conducted by the Division on Aging. The report released in May 1970 stated:

> 1. Lack of sufficient and/or appropriate institutions to meet both chronic health and mental health needs,
> 2. Lack of comprehensive supportive and follow-up services,
> 3. Lack of trained personnel experienced in serving such persons in general community agencies,
> 4. Lack of sufficient resources to pay for the proper care of retired, dependent or mentally disturbed persons,
> 5. Lack of adequate comprehensive planning to meet the multiple needs of such persons and, above all,
> 6. Lack of delineation of responsibility for resolution of various aspects of the problem among the multiple community components involved.[111]

Early in 1971, the *Chicago Tribune* and the Better Government Association of Chicago joined forces for a survey of nursing home conditions in that city. They concluded that patients in "warehouses for the dying" were receiving poor treatment, that several owners were making excessive profits and that shocking conditions existed because of lax inspections. The investigators concluded that the transfer program had contributed to the problem.[112]

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[110] Letter in Committee files.
[111] Op. cit., footnote 115, p. 1323.
[112] *Ibid.*

Miss Myrtle Meritt and Dr. Colette Rasmussen of the Cook County Department of Health confirmed this charge. One example follows below:

> This home has at most a double file, considering its length of service. We have many, many complaints on them.
>
> It is phenomenal in its infestation with roaches. The smell on the patient floors, which are the second and third floors, is nauseating.
>
> The home itself, very shortly after it opened, was filled with busloads of conditionally discharged mental health patients all of whom now are permanent dischargees; none of whom appear to be getting rehabilitation in any way.
>
> Now, what is distressing to me is that we have mentally retarded people here, although they don't seem to be threatening in any way. I know that many of them at least by face and a few of them by name because I have been there that often and the patients they have and the bedrooms that they stay in are just unbelievable.[113]

Another of the nursing homes singled out by the Better Government Association was the Carver Nursing Home in Springfield, Ill., which suffered a fire and the loss of 10 lives in May 1972. The BGA working with the Committee staff confirmed that about one-third of the homes' residents were discharged mental patients. BGA testimony with respect to the Carver Home follows:

> The Carver Convalescent Home in Springfield mainly has Negro patients. A 1968 letter to the Director of Public Aid describes in gruesome terms the plight of one patient there. I quote the following:
>
> "A disability assistance recipient, Mrs. Annie T. Bond, received nursing care in the Carver Convalescent Home from October 1965 to February 1968, on which date she transferred to Mary Ann's Nursing Home in Decatur.
>
> "Mrs. Bond's condition upon admission to Mary Ann's Nursing Home was such that her attending physician and the nursing home staff were quite concerned. The following is a description of Mrs. Bond's condition at the time:
>
> "'Mrs. Bond was covered with decubiti (bedsores) from the waist down, that decubiti on hips were the size of grapefruits and bones could be seen; that the meatus and labia were stuck together with mucous and filth that tincture of green soap had to be used before a Foley catheter could be inserted; that her toes were a solid mass of dirt stuck together and not until they had been soaped in T.I.D. for three (3) days did the toes come apart; that body odor was most offensive; edema of feet, legs, and left hand.'"
>
> Although this incredible report was in State files and an investigation was ordered, absolutely nothing happened.[114]

At the time of the fire, May 6, 1972, there were 42 patients in the home, 14 were discharged mental patients.[115]

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[113] "Trends in Long-Term Care," Part 12, Chicago, Ill., p. 1042, Apr. 2, 1971.
[114] *Ibid.*, p. 1018.
[115] Report to the Senate Committee on Aging by Bill Recktenwald, chief investigator, Better Government Association, Chicago, Ill., in Committee files.

To City Health Commissioner, Dr. Murray C. Brown, there was a clear relationship between the State discharge program and the shocking conditions in nursing homes discovered by the *Tribune* and BGA:

> We believe that the deterioration of facilities and care in Chicago nursing homes is directly related to the aforementioned policy changes made in 1969 by the Illinois State Legislature, the Governor, and the State Department of Mental Health.[116]

Also critical of the State's program was Dr. Jack Weinberg, clinical director of the Illinois State Psychiatric Institute and former chairman of the Group for Advancement of Psychiatry, Committee on Aging. His testimony rebutted:

> . . . "the notion, the idea of transferring inordinately large numbers of people into nursing homes from mental hospitals." He also said that he had been overruled when he had suggested in 1969 that a committee of known, proven gerontologists be established to determine, on a case-by-case basis, who was to be transferred out of the hospitals, "in consonance with the person's needs.[117]

The Community Mental Health Board, through its chairman, charged that there were 102 nursing homes as of March 4, 1971, housing 7,334 discharged patients; 25 homes for the aged with 1,379 more; 10 shelter care facilities with a population of 3,349; 14 residential care facilities; and 5 nonlicensed facilities with a population of 512. The board charged that these 13,000 had been discharged "wholesale and indiscriminately" and that followup care was lacking:

> Our personal investigations, and interviews with concerned relatives confirmed that persons transferred to private facilities were not receiving followup care and treatment by the Illinois Department of Mental Health. On numerous occasions we called this to the attention of those responsible.[118]

The board also criticized the use of unlicensed facilities:

> We do not criticize the intent of the Copeland Bills. We do seriously criticize the conduct and activities of the placement teams. It has been obvious to us that their principal concern was the meeting of a quota and not the ultimate welfare of the persons they transferred. It is also apparent that the provision for (1) Visitation every three months and a report submitted on the environment and (2) assignment of full-time employees of the Department of Mental Health to any unlicensed facilities where 25 or more persons are placed by the Department. Many persons have been placed in Rooming and Boarding houses in Chicago

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[116] Op. cit., footnote 119, p. 1108.
[117] Op. cit., footnote 115, p. 1219.
[118] Letter to Murray C. Brown, commissioner, Chicago Board of Health, Mar. 30, 1971.

which are not licensed. The above provisions have not been met.[119]

For their part, State witnesses in the April 1971 hearings and later in the September hearings defended that State policy, telling the Committee that:

1. Careful standards of selection, preparation, placement, and follow-up are followed.
2. Readmissions to mental hospitals from the elderly placement group is less than 10 percent.
3. Elderly patients placed through the Geriatric Transfer Program represent a small portion of the nursing home occupancy, not exceeding 5 or 6 percent.[120]

Dr. Al Snoke, Coordinator of Health Planning, State of Illinois, told the Committee:

> Dr. Murray Brown and Dr. Jack Weinberg referred to the 7,000 patients and maintained that this was a major reason why the nursing homes were flooded with geriatric patients, and that it was a major explanation or excuse for the nursing home deficiencies.
>
> . . . The 7,000 is essentially a myth.
>
> There were never any 7,000 elderly patients discharged in 1 year from the mental hospitals.
>
> The record is as follows. The Copeland bill upon which this massive discharge was blamed, provided for an orderly discharge and transfer of aged individuals from mental hospitals into the nursing homes. The Copeland bill was passed in July of 1969, but was not signed until September 1969. It actually did not start functioning—the geriatric placement program did not start until November 1969. In 1968—before the Copeland bill was passed—there were 3,405 patients over 65 discharged. In 1969, the figure dropped to 2,849 but the Copeland bill was not even started until November of that year.[121]

In March 1972, the Better Government Association, this time in conjunction with the *Chicago Sun-Times* and the local Chicago ABC–TV affiliate, announced the results of their investigations into the transfer of perhaps as many as 15,000 of these individuals into an area of Chicago known as Uptown which has been described as a psychiatric ghetto. Dr. Weinberg stated that this kind of mass transfer, a reversal of the mistaken hospitalization policies of decades "cannot work out." He continued:

> They made hotels into hospitals and turned the community into a hospital. We've moved Chicago State Hospital into Uptown.[122]

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[119] Mar. 1, 1971, letter to the Illinois Association of Mental Health, in Committee files.
[120] See testimony of D. Albert Glass, director, Illinois Department of Mental Health, op. cit., footnote 115, p. 1279.
[121] See p. 1467, reference cited in footnote 14.
[122] *Chicago Sun-Times*, Mar. 15, 1972, p. A-1.

The investigators concluded that patients were being discharged "wholesale" and "indiscriminantly." The principal motive for the transfers was cost savings. More specifically the investigators found:

> (1) Overcrowding, understaffing and pressure to discharge patients prevented State mental health workers from providing proper treatment and from preparing the patients for placement in shelter care homes.
>
> (2) Shelter care residents appeared lethargic due to overmedication. This observation was confirmed by State officials who were highly critical of the heavy use of tranquilizers.
>
> (3) There was poor security in the homes in guarding drugs that have potential value if sold on the street. Numerous employees—including an undercover BGA investigator who had received no training—had access to the drugs.
>
> (4) Some shelter care homes had long records of building and fire code violations.
>
> (5) Few recreational programs existed in the homes. Most provided no therapeutic treatment. The staffs at the homes were often well-meaning but almost always untrained.[123]

Perhaps most importantly, they found that patients had simply been sent "from one inhumane institution to another." BGA Director J. Terrence Brunner stated that the State's shelter care facilities—

> . . . seemed to provide just another form of institutional existence. The homes were found to be depressing, gloomy places where indigent, troubled people were provided, at best, the minimum treatment the State required. State inspection was inadequate to insure even minimal compliance by the privately owned homes on a consistent basis.[124]

Dr. Jack Weinberg put the Illinois situation in focus. He characterized the State's program as "good theory, bad execution": the point being that State hospitals have and deserve a reprehensible image and that individuals should be prevented from having to enter such facilities. If supportive and protective services were available in the community, then that is where the disturbed elderly should be served. However, these services are not available in the community which is the reason that Dr. Weinberg and others have pause about "returning individuals to a nursing home in a portion of the city they left 30 years before and calling it 'returning them to the community.'"

Dr. Weinberg stated that apparently some policymakers forget that mental patients are human beings and not commodities. He said they need services and care, not simply storage; the needs of the patients should be the overriding concern and principal determinant of where the patient is housed. Dr. Weinberg made the point that boarding homes or nursing homes may have a more deleterious effect on patients than State hospitals. He told the Committee:

> I believe further that many of our mental institutions, even though some of them may be snake pits, are better places than some of the nursing homes in view of the fact that they, at least, have such necessary items of care as 24-hour coverage

[123] See testimony cited in footnote 3.
[124] *Ibid.*

by a nurse, a fire alarm system and the food in the State hospitals is nutritionally adequate; and some facilities for some minimal activities is also present in most mental institutions of the States.[125]

Dr. Weinberg's conclusion was later given great weight by the investigators into the deaths of seven patients at the Illinois Extended Care Center, a for-profit nursing home in Rockford, Ill. The inquiry was conducted by the Illinois Legislative Investigating Commission which reports as follows:

PATIENT DEATHS

1. William Redford, 73 years of age, died on October 24, 1973 from "bronchopneumonia," after being placed at the Illinois Extended Care Center (IECC) for a period of 22 days. The severely mentally retarded Redford received inadequate and unresponsive nursing care and treatment. He continually exhibited physical problems which either went unheeded or unattended to by the facility's nursing staff. These physical problems culminated in Redford's death.

Redford's death raised serious questions. There was little, if any, justification for the Illinois Department of Mental Health and Developmental Disabilities to place a 73-year-old person with over 57 years of institutionalization in the Illinois Extended Care Center. Redford's residency at IECC was devoid of any aftercare supervision by Department personnel.

2. Diane Balsiger, a 19-year-old profoundly retarded and severely physically handicapped individual, died of "pneumonia" on October 28, 1973, 10 days after her placement at IECC. Balsiger required, but did not receive, complete nursing care and attention. Insufficient staff observation and treatment, unacceptable and unprofessional attitudes, and general irresponsible nursing performances were the rule rather than the exception.

Contributing to these deficiencies in care and treatment was the absence of aftercare supervision by Department personnel. We believe the circumstances surrounding Balsiger's death were replete with instances of neglect and complete disregard for the health, safety, and welfare of this patient who was forsaken by the Department.

3. Everett Asker was a 38-year-old, profoundly retarded individual who expired at IECC on November 4, 1973, from acute "bronchopneumonia." Asker was also severely physically handicapped with cerebral palsy and spastic quadriplegia. He was considered one of the more difficult and less desirable individuals to care for because of his multiple impediments and unsightly appearance.

The Commission found that the minimal care and attention given to Asker was due to the aversion and revulsion displayed by IECC's nursing staff toward this patient. Asker received no aftercare supervision from the H. Douglas Singer Zone Center, the Department agency responsible for this

[125] Op. cit., footnote 115, p. 1222.

critical area. The Commission believes Asker's death was avoidable, and may have been caused by inhalation of vomit or suffocation due to poor positioning.

4. Elmer Johnson was 89 years of age when he died from "coronary insufficiency" on November 29, 1973, at IECC. This profoundly retarded individual was a resident at IECC for 27 days, after spending approximately 65 years in State institutions. Johnson's death illustrated the unfortunate consequence of placing a long-term State patient in a private facility, which was not conducive to proper physical and mental adjustment to a new and very strange environment.

The Commission concludes that the Illinois Extended Care Center was not culpable in the death of Elmer Johnson, although the level of nursing care was still substandard. But we do question the propriety of placing this type of resident within a new environment with no period of adjustment and with no monitoring of such difficult adjustment.

