REPORT TO THE CONGRESS

BY THE COMPTROLLER GENERAL OF THE UNITED STATES

Returning The Mentally Disabled To The Community: Government Needs To Do More

Department of Health, Education, and Welfare and Other Federal Agencies

Care and treatment of mentally disabled persons in communities can be an effective alternative to institutional care. However, many mentally disabled persons have been released from institutions before sufficient community facilities and services were available and without adequate planning and followup. Others enter, remain in, or reenter institutions unnecessarily.

The Congress and the Office of Management and Budget can help solve some of these problems by

--giving Federal agencies a clear mandate to devote resources to this problem,

--defining more clearly the appropriate roles, responsibilities, and actions for Federal agencies, and

--changing aspects of Federal programs that hinder or discourage the appropriate placement of mentally disabled persons.

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COMPTROLLER GENERAL OF THE UNITED STATES
WASHINGTON, D.C. 20548

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To the President of the Senate and the
Speaker of the House of Representatives

This report describes many of the problems associated with Federal efforts to help States serve mentally ill and mentally retarded persons in communities rather than in large public institutions. It discusses the need for a more concerted and systematic Federal effort to make certain that mentally disabled persons are cared for in the setting and with support services most appropriate to their needs.

Our review was made because the Congress has shown interest in helping States serve mentally disabled persons in communities, many problems have been reported in this area by the news media, and many Federal programs affect the mentally disabled. We made our review pursuant to the Budget and Accounting Act, 1921 (31 U.S.C. 53), and the Accounting and Auditing Act of 1950 (31 U.S.C. 67).

We are sending copies of this report to the President and President-elect of the United States; the Director, Office of Management and Budget; the Attorney General; the Secretaries of Health, Education, and Welfare; Labor; and Housing and Urban Development; and ~~the~~ Director of ACTION.

Elmer B. Staats

Comptroller General
of the United States

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ABBREVIATIONS

BHI	Bureau of Health Insurance
CMHC	community mental health center
DDO	Developmental Disabilities Office
GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
HUD	Department of Housing and Urban Development
ICF	intermediate care facility
JCAH	Joint Commission on Accreditation of Hospitals
MBO	management by objectives
MSA	Medical Services Administration
NIMH	National Institute of Mental Health
OLTC	Office of Long Term Care
OMB	Office of Management and Budget
PCMR	President's Committee on Mental Retardation
PSA	Public Services Administration
RSA	Rehabilitation Services Administration
SNF	skilled nursing facility
SRS	Social and Rehabilitation Service
SSA	Social Security Administration
SSI	Supplemental Security Income

COMPTROLLER GENERAL'S
REPORT TO THE CONGRESS

RETURNING THE MENTALLY DISABLED TO THE COMMUNITY: GOVERNMENT NEEDS TO DO MORE

Department of Health, Education, and Welfare and Other Federal Agencies

DIGEST

Care and treatment for the mentally disabled in communities rather than in institutions has been a national goal since 1963. Some Federal courts have held that the mentally disabled have a constitutional right to be treated in communities when community care serves their needs more and restricts their freedom less. (See ch. 1.)

Nevertheless, many mentally disabled needlessly enter, remain in, or reenter institutions. Others have been released from institutions before enough community facilities and services were available and without adequate planning for, and later review of, their needs. This review did not include the criminally insane and did not consider the quality of care in institutions. (See ch. 2.)

Because Federal programs provide the financing, States are encouraged to transfer the mentally disabled from institutions to nursing homes and other facilities that often are inappropriate. Federal programs can, do, or should affect "deinstitutionalization"--that is, serving only those needing institutional care in institutions and serving others in the community.

These programs need to be better managed, responsibilities and accountability of Federal agencies need to be clearly defined, and Federal agencies need to work harder together to help achieve deinstitutionalization. (See ch. 3.)

There is no overall plan and management system to

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- --set forth specific steps needed to accomplish deinstitutionalization,

- --define specific objectives and schedules,

- --define acceptable community-based care, or

- --provide central direction and evaluation.