5. Betty Youbles, a 47-year-old profoundly retarded, blind, and physically handicapped individual, died at IECC on December 21, 1973. The cause of her death, as indicated by the autopsy, was "aspiration pneumonia."

The Commission concludes that Youbles' death was avoidable, and resulted primarily from a lack of proper nursing care and untimely medical attention. Her death illustrated the lack of expertise in this type of patient on the part of the H. Douglas Singer Zone Center's aftercare supervisor, who was present during Youbles' physical distress but took no steps to obtain medical attention for her.

6. Abraham Libman was 26 years of age when he expired at St. Anthony Hospital on January 2, 1974, less than 12 hours after being transferred there from the Illinois Extended Care Center. This profoundly retarded and severely physically handicapped individual was determined by an autopsy to have died from acute bronchopneumonia with aspiration of a moderate amount of food material.

The Commission believes the IECC nursing staff was neglectful in the care and treatment of Libman. All of the problems found in the previous deaths were prevalent in the minimal care and attention received by Libman, both from the facility's personnel and the Department's personnel. This patient was simply forsaken by the persons charged with the responsibility for his well-being.

7. Sidney Glazer, 52 years of age, died from "possible aspiration pneumonia" on March 21, 1974, at St. Therese Hospital, 9 days subsequent to his transfer from IECC. The Commission does not believe this facility was responsible for Glazer's death.

The Commission commends the efforts of the new Director of Nursing, Nan P. Flemming, R.N., in promptly and significantly upgrading the level of nursing care at IECC. We further commend the efforts of Dixon State School personnel in assisting this facility's progress from a "life-death" situation to a relatively stabilized environment.[126]

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[126] See p. 203, a reference cited in footnote 65.

The report of the Commission was released in June 1975. Three months later BGA officials were again testing the quality of care and services offered in Illinois shelter care facilities at the request of the Subcommittee. BGA Director Brunner testified before the Subcommittee on September 29:

> We found conditions in the homes to be substantially the same. Cosmetic changes have occurred. Walls that were covered with chipped plaster three years ago are adorned with colorful posters and nicely printed meal schedules. More recreational activity is provided. Homes that once saw 40 elderly residents huddled around a single television now include classes in personal hygiene, sewing and arts and crafts. But the basic problems remain: the privately owned facilities lack trained personnel, many residents are continuously oversedated, and there is no real attempt to accomplish the primary mission of integrating the residents into the life of the surrounding community.
>
> Despite the publicity that surrounded the 1972 BGA, *Sun-Times* and Channel 7 findings as well as the recent nationwide publicity concerning private shelter care homes, the state's policy of shifting its responsibility to ill-equipped private homes and unprepared local communities continues. And it continues when the state's own statistics and reports present convincing evidence that the policy is a disaster.[127]

He added that the State had continued its policy despite every indication that it merely leads to a "revolving door." He noted that since 1970, readmissions as a percent of total admissions has held steadily at 60 percent. He suggested that if shelter care homes were performing their function former patients would not have to return again and again. He continued:

> The emphasis on discharges has led to a numbers game that borders on the absurd. The bureaucratic techniques employed to reduce the resident population would be terribly amusing if they did not have such a disastrous consequence for the patients concerned.
>
> For example, at the Read Zone Center in Chicago the name of the game appears to be "musical beds." Read personnel told BGA investigators that the ward census is not to exceed 28 patients. If it does so, home visit passes will be issued to the excess patients. The patients will live in the ward during the day but will be released to their homes at night. The census of the wards only count those patients that are sleeping in the ward so in this way the "excess" patients would not be included in the official census.
>
> Nobody told us what happened to those excess patients who did not have a home. We do not know where they might have spent their evening hours.
>
> At Manteno State Hospital the pressure to discharge is equally as strong. According to its staff, the discharge rate is to hold firmly at four per month. For the first time at Man-

[127] See testimony cited in footnote 3.

teno, patients are being discharged from the acute ward. Staff personnel there said that these were mostly elderly patients with severe physical as well as mental problems.[128]

Mr. Brunner stated that an analysis of inspection reports indicated that four shelter care homes in Uptown were chronic violators of standards. These included Somerset House, Traemour House, Commodore Inn, and Stratford House. Together they supply 1,465 beds for patients needing shelter care. Mr. Brunner gave the following examples of abuses:

● Somerset House has consistently been found to provide inadequate care and in January of 1975 was threatened with decertification. Among the problems cited at Somerset was the "inadequate and indifferent care" received by one resident, Cletis Weaver, during his fatal illness. A cutoff date was set for State aid to the institution, but somehow the facility managed to pass an inspection the day before aid was to be terminated.

● Public Health files on Stratford House, located on the southern edge of Uptown, expressed a sense of urgency. One report stated: "In the light of the overall horrible conditions at Stratford Home, we feel drastic action is necessary to safeguard and protect the residents of this facility."

The events that led to the report include findings that:

(1) There was inadequate personnel. There were several periods when no registered nurse was on the staff.

(2) There was a lack of coherent, up-to-date medical records, treatment plans and records of medications administered to the residents.

(3) The facilities failed to take a patient to the hospital until drastic symptoms developed—a loss of 20 lbs. in 48 hours—forced the home to call an ambulance. The patient died 2 days later.

(4) Fifteen to 20 percent of the residents were oversedated.

Despite these serious problems, and the ominous warnings contained in the report, Stratford Home continues to receive state funds and is trusted to care for the state's former wards.

● At Traemour House, which is also located in Uptown, State inspection reports disclosed a particularly lucid example of one theme that emerges repeatedly: lack of trained personnel.

At Traemour, one nurse serves 271 beds. The nurse is also burdened by having to supervise 22 nurses aides. As a result monthly inservice training is conducted by a drug company representative.

● At Fellowship House, located on Chicago's west side, BGA investigator Jim Huenink was able to obtain facilities' charts that indicate irregularities in the use of certain medication and dangerous drugs. I have provided the Committee staff with copies of the charts for your examination.

These charts show that certain medications cannot be

[128] *Ibid.*

accounted for; for example, there are discrepancies between the number of pills ordered and administered to residents. We were also able to confirm that narcotic drugs were improperly stockpiled in the safe of the facility's administrator. These drugs have a considerable street value.

Mr. Brunner added that BGA had not stopped with evaluating the four facilities mentioned above. Their investigation included a look at State records. After analyzing reports on over 27 percent of the facilities and fully one-third of the shelter care beds in the city of Chicago, Mr. Brunner's conclusion on behalf of the BGA provides an excellent summary for this section of this paper. He said:

> The State's own records constitute a serious indictment of shelter care in Chicago. Their reports charge facilities containing 40 percent of the city's shelter care beds with glaring deficiencies. But the policy of emptying the State's mental institutions continues.
>
> The BGA does not argue with the concept of community-based treatment. In theory, the concept makes a lot of sense. However, in the context of our findings—inadequate private shelter care facilities, spotty State inspection, and lax State enforcement—the policy degenerates into a practice whereby the State abdicates its own responsibilities to provide care for those who desperately need it.[129]

## B. NEW YORK

On February 23, 1976, Assemblyman Andrew Stein released a report, "Adult Homes: The Nursing Home Scandal of the 1980's." The report charged poor care and profiteering in the boarding homes of New York State, also called: Domiciliary care facilities (DCF's), adult care homes, or private proprietary homes for the aged. Senator Frank E. Moss, Chairman of this Subcommittee, promised to make a personal investigation, and to report the previous findings of the Subcommittee staff which had been evaluating the New York boarding home crisis since March 1975.

In March 1976, Senator Moss announced that his findings closely paralleled those of Assemblyman Stein and other critics. He said in part:

> I have visited the psychiatric ghettos of Long Beach and Far Rockaway, N.Y. I have toured several of the old hotels and boarding homes where thousands of former mental patients live. I have seen their world of cockroaches and peeling wallpaper, of flaking paint and falling plaster.
>
> I have seen the broken windows letting cold air into rooms without radiators. I have seen holes in the ceilings of patients' rooms and I have seen roofs that leak. I have seen exposed wiring, overloaded sockets, and fire extinguishers that haven't been inspected for years. I have seen steep staircases with low clearance, and makeshift doors made out of cardboard and burlap.

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[129] *Ibid.*

I have seen hungry people with their faces up against vending machines begging for a quarter. I saw three patients huddled together in one room cooking eggs on a hotplate while breakfast was being served. I learned they bought the eggs with money they received from begging. These patients, distressed by the quality of food, had formed their own co-op. Pooling their meager resources they had purchased a small supply of foodstuffs, including a little sugar and some instant coffee, two bananas, and a few other items.

I saw a patient bundled in a topcoat and hat mopping his own room. He said no one else would clean up if he didn't.

I saw a patient who complained of a head injury, who said she had asked to see a doctor several days before, but nothing was done by the boarding home operator.

There were large groups of patients blankly staring at a television set at 9:30 in the morning; the picture on the set was continuously rolling.

I talked with patients who received no personal spending allowance. Others said that the operators required them to work hard and paid them little. One man told us he helped out in the kitchen 8 or more hours a day for which he was paid $5 a month.

I saw medicine cupboards that were wide open. Almost anyone could walk off with large quantities of amphetamines and barbituates (some of which have tremendous street value). I met no licensed nurses on my tours; most drugs were administered by unlicensed personnel, who most likely could not detect possible adverse reactions and side effects that occur when patients take large amounts of psychoactive drugs.

I saw activities schedules posted but few activities in progress.

It became evident to me that operators were cutting corners in order to be able to maximize profits. SSI pays $386 per patient per month in New York. This flat payment means there is no accountability. Whatever is not spent becomes profit. Apparently, former mental patients are as good an investment in New York as we found them to be in Illinois. In that State, one operator received $385,000 to care for about 100 former patients. He kept 13 percent of patient income (over $50,000) as profit. Another increased his investment (equity) in an old hotel from $10,000 to $250,000 in 10 years. He housed about 180 former mental patients, receiving $400,000 a year and managed to keep $185,000 in profits (fully 46 percent of total revenues). One of the ways in which he accomplished this was to spend 58 cents per patient per day for food. A third partnership received over $1 million to care for ex-inmates and kept 30 percent of it, over $300,000, as profit.

Given the marginal quality of life that we found in these facilities in New York and all over the United States, I have every reason to believe that other operators are making similar profits. Since the source of these funds is primarily

> SSI, the new Federal welfare program for the aged, I intend to do everything in my power to restore some accountability to this program. The taxpayers deserve to know how their money is being spent. Right now it looks as if much of the funds are going to line the pockets of the greedy who pretend to be offering care and services to the needy.

Senator Moss added that he and the Subcommittee staff had found "virtually all the abuses" they had uncovered in their nursing home investigations, "plus a few new ones." The abuses he listed were essentially in 10 categories, many of which were also reported by Assemblyman Stein and by the June 30, 1975, audit of adult care homes conducted by Arthur Levitt, New York State Comptroller. They include:

1. *Poor care and abuse.* The January 19, 1975, report by the Task Force on Domiciliary Care Facilities in New York City quotes one study which disclosed that more than 90 percent of DCF patients were ex-inmates; 65 percent had been diagnosed as schizophrenics and 32 percent of them had serious *physical* health problems in addition to their mental problems. This Subcommittee's finding was similar, and yet there was no evidence of medical care, psychiatric services, therapy or recreational services for patients. In the past, there have been examples of negligence in DCF's, such as patients wandering away, being hit by cars or freezing in the snow. The most extreme instance of this sort was the recent grand jury report on the death of William Maltzman, a resident of Hi-Tor Manor (adult care home), who allegedly died from malnutrition in 1975.

2. *Unsanitary conditions.* The comptrollers report notes that unsanitary conditions were found in some New York boarding homes: Senator Moss reached a similar conclusion:

> Many homes we visited had that all too familiar urine smell. Some of the kitchens were less than exemplary. Patient rooms often were in need of cleaning or paint. Bathrooms were the dirtiest of all.

3. *Poor food or poor preparation.*

Said Senator Moss:

> One of the homes we visited had very few food supplies. The home's refrigerator contained about 20 pounds of very dark hamburger to feed more than 100 patients. In the same refrigerator, potato peelings, and other assorted vegetable scraps had been saved, presumably for soup. Some of the kitchens were far from clean. One kitchen was in a basement. The windows were open, to allow a garden hose to be brought in from outside. There were no screens. This means that rats and mice could have easy entry to the home.

4. *Theft.* A particular problem exists with respect to the possessions of patients and the disposition of these items after a patient's death. The primary resource for patients is the Social Security or Supplementary Security Income checks which are delivered to the boarding home. These checks are sent in the names of the patients. The patients often endorse these checks to the operators who cash them and give back $20 as a personal spending allowance. In many cases, the patients

never see the checks at all. Endorsement is often in the form of an "X" on the back of a check signed by the operator himself. Most former mental patients are not in a position to challenge the operator for expropriating their funds. Both Assemblyman Stein and Comptroller Levitt took note of this problem in their reports.

5. *The inadequate control on drugs.* The lack of controls on drugs is a significant problem. Licensed nurses are not in evidence in most boarding homes. The unlicensed aides who administer drugs are generally unable to identify the adverse reactions and side effects which come from taking large amounts of several kinds of drugs over a protracted period. Oversedation (overtranquilization) is a recurrent problem in boarding homes. This abuse is mentioned in the Stein report, in the comptroller's report, and also in the grand jury report investigating the death of William Maltzman.