Three organizations are responsible for directing and coordinating efforts of Federal agencies: the Office of Management and Budget, Federal regional councils, and the President's Committee on Mental Retardation.

The first two have not taken action on deinstitutionalization; the President's Committee has been only partly effective in coordinating the work of Federal agencies.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

The Department of Health, Education, and Welfare's (HEW's) approach to deinstitutionalization was disorganized.

- --Plans to make community placement work had not been made.

- --Instructions to constituent agencies had not been issued.

- --No one organization had been assigned responsibility for overseeing deinstitutionalization.

Although they are helpful, developmental disabilities programs and the community mental health centers program have not done as much as expected and have not provided the resources or services needed to place mentally disabled people in the community.

Developmental disabilities program

The developmental disabilities programs in the five States reviewed provided funds to develop and expand community resources and worked productively with other agencies. But success was not commensurate with need.

The Developmentally Disabled Assistance and Bill of Rights Act of 1975, if properly implemented, should resolve many problems. HEW and other Federal agencies must support State developmental disabilities programs by identifying specific actions that other federally supported agencies need to take. Greater commitment and cooperation from other federally supported State and local programs also are needed. (See ch. 4.)

Community mental health centers and clinics

Increased services available from community mental health centers and clinics have not always reduced unnecessary admissions to mental hospitals or provided services to people released from mental hospitals. Medication was the only service provided to many patients.

The mental health centers program has developed separately from the public mental hospital system, making integration of the two difficult. Funding for community-based mental health services has not grown in proportion to the need.

Allocations for mental hospitals still dominate most State mental health budgets, and restrictions and other problems have prevented the use of other funds to improve community-based care for the mentally ill. Declining Federal funding for centers has caused several communities to avoid the program. (See ch. 5.)

Medicaid

Lacking alternatives, local programs use money provided by the Medicaid program to place the mentally disabled in nursing homes. Many homes are not staffed or prepared to meet the special needs of the mentally disabled or are not the best setting for persons so placed.

People were also placed in nursing homes or elsewhere without any release plans, with plans that did not identify all services needed, or without adequate provisions for followup services.

HEW has started to improve the quality of care nursing homes provide but has not dealt specifically with the special needs of the mentally disabled in these homes. HEW can help by systematically evaluating and enforcing Medicaid requirements for deinstitutionalization and by integrating related requirements in Medicaid and other agency programs.

How do HEW standards for institutions for the retarded that participate in the Medicaid program affect a State's ability to help those inappropriately placed in such facilities or who risk being admitted to them?

HEW must answer this question, because States must improve facilities to comply with the standards by March 18, 1977, and must also expand community programs for the retarded. Sufficient funds often are not available to do both. (See ch. 6.)

Under the Social Security Act, States must find and correct situations in which Medicaid recipients are wrongly placed in mental hospitals, institutions for the retarded, or nursing homes or do not receive appropriate services there. HEW must also survey these programs to validate their effectiveness.

State and HEW efforts in this area should be improved because they were inadequate to meet the needs of the mentally disabled. (See ch. 7.)

Medicare

Medicare provides insurance for only limited outpatient care for the mentally ill. Because of this, many people may be placed unnecessarily in mental hospitals.

HEW monitors State surveys of mental hospitals for compliance with Medicare standards, including those on discharge planning, but this has been limited. HEW has recognized these problems and was trying to solve them. (See ch. 8.)

Supplemental Security Income

Although Supplemental Security Income has helped mentally disabled people return to communities, some of these people have been placed in substandard facilities, placed without provision for support services, or placed inappropriately. Standards on group housing for Supplemental Security Income recipients were not required; this aggravated the problem.

Supplemental Security Income payments were reduced or not authorized when public agencies helped maintain or operated community residential facilities for the mentally disabled. Legislation enacted in August and October 1976 eliminated many of these reductions in Supplemental Security Income and authorized such payments to persons in certain publicly operated community residences. (See ch. 9.)