6. *The hazards of fire.*

Senator Moss said:

> Boarding homes rank No. 1 on the list of unsafe places to be from the point of view of danger from fire. Former mental patients have often been found to be significant fire risks. There have been recent fires in Utah, Illinois, Wisconsin, the District of Columbia, and California, in which mental patients have been involved. This is an argument for fire protection at least equal to that offered by nursing homes. Unfortunately, few boarding homes could comply with the Life Safety Code of the National Fire Protection Association, the Federal minimum standard for nursing homes.

In fact, according to the comptroller's report and that of Assemblyman Stein, many facilities which once functioned as nursing homes in New York (and which could not meet fire standards), have been downgraded into adult care homes.

7. *Reprisals against those who complain.* The Stein report refers to "intimidation," saying residents were afraid to talk to visitors because they are afraid of being turned out into the streets. Senator Moss and the staff experienced this problem in their recent tour of New York homes. In the presence of the home's operator residents would praise the facility and the food only to bitterly complain about conditions when the operator was out of hearing distance.

8. *Lack of activities or recreational services.* Most facilities provide little for patients in the way of activities or recreation. Social services are not provided. Unhappily, too many patients are forced to work and paid little, operators rationalize this calling it "occupational therapy." Operators say that the $386 SSI payment does not allow them to offer the services that they would like to be able to offer.

9. *Poor physical conditions.* The comptroller's report refers to "unsuitable facilities" referring to unsuitable physical conditions. Senator Moss' comments (above) indicate that the Subcommittee found this to be a problem as well.

10. *Assaults on human dignity.* "Perhaps my most serious concern of all was the lack of human dignity," said Senator Moss. "There was a lack of privacy. Patients were treated as objects rather than like individual human beings. There was a seeming indifference on the part of many operators to their needs. We heard some verbal abuse.

67-475 O - 76 - 6

We saw no physical abuse of patients but it is a reasonable inference that it exists in some of these facilities."

In the words of the report prepared for the Subcommittee use by temporary staff member John Hemmington in March 1975, "There is a general agreement that significant problems exist in New York's domiciliary care facilities but there is no general agreement as to why these problems exist and as to what to do about the problem."

With respect to the question of why these problems exist, the Subcommittee has concluded that a major contributing factor has been the transfer of thousands of former mental patients into adult care homes which were never intended to be able to provide the care and services these individuals need. Domiciliary care facilities were seen as offering room and board and personal care to ambulatory patients who are (1) physically well, (2) in good mental condition, and (3) able to take care of their daily needs. Former mental patients, by contrast, are generally unable to take care of their daily needs; they take large quantities of drugs which require sophisticated supervision; moreover, at least 30 percent of these patients are physically ill and require medical care.

The extent of the problem can be seen by looking at statistics.

There were 85,000 patients in State mental hospitals in New York in 1964 but only 39,770 10 years later.[130] Large-scale transfers of patients began in 1968 with a Department of Mental Hygiene directive which stated that patients would be better off in their own communities than in large institutions. In March of 1972, "convalescent leave" was abolished and all patients were permanently discharged. The State was no longer to be responsible for their care.[131]

The ever increasing number of dischargees from the State hospitals inevitably brought great public concern. The Community Service Society of New York issued a report which stated in part:

> Despite the substantial numbers of persons involved, no one knows who the aged are who have been turned away or where they are. Have they died? If not, how are they living? Has their distress been alleviated and if so in what setting, and by whom have they been helped? What strains have been placed upon families and what is the effect on family relationships? [132]

The 34,000 people who live in the faded resort city of Long Beach, N.Y. had no difficulty answering these questions. Something like 3,000 welfare cases and 300 to 800 former mental patients were placed in that city's old hotels. The result was countless reports of bizarre behavior—ex-mental patients wandered unattended, defecated in public, and exposed themselves. An enraged citizenry clamored for action and their city council responded with an ordinance banning the placement of discharged mental patients in the city's hotels. This statute—of questionable constitutional validity—is evidence of the importance one city attached to the problems associated with the dumping of large numbers of former mental patients within its geographical boundaries.[133]

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[130] See table 2, p. 719.
[131] See p. 26, reference cited in footnote 73.
[132] See p. 16, reference cited in footnote 8.
[133] See *New York Times*, series by Murray Schumach, p. 1, Aug. 16, 1974, and almost daily thereafter through January 1975.

As a result of the public indignation, New York City's Comprehensive Health Planning Agency appointed the aforementioned Task Force for Domiciliary Care Facilities. A report was written for this task force by Samuel Levey and Hirsch S. Ruchlin, entitled: "Domiciliary Care in New York City: Current Analysis and New Directions for the Future." The report stated that adult homes were becoming a catchall: for the aged, for mental patients of all ages, for alcoholics, and drifters. It cites the need for health services in DCF's and to establish clear criteria for establishing who were appropriate patients to be housed in adult care homes.

The report notes that cost pressures push patients out of hospitals and nursing homes into adult care homes (which also allows the States to transfer their burdens through SSI to the Federal Government). It pointed out that there were few efforts to reevaluate patients after their entry into adult homes, charging that many patients needed more extensive nursing home care or admission to a general or psychiatric hospital.

A primary obstacle to the smooth flow of patients to the level of care they need, is the fact that neither the State nor the city health department has any jurisdiction over adult care homes, according to the report. Jurisdiction is in the hands of the State Board of Social Welfare which the report criticizes for its "laissez-faire," "hands off" policy toward the enforcement of boarding home standards. The report warns that the $386 flat SSI payment guaranteed by the Federal Government, coupled with the low standards, anemic enforcement, and "relatively lower costs . . . offer enticing opportunities for the realization of significantly larger profits in domiciliary care than in nursing home or health related facility care."

The report offered a series of recommendations, including convening a Federal task force to study the effects of SSI and the creation of a for-profit nursing home and boarding home industry. It recommended the funding of alternatives such as home health care, homemakers services, day care, foster family care, and halfway houses. It recommended that the responsibility for enforcement of standards be shifted to the State Department of Health to include DCF's in the continuum of health care. It recommended that DCF's be required to file annual cost and financial statements as well as disclosing real estate transactions, ownership data, interlocking ownership and financial intertsts of operators in various vending and supply companies doing business with the facilities.

Many of these recommendations are made in the so-called second draft of the task force produced on January 10, 1975; the June 30, 1975 comptrollers report, the report of the grand jury to investigate the death of William Maltzman and the Stein report each make some of these same recommendations.

The crux of the problem involves a decision on the part of the State of New York as to what kinds of services domiciliary care facilities will offer for what kind of patients.

It is charged that the imposition of the recommendations listed above and a more aggressive enforcement posture will make DCF's into carbon copies of the next level of facilities (and care) above them, i.e., nursing homes known in New York as health related facilities (intermediate care facilities in most of the country). The distinction

between HRF's and DCF's in the law is that the former provide some medical care and the latter do not. However, given the evolution of this problem there have been thousands of former mental patients placed in DCF's who need medical care. The conclusion is that such individuals are improperly placed, and that they should be in HRF's. What prevents this from happening is that HRF's are nursing homes supported by Medicaid which is half Federal and half State money and the fact that costs in New York HRF's vary from $600 to $900 a month as contrasted with the $386 in SSI funds for adult homes.

This fact underscores the importance of establishing a criteria and procedures for ascertaining the appropriate level of care for each patient and then selecting facilities which best meet the patients needs. The establishment of such screening procedures was recommended in all the reports mentioned in this section. Moreover, most experts agree that the jurisdiction and responsibility for administering the DCF program should be transferred to the State Health Department rather than the State Board of Social Services.

If, in the alternative, the State Board of Social Services is to retain jurisdiction, then it would be advisable to reduce the number of board members from 15 (who serve part time) to a smaller number who serve full time. The 1975 revision of the New York State Commission on Correction provides an appropriate precedent. The staff should be increased so that it can adopt a more rigorous inspection and enforcement policy. The board should be given authority to promulgate regulations requiring the disclosure of DCF ownership, the filing of cost and financial data. It should be given the authority to audit DCF accounts. One of its first priorities should be regulations to require the protection of patients' funds and to insure that each resident receives the minimum $20 personal spending allowance.

The reports prepared by Assemblyman Stein and the others also agree that the Congress must quickly enact some amendments to the SSI law. Among these suggestions are, the requirement of Federal minimum standards for fire safety, physical environment, food, recreational services, social services, medical, and psychiatric care. The reports are unanimous on the need to put controls on the $2 billion SSI program to prevent the growth and proliferation of another uniquely American phenomenon, the for-profit boarding home industry.

As Senator Moss noted:

> **Unless the Federal Government acts quickly, we will be confronted with a full grown, entrenched industry, infiltrated by speculative investors, with its full complement of lobbyists and we will be saddled for all time with a for-profit boarding home industry, at which time real reform may be impossible.**

# PART 5

## SUMMARY AND CONCLUSION: FAILURE TO ESTABLISH A NATIONAL POLICY

Previous reports in this series have stressed the failure to create a coherent national policy with respect to the physically infirm elderly. This Supporting Paper indicates that this failure also extends to the mentally impaired who are patients in long-term care facilities including the mentally impaired.

This paper also explains why:

**(1) Two and a half million elderly are going without the mental health services that they need;**

**(2) Current programs (Medicare and Medicaid and Community Mental Health Centers) are ineffective and poorly administered;**

**(3) Responsibility for Federal and State mental health programs is fragmented among dozens of Federal, State, and local agencies;**

**(4) Thousands of patients continue to be housed in State mental hospitals for no reason except that they have no place else to go;**

**(5) Thousands of individuals who need the intensive services offered at State hospitals have been precipitously discharged into smaller community based services;**

**(6) There is a distinct lack of any programs to help nursing homes to care for discharged mental patients;**

**(7) Thousands of former patients have been "returned to the community" and then shuttled back again to State hospitals;**

**(8) Thousands of former mental patients are placed in slum housing throughout America's major cities with the taxpayer paying the rent in Supplementary Security Income payments; and**

**(9) A for-profit boarding home industry has blossomed overnight to take advantage of the government's policy of indecision or, at best, inaction.**

**The end result is that the States play musical chairs with the frail and impaired elderly, moving them away from home, away from town, from mental hospital to nursing home, from nursing home to mental hospital to boarding homes, from floor to floor, and from room to room in whatever direction will save the most money.**

The amount of "savings" in monetary terms is difficult to measure with some people suggesting that short-term savings are offset in the long run. Measured in human terms there are intolerable losses to society.

**It is incontestable that the transfer of individuals in and out of institutions results in sharp increases in morbidity and mortality, a phenomenon known as "transfer shock." To former mental patients, transfers (particularly to boarding homes without a modicum**

**of therapy, medical care, services, or recreational programs) mean regression; it may mean injury to themselves or others; it may mean death.**

Even if none of these harmful effects becomes manifest following a wholesale transfer to a boarding home and because of inadequate followup, patients are not helped with reorientation so that they may rejoin the community. Generally, they are left to vegetate in unspeakable conditions.

**This Subcommittee concludes that this Nation can no longer tolerate this tremendous waste of resources and this inhuman treatment of American citizens. As citizens they are entitled to the opportunity to lead meaningful lives. This opportunity has been denied to them for too long. What is needed is a national policy which will recognize the diverse needs of the mentally impaired elderly and provide comprehensive programs to meet these needs.**

# PART 6

# RECOMMENDATIONS

1. Present restrictions on Medicare out-patient psychiatric care should be removed so that Medicare pays the same benefits for out-patient psychiatric treatment as it does for all other medical care. We further recommend that the 190-day lifetime limitation under Medicare for in-patient treatment in a psychiatric hospital be removed.

2. Day care services should be authorized for the mentally impaired under Medicare.

3. Section 1844(o) of the Social Security Act should be amended to permit agencies providing care for the mentally ill or retarded in their homes to qualify as home health agencies under Medicare.

4. Medicare's home health coverage should be expanded to include the full ranges of services including habilitative programs to aid the mentally impaired or retarded.

5. The number of community Mental Health Centers should be expanded. An attempt should be made to locate them in areas of greatest need including poverty and minority areas. Governing boards should be established for such centers and include representatives from the community as well as consumers and representatives of health care professions.

6. Medicaid and SSI legislation should be amended to allow the use of these funds to care for residents in State mental hospitals. In return for this authorization the States should insist that State facilities are licensed, that they meet certain minimum Federal standards.

7. SSI funds should be authorized to patients in Shelter Care Facilities, provided that such facilities offer minimum supervision 24 hours a day, compliance with Federal minimum standards, and the States agree to supplement the standard Federal SSI payment by not less than $100 per patient per month for each authorized patient.

8. All States should establish effective geriatric screening centers to evaluate the condition of patients. However, when patients, especially the elderly, need the services of a State hospital, such services should be available to them.

9. Communities should establish outreach programs from State hospitals to allow the treatment of individuals in the community.

10. Before individuals are discharged to nursing homes there should be effective screening procedures conducted by a team of medical and psychiatric experts.

11. The departments of mental health should execute a written agreement with the facility to receive such transferees indicating what is expected from the facility and the responsibilities of the department.

12. There must be appropriate followup care to determine if patients are properly placed.

13. The patients must be provided with recreational and other activity programs.

14. Requisite minimum standards should be promulgated for all facilities housing the discharged patients such as the Life Safety Code of the National Fire Protection Association. The mentally retarded or those with related conditions should not be viewed as being able to protect themselves in the case of a fire or other emergency.