Social services

Although many mentally disabled have been released from public institutions without provision for needed services, many States have not used all Federal funds available under social services programs. This is partly because of the controversy and confusion about the program and the inability or unwillingness of States to provide necessary matching funds.

HEW had not monitored or enforced its requirements that social service plans respond to individual needs or that foster placements be appropriate.

A new social services program started in 1975 does not include these requirements. Although deinstitutionalization is one goal of the new program, HEW does not require States to coordinate their program plans on this goal with those of mental health agencies, community mental health centers, or other agencies. (See ch. 10.)

Vocational rehabilitation

State vocational rehabilitation agencies have helped mentally disabled persons remain in and return to communities. Since the enactment of the Rehabilitation Act of 1973, these agencies have reported some increased efforts to rehabilitate persons with mental handicaps classified as severe disabilities. This act required emphasis on service to the more severely disabled.

Vocational rehabilitation for the mentally retarded has been provided primarily for the mildly retarded or persons with nearly normal intelligence quotients in the community (rather than in institutions). Vocational rehabilitation for the mentally ill often was focused on drug addicts, alcoholics, and persons with mental disabilities not considered severe by HEW.

HEW needs to improve its management of the vocational rehabilitation program so that appropriate emphasis is given to the more severely mentally disabled. (See ch. 11.)

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

Only one of eight local housing authorities contacted considered the needs of the lower income, mentally disabled people in its housing assistance plan. This consideration is required by the Housing and Community Development Act of 1974.

In 1971, the President directed the Department of Housing and Urban Development to help develop special housing for the retarded. However, the Department had not

--made plans for this,

--told local housing authorities and managers or sponsors of HEW-assisted housing to consider the needs of the mentally disabled, or

--informed its headquarters and field staffs of their responsibilities under the President's directive. (See ch. 12.)

DEPARTMENT OF LABOR

Labor job training and placement programs often have helped mentally disabled persons, but they have not been available to many mentally disabled persons in or released from institutions.

The Secretary of Labor had not informed the Department staff of their responsibilities in helping accomplish deinstitutionalization, and program administrators had not considered their programs' effects on this objective.

Many people served by sheltered workshops were not placed into competitive, productive employment; others needed job training and placement to help them lead normal or nearly normal lives in the community. (See ch. 13.)

RECOMMENDATIONS TO THE CONGRESS

The Congress should consider:

--Designating a committee in each House with the responsibility for monitoring all Federal efforts to help place the mentally disabled in the community so that Federal agencies work together and support State efforts to serve the mentally disabled. (See p. 182.)

--Requiring State developmental disabilities programs to concentrate on coordinating activities at the local level. (See p. 182.)

--Amending the Social Security Act to increase the outpatient mental health services available under Medicare. (See p. 183.)

--Consolidating the funds earmarked for mental health under the special health revenue sharing and the community mental health center programs into a formula grant to State mental health agencies. (See p. 183.)

The Congress should also consider whether additional legislation is needed to help Federal, State, and local agencies provide more job training and placement services to the severely mentally disabled, who have particular disadvantages in the job market. (See p. 184.)

RECOMMENDATIONS TO THE DIRECTOR, OFFICE OF MANAGEMENT AND BUDGET

At least 135 Federal programs--administered by 11 major departments and agencies of the Government--affect the mentally ill or mentally retarded. Therefore, the Director should

--instruct Federal agencies to develop and help implement deinstitutionalization,

--see that the responsibilities and specific actions to be taken by Federal agencies are clearly defined, and

--direct Federal regional councils to mobilize, coordinate, and evaluate Federal work affecting this goal throughout the country. (See p. 184.)

RECOMMENDATIONS TO THE SECRETARY OF HEW

The Secretary should:

- --Define responsibilities of and actions to be taken by HEW agencies.
- --Designate an agency or official responsible for coordinating this work.
- --Determine how to make sure that State and local agencies administering HEW-supported programs develop and implement effective case management systems for people being released from public institutions.
- --Evaluate the need and desirability of providing incentives for care for the mentally disabled other than in intermediate care facilities.
- --Determine a clear and consistent Federal role in mental health and retardation programs and make recommendations to the Congress. (See p. 184.)
- --Improve individual Department programs. (See pp. 186 to 190.)

RECOMMENDATIONS TO THE SECRETARIES OF LABOR AND HOUSING AND URBAN DEVELOPMENT

The Secretaries should each make community care for the mentally disabled a departmental objective and improve existing programs. (See pp. 190 and 191.)

AGENCY COMMENTS

The Office of Management and Budget; HEW; the Departments of Housing and Urban Development, Labor, and Justice; and the National Association of State Mental Health Program Directors generally agreed with GAO's findings.

The Departments of Labor and Housing and Urban Development generally agreed with the recommendations and outlined several actions they have taken, were taking, or planned to take to help return the mentally disabled to the community.

HEW did not specifically comment on the recommendations, but said that it would study them and develop a plan for implementing those it concurred in.

The Office of Management and Budget outlined actions it would take, but disagreed with the recommendations to it, arguing that they were unwarranted and would unjustifiably interfere with State and local responsibilities. GAO continues to believe that the actions recommended are needed and, if implemented, would not interfere with State and local responsibilities.

State agencies commented on findings related to them that were contained in separate reports GAO issued on each State reviewed.

CHAPTER 1

INTRODUCTION

In 1963, the Government embarked on a bold new approach to improve the care and treatment of the mentally retarded and mentally ill. This new approach involved starting a series of programs to stimulate and support an array of community services, as alternatives to institutional care, which enable mentally disabled 1/ persons to remain in or return to their communities and to be as independent and self-supporting as possible. This approach recently has been referred to as "deinstitutionalization," which can be defined as the process of (1) preventing both unnecessary admission to and retention in institutions, (2) finding and developing appropriate alternatives in the community for housing, treatment, training, education, and rehabilitation of the mentally disabled who do not need to be in institutions, and (3) improving conditions, care, and treatment for those who need institutional care. This approach is based on the principle that mentally disabled persons are entitled to live in the least restrictive environment necessary and lead their lives as normally and independently as they can.

The Department of Health, Education, and Welfare (HEW) estimates that about 10 percent of our population, or about 20 million people, has some form of mental illness, which is defined as an affliction resulting in a disturbance in behavior, feeling, thinking, or judgment to such an extent that a person requires care and treatment. HEW also estimates that about 6 million persons in the United States are mentally retarded, with 95 percent of those persons being mildly or moderately retarded and 5 percent severely or profoundly retarded. Mental retardation, which is different from mental illness, is defined as significant subaverage general intellectual functioning which originates during the developmental period (between conception and age 18) and is associated with impairment in adaptive behavior.

Mental illness cost the country an estimated $36.7 billion in 1974 including both direct costs of treatment and economic losses. In 1974 HEW estimated that the annual cost of mental retardation was between $8.5 and $9 billion annually. In 1974, the total cost of caring for mentally disabled persons was estimated at $2.8 billion in State and

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1/ The term "mentally disabled" is used throughout this report when referring to both the mentally ill and mentally retarded. Our review did not include persons determined to be criminally insane.

county mental hospitals and $1.9 billion in State institutions for the retarded. HEW estimated that it alone spent over $1.5 billion for the mentally retarded in fiscal year 1975. (See app. IV.) The most recent data available at HEW shows that Federal agencies spent an estimated $4 billion for the mentally ill in 1971. (See app. V.)

Traditionally, State and local governments have been responsible for the care and treatment of mentally disabled persons. The Federal role has been to support and stimulate improvements in the care of the mentally disabled and, more recently, to assure their equal protection including their civil rights and their rights to adequate treatment and care. Today the Federal Government helps to support the care of many mentally disabled persons both in institutions and in the community.

Until the 1960s, mentally disabled persons who could not afford private care had to rely primarily on public institutions. Conditions in the institutions generally were harsh. Treatment programs were very limited; living quarters were crowded; few recreational or social activities were available; and individual privacy was lacking. In general, the institutions served as custodial settings, often with unpleasant conditions; consequently, many people remained in institutions for years.

Many factors have contributed to the release of persons from public institutions. Some of these were

--the humanitarian concern over the deplorable conditions in many of these facilities;

--new treatment methods;

--new treatment philosophies adopted by mental health professionals favoring community-based care rather than institutional care;

--the availability of Federal and State funds for developing and expanding community facilities and services and for income support;

--the advent of psychotropic (tranquilizing) drugs in the 1950s;

--the cost savings to the States from placing persons in nursing homes and other facilities costing less than mental institutions and where the Federal Government would pay part, most, or all of the cost;

- --changes in State commitment laws which made it more difficult to involuntarily commit persons to mental institutions; and

- --the impact of court decisions protecting the constitutional rights of mentally disabled persons to liberty, treatment, due process, and equal protection under the law, and to be free from cruel and unusual punishment.

In 1963 President Kennedy proposed and the Congress approved two major Federal grant programs aimed at developing community services and facilities needed to shift the place of care away from State institutions. At that time there were more than 680,000 mentally disabled persons in public institutions. The President's special message to the Congress, which cited deplorable conditions in institutions and the Nation's limited ability to treat the mentally disabled in or out of the institutions, called for a bold new approach to the problems of mental disability. Three major objectives were included in the approach; they were (1) to seek out the causes of mental illness and mental retardation and eradicate them, (2) to strengthen the underlying resources of knowledge and skilled manpower needed by the Nation to attack mental disability, and (3) to strengthen and improve the program and facilities serving the mentally disabled, with emphasis on developing community-based services. The President stated that the new mental health program would make it possible, within a decade or two, to reduce the numbers of mentally ill persons in institutions by 50 percent or more. No specific numbers were cited for reducing the institutionalized mentally retarded population.

The resulting Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (42 U.S.C. 2689) became the basis for a major part of the Federal Government's involvement in deinstitutionalization. In subsequent years, other Federal programs, such as Medicaid, Supplemental Security Income (SSI), Vocational Rehabilitation, and Developmental Disabilities, have been initiated or changed to make it possible for more mentally disabled persons to live and be treated in their communities.

The deinstitutionalization effort was further enhanced in November 1971 when President Nixon established, as a national goal, the return of one-third of the over 200,000 mentally retarded persons in public institutions to useful lives in the community. 1/ He also called upon the Department of Justice to strengthen the assurance of full legal rights for the retarded and called upon the Department of Housing and Urban Development (HUD) to assist in the development of special housing arrangements to help retarded persons live independently in the community. In October 1974, President Ford issued a statement in support of the November 1971 goal.

Federal courts have been instrumental in both requiring the return of institutionalized persons to the community and preventing the placement of others into institutions. As of June 1975, there were over 100 completed or pending court cases in 39 States and the District of Columbia affecting the rights of the mentally disabled. Federal courts have held that mentally disabled persons have the right: (1) to treatment in the least restrictive environment appropriate to their needs, (2) to liberty, and (3) to a minimum level of education. These rights have been based upon the Eighth Amendment's prohibition of cruel and unusual punishment, and upon the equal protection and due process clauses of the Fourteenth Amendment. Additionally some State courts have struck down zoning ordinances which discriminated against the mentally disabled.

As of March 1976, public institutions in at least 10 States were under court order to provide services to the mentally disabled in a less restrictive environment appropriate to their needs, and similar cases were pending in several other courts. Over half the States were involved in cases involving the right of mentally disabled persons to an education. The Department of Justice has been involved in many of these cases as either the complainant or friend of the court.

The Federal role in deinstitutionalization has grown substantially since 1963 to the point that the amount and types of financial assistance provided; the requirements, standards, and restrictions imposed; and the policies of Federal agencies have significantly influenced both the progress made and problems encountered by the States in their efforts. Appendix I shows the major events in the growth of Federal involvement in deinstitutionalization of the mentally disabled and others.

1/ The over 200,000 included about 181,000 in public institutions for the retarded and nearly 30,600 retarded persons in State mental hospitals.

At least 135 Federal programs, operated by 11 major departments and agencies, impact either directly or indirectly on the mentally disabled; an estimated 89 are operated by HEW. Almost every component agency within HEW has programs which impact on the mentally disabled. Other Federal agencies include HUD, Labor, Justice, and ACTION.

Under these Federal programs almost every type of service needed by mentally disabled persons in communities can be financed wholly or partly with Federal funds. The programs generally provide income support payments directly to individuals or provide grants to States to cover part of the cost of providing services to the poor, needy, or disabled. Each program generally provides for one or more services, but not for all of those needed by mentally disabled persons. Eligibility requirements, such as age, income, and degree of disability, and State limitations vary among the different programs.

COST OF INSTITUTIONAL VERSUS COMMUNITY CARE

During fiscal year 1974, the estimated average annual cost of caring for a person in a public mental hospital was $11,250, and $9,500 in a public institution for the retarded. The average daily rate per person was about $31 and $26, respectively.

We did not compare the cost of institutional care with community-based care because the relative costs of institutional and community care have not been the criterion for placement under Federal law or court decisions.

We reviewed seven studies which compared institutional-care costs with community-care costs. Four of the studies included the mentally retarded, two included the mentally ill, and one included both. Five of the studies concluded that community care was less expensive than institutional care. The two other studies concluded that costs did not differ significantly assuming a full range of needed services were provided in both settings.

The study that covered both the mentally ill and mentally retarded concluded that three factors--housing, employability, and primary source of funds--had the most influence on both cost and benefit. The study was a 3-year research and demonstration project funded by HEW and showed, for the clients studied, an average net savings to the public of $20,800 per person for community care over a 10-year period. The savings ranged as high as $39,400. The cost of community care exceeded the benefits to the State, but then only by a slight amount, when the clients were living in intensive care facilities, unemployable, and supported by public funds. This study concluded that (1) it is cost-beneficial to the State to place and maintain mentally disabled persons in the community and (2) much of the cost burden shifts from the State to the federally supported programs when mentally disabled persons are placed in the community.

Cost is an important factor for program planning, management, financing, and evaluation. It is difficult to make generalizations about the relative costs of institutional and community care because several factors must be considered. These include the amount, kinds, and quality of services provided, the nature and severity of individual disabilities, the time periods involved, and difficulties in ascertaining complete and accurate costs for community care and what costs are to be considered.

HEW believes that the state of the art of determining the costs in alternative long-term care settings is still in the early stages of development. In view of Federal legislation and court decisions, however, the most important question appears to be how to most cost effectively serve mentally disabled persons in the least restrictive environment appropriate to their needs.

SCOPE OF REVIEW

Our review objectives were to (1) evaluate the progress and identify the problems of selected States in developing alternatives to institutional care and providing an array of coordinated community-based services to mentally disabled persons who would otherwise be institutionalized, (2) ascertain whether prescribed services were provided to persons released from institutions, (3) evaluate the adequacy of HEW enforcement of the requirements placed on States, (4) determine whether selected Federal programs have encouraged or hampered deinstitutionalization, (5) determine the emphasis, direction, and coordination given to deinstitutionalization by HEW and other Federal agencies, and (6) ascertain the adequacy of Federal efforts to monitor and evaluate deinstitutionalization efforts.

Our work was done principally at HEW, HUD, Department of Labor, Office of Management and Budget (OMB), and ACTION headquarters; HEW, HUD, and Department of Labor regional offices and Federal regional councils in Boston, Philadelphia, Chicago, Seattle, and Kansas City, Missouri; and at State and local agencies, selected public institutions, private agencies, and service providers in Massachusetts, Maryland, Michigan, Nebraska, and Oregon. Our review included agencies involved in public health, mental health and retardation, public welfare and social services, vocational rehabilitation, education, housing and community development, employment, and comprehensive health planning.

We reviewed pertinent Federal and State legislation, regulations, and administrative documents, relevant reports of various committees, task forces or other researchers, and court decisions relating to the rights of the mentally disabled. We also contacted representatives from various advocacy groups and performed a limited amount of work at St. Elizabeths Hospital in Washington, D.C.

We traced 266 mentally ill and 164 mentally retarded persons who had been released from institutions to community service providers. We did not assess the quality of care provided in the institutions or the community. Our fieldwork was done between January and August 1975.

We issued separate reports on our findings in each of the States reviewed. State and Federal regional agencies commented on these reports.

CHAPTER 2

WHAT HAS HAPPENED TO THE PEOPLE

Many mentally disabled persons have been released from institutions and placed into decent housing in clean, safe neighborhoods with such structured in-house activities and outside programs as work, education, day activity centers, and recreational programs. In this environment, many mentally disabled persons have become less dependent on either public support or other people for financial and daily living needs and have learned to live normal or nearly normal lives.

However, many other mentally disabled persons enter, reenter, or remain in public institutions when they could be treated in the community. Others have been placed into substandard and crowded facilities in unsafe neighborhoods, or facilities that could not or did not provide needed services or assurance that they would receive needed services.

Many mentally disabled persons who remain in public institutions or who have been placed into the community are recipients of or eligible for assistance under Federal or federally supported programs.

REDUCTION IN INSTITUTIONAL POPULATIONS

The resident population of public mental hospitals has steadily declined nationwide since reaching a peak of 559,000 in 1955. In 1963, when the President stated that it would be possible to reduce the population of public mental hospitals by 50 percent or more within a decade or two, about 504,600 were in such facilities. By June 30, 1974, the resident population of such facilities had been reduced to about 215,500, or by 57 percent.

Public mental hospitals in the five States included in our review also experienced substantial declines in their inpatient populations. As the table shows, the inpatient populations decreased by 34,600, or 65 percent, between 1963 and 1974.

The resident population of the Nation's public institutions for the mentally retarded has also declined, but at a slower rate than for the mentally ill. In 1963, there were about 176,500 persons in the Nation's public institutions for the retarded; the resident population increased to a peak of 193,200 in 1967. By 1971, when the President established the national goal to reduce this residential population by one-third, the resident population was about 181,000. 1/

State	Mentally ill inpatient population 1963	1974	Reduction	Percent
Maryland	8,100	5,000	3,100	38
Massachusetts	17,500	6,000	11,500	66
Michigan	20,100	6,000	14,100	70
Nebraska	3,700	600	3,100	84
Oregon	4,060	1,260	2,800	69
Total	53,460	18,860	34,600	65

A survey conducted by the National Association of Coordinators of State Programs for the Mentally Retarded showed that as of January 1975 there were an estimated 168,300 persons in public institutions for the retarded. Therefore, between 1971 and January 1975, the resident population in such facilities declined by an estimated 7.5 percent.

The resident populations of the public institutions for the retarded in the five States included in our review declined by 25 percent between 1971 and 1974 and by about 30 percent between 1963 and 1974. The table below shows the resident population for the 3 years.

Although there were more persons in public institutions in Maryland in 1974 than in 1963, the State has been reducing its institutional population in recent years. Maryland has also recently constructed smaller institutions and has shifted residents from its largest institution to the smaller ones.

1/These figures do not include the 30,600 mentally retarded persons in State mental hospitals.

	Resident population of public institutions for the mentally retarded		
State	1963	1971	1974
Maryland	2,690	3,260	2,800
Massachusetts	7,100	7,200	5,790
Michigan	12,740	10,970	7,340
Nebraska	2,220	1,480	[a]1,070
Oregon	2,870	2,845	2,220
	27,620	25,755	19,220

[a] As of January 1975.

EXTENSIVE USE OF NURSING HOMES

Many persons