# APPENDIXES

## Appendix 1

## EXCERPT FROM PROPOSED DESCRIPTION OF CONTRACT SERVICES; SUBMITTED BY CENTRAL BERGEN COMMUNITY HEALTH CENTER, 26 PARK PLACE, PARAMUS, N.J.[1]

Project Director: F. William Bailey, ACSW.
Project summary.

Under Project Haven, our center contracts to make available a total of 100 placements for patients eligible under title VI of the Social Security Act. Patients placed in the project will be comprehensively serviced by Project Haven staff under the direction of F. William Bailey. At any one given time there will be 55 placements within our facilities, 30 in the Day Treatment Center, 10 in the Vocational Rehabilitation Center, and 15 in the Sheltered Workshop and Activities Center. These 55 onsite placements will be complemented with 45 placements to be serviced offsite by our visiting and support team. The social services we offer range from appropriate day activities, individual evaluation and counseling, family counseling, treatment, medication, and sheltered workshop activities.

Of the 100 placement opportunities, 40 will be in our transitional residences, 10 in contracted nursing homes, and 50 living by themselves or with their families. It is understood that there will be a ready patient flow between all the facilities and the programs offered by us, and it is anticipated that an individual patient may attend any and all of these service programs in sequence or simultaneously. The important point is that we will gear the services to fit the need of the individual patient at any one given time.

The obligations undertaken as part of Project Haven are considered to be for a minimum term of 5 years, subject upon annual review of the Project and renewal of the contract.

LILA HERSHEY, *President.*
ARISTIDE H. ESSER, M.D., *Director.*

[Enclosure]

CONTRACT SERVICES

Under Project Haven these will be provided on a voluntary basis. Should a patient want to leave the program, we will do everything in our power to arrange proper transfer to another agency or institution.

[1] It was upon this description that a contract between the center and the N.J. Department of Institutions and Agencies was based in March 1975. (See p. 730 for additional discussion of this project.)

When, in our opinion, the patient is ready for independent living, we will do everything to make this possible and then offer his placement to another patient.

We will operate within the customary responsibilities of volunteer agencies toward their clients and patients. No patient will be deprived of his rights in accordance with current social service regulations. Our activities with and for the patients will be under routine monitoring by our Institutional Review Committee (IRC).

INTRODUCTION

Central Bergen Community Mental Health Center, Inc., began its program as a federally funded Community Mental Health Center on August 1, 1971 to serve the 160,000 people residing or working in the 10 towns that make up Catchment Area No. 46. Its programs have been developed both through new facilities operated by Central Bergen and the expansion of programs conducted by affiliate agreements with the Bergen Pines County Hospital, the Fair Lawn Mental Health Center and the Pascack Mental Health Center.

The hospitalization rate at the Bergen Pines County Hospital for psychiatric patients from our catchment area used to be approximately 400 per year, the average over the years 1969 through 1971. In the 3 years that our center has been in operation the hospitalization rate is down to approximately 330 patients (average of 1972–1974).

Very few patients, less than 10 per year are still being sent to Greystone State Hospital. This hospital used to serve the chronic patients of all of Bergen County in the Currie Building and in their geriatrics building. Presently our Catchment Area has approximately 65 patients of diverse age groups in the Greystone State Hospital. At any one time therefore, in 1974 we may assume that approximately 85 patients of the Catchment Area are in a hospital, either at the county or at the State level (taking into account that the average stay at Bergen Pines County Hospital is 20 days).

Catchment Area No. 46 is primarily a middle and high-income living area. Of the 10 towns in the Catchment Area, the northern ones have extremely high standards of living even by Bergen County (the tenth highest income county in the Nation) standards. The problems of housing patients in our Catchment Area are therefore problems of middle and upper income style of life. With a median income level of $18,000 and an average house sale price of $50,000 it is extremely hard for someone without independent income or a job to maintain himself in the area.

The history of our center's efforts to obtain transitional residences for patients to be released from Greystone State Hospital, has proven that it takes much work and overcoming of community resistance to even get the permission to move patients into the community. It is fair to say that in the more than 1 year that we have tried to provide this type of living for our patients, we have had no better than 50 percent community acceptance and that at an enormous cost in professional staff time, volunteer efforts, and community good will. We feel, however, that with the appropriate financial resources our center could return the majority of chronic state hospital patients to the community. The background for our claim is as follows:

The center receives notification of all area No. 46 admissions to Greystone Park Hospital and to Bergen Pines County Hospital. In cooperation with the hospital staffs our psychiatric social worker interviews the patient who is advised of the services provided by the center. Whenever possible, a release is obtained from the patient permitting the center to contact the patient's family. The family is encouraged to make at least one visit to the center for counseling on plans, preparation and expectations and anxiety related to the anticipated discharge. Where indicated, this is continued by regular meetings of family groups. Meanwhile, the patient is given an opportunity to meet individually or in a group with center personnel at the hospital to plan for the discharge.

The center participates in predischarge planning with the hospital staff. When the date of discharge is set, an appointment is made for the patient to visit the center location nearest to his home. On the basis of this visit and the recommendation of continuity of care worker, the patient is assigned to the modality appropriate to his case. This may involve a sheltered living arrangement (provided in our transitional residence), day treatment or partial hospitalization, vocational rehabilitation, inclusion in another of the center's many programs. If it is appropriate referral is made to other community treatment resources such as Friendship House, the psychiatric rehabilitation facility in Hackensack.

Encouraged by our experience with the partial hospital in handling both acute and chronic cases, the Greystone Park and center staffs have been seeking to reach a number of "backward" patients to establish whether these could be prepared for discharge by being transported daily to the center. Implementation of this plan has experienced difficulties because no regular transportation has been found. However, an important result has already been realized. In four cases (one of which the patient had been hospitalized for 12 years), the family, advised of the partial hospital program, agreed that they would now care for the patient at home with the support and resources offered by the program. In addition, we established the transitional residence program which is the focal point of this application.

Our residential transitional facilities were initiated when both the center and the Bergen County Mental Health Board's committee on continuity of care had found that there exists a most urgent need for patient homes. For example, housing is so scarce and expensive in Bergen County that a number of Bergen residents in Greystone Park State Hospital are being placed in foster homes in Morris County. Children are being sent to out-of-State boarding schools as far away as Texas by the Division of Youth and Family Services. As a result of this situation, the Bergen County Mental Health Board in 1972 awarded a $10,000 grant to CBCMHC to establish a transitional residency that serves selected patients as a link between inpatient status and independent, self-sufficient outpatient status. A female residence with a capacity for four patients has now served to release nine persons from Greystone. In 1973, a special grant was obtained from the Department of Institutions and Agencies to open a male transitional residence, presently housing four ex-patients.

PURPOSE AND AIMS OF "PROJECT HAVEN"

Encouraged by the success of its transitional residences the Central Bergen Community Mental Health Center would like to expand its capacity to care for Area No. 46 chronic psychiatric patients. All residents of our catchment area who are hospitalized at Bergen Pines Coun ty Hospital or Greystone Park State Hospital should be able to receive special help in discharge planning and followup services. Our investigation of specific cases chronically residing at Greystone have led us to the conclusion that at least 75 percent of so-called "chronic" patients are capable of returning to more normal community life provided that our present array of supportive social services is adequately funded to serve more patients. Starting in 1973, with the aid of a grant from the Bergen County Board of Chosen Freeholders and a subsequent State of New Jersey special projects grant, two transitional residence programs were initiated, each with a capacity to accommodate four residents. The residences are conventional five-room apartments in which the occupants share among themselves the daily routines of cooking, cleaning, and shopping. A visiting team composed of a psychiatric social worker and a community worker are available on a 24-hour-per-day basis and meet regularly with the residents on at least a once-a-week basis. Residents pursue a variety of daily programs depending on individual need and ranging from daily, full-time participation in our day center to full-time employment and supportive counseling services. To date, 13 patients, 9 women and 4 men, have been discharged from hospital care and placed in these facilities.

We feel on the basis of this and our knowledge of presently hospitalized patients that it is possible to provide this service for 50 presently hospitalized patients who can be accommodated in community residences and provided with a range of necessary life support systems. The most basic aspect of such a system is a place to live.

We feel that four levels of care will be sufficient to meet the needs of our patients with a high degree of individualization. These levels are as follows:

A. Two-bedroom apartment or home settings to accommodate four patients who are capable of self care 'round the clock and do not require "in-house" staff. They will do all their own cooking, cleaning, and shopping. The staff will be on call at all times and will meet with them at least once each week as a group to handle their community needs. Individual contact with each patient will also be maintained.

B. Two-bedroom apartment or home settings, with a bias toward the acquisition of two-family houses to accommodate eight patients who are essentially capable of self care but who need part-time supporting staff to assure that daily routines are accomplished. Staff coverage during the hours from breakfast thru the evening meal will be required with staff on call at other times.

C. Two-bedroom apartment or home settings again with a bias in favor of two-family houses for up to eight patient who are more severely disabled and therefore require the presence of in-house staff on a 24 hour per day basis. Staff will be more directly

involved here in the actual performance of daily routines because of the patient's deficit but the units' orientation will still emphasize the maximum possible self care.

D. Nursing home placements will be secured on a local basis for those older patients who are judged able to leave the hospital but who need more supportive care, particularly medical, than would be possible in levels A, B, or C.

The provision of a suitable place to live is only the first step in our program, however. Additionally, job placement and socialization will have to be developed that aim at enhancing the individual's capacity to become independent, so that a "baby-sitting" approach to care does not develop. The following services will be available to those served by "Project Haven":

1. Day care center (DCC).
2. Vocational rehabilitation and sheltered workshop.
3. Recreation and socialization programs.
4. Transportation.
5. Individual and group counseling.

## Appendix 2

## ARTICLE IN *THE RECORD*, HACKENSACK, N.J., FEBRUARY 20, 1975

### Homes for Patients

(By R. Clinton Taplin)

New Jersey mental health officials are preparing to spend $2.9 million in Bergen County to care for state hospital patients in much the same way that Gheel, Belgium has been doing since the Middle Ages.

Trenton officials are in the final stage of reviewing three projects to relocate patients from Greystone Park Psychiatric Hospital to small boarding homes, group homes, and foster homes—a technique that has made Gheel a haven for the mentally ill since the 14th Century.

Gheel is a town of 30,000 south east of Antwerp. What makes the town unique is that nearly 20 percent of its population is made up of psychiatric patients, nearly all of whom live in private homes and have the status of adopted family members.

The patients in Gheel live and work in the community, socialize, and walk about the town square indistinguishable from the normal population.

#### THREE PROJECTS PROPOSED

Taking a leaf from Gheel, New Jersey officials are reviewing the following projects:

Operation Haven, sponsored by the Central Bergen Community Mental Health Center, Paramus. The project envisions spending $1.7 million over a two-year period to relocate 50 patients a year and provide residential care for another 40 or 50 who would otherwise have to go to a hospital.

Link-Up Extended Care, a foster home program proposed by the Community Center for Mental Health, Dumont, involving some $600,000 over a three-year period to place former state hospital patients in private homes.

Project Advance, proposed by Hackensack Hospital and Friendship House. It is a three-year, $600,000 program to include a boarding home for up to 20 former hospital patients and psychiatric follow-up to 20 additional persons already living in boarding homes in Hackensack.

Ann Klein, commissioner of institutions and agencies, the state department responsible for psychiatric patients, is sending a representative to Paramus Monday to work out a contract for the first program.

State officials in Trenton say they hope to have all three programs going by midsummer. The funds will come from the federal Social Security program rather than through federal mental health appropriations.

HAGEDORN PLAN DEFERRED

In focusing on the three proposals, local and state officials have deferred indefinitely a plan prepared by the Central Bergen Community Mental Health Center and made public by state Sen. Garrett W. Hagedorn, R-Bergen, last fall.

The so-called Hagedorn proposal would have cost $2.6 million and involved moving 500 patients out of Greystone and back to Bergen over a three-year period. The plan has been all but abandoned as too ambitious.

If approved as proposed, Central Bergen mental health officials will get funds to buy or lease 10 homes in the central part of the county and to place patients in the homes under varying degrees of supervision.

Teams of mental health professionals would visit the homes to provide psychiatric and social services.

Central Bergen is already operating similar facilities in Park Ridge and Fair Lawn and has cared for 13 former patients in the last two years.

F. William Bailey, Central Bergen's program coordinator, said yesterday: "It's interesting to note that since our programs started in Park Ridge and Fair Lawn, none of our clients have attacked anyone. However, one of the clients was attacked." He would not elaborate.

Martin Adler of the Dumont center proposes a program more closely akin to Gheel's. He plans to place 40 or 50 Greystone patients a year in homes where older couples need additional income or want the company of someone they can help.

Donald Springer, director of Friendship House of Hackensack, a psychiatric day-care center with a sheltered workshop program, has plans to accommodate 20 former hospital patients in a single facility in Hackensack. Location of the building has not been decided.

These patients would receive psychiatric care from Hackensack Hospital's Community Mental Health Center.

Springer plans to care for another 20 or so persons, now living in boarding homes, by having teams of mental health professionals make home visits.

The Bergen County Mental Health Board has approved in principle the Central Bergen proposal, as long as there is no unnecessary duplication of services.

The other two projects are now before the county board's professional advisory committee, and reports and recommendations from the committee are expected within six weeks.

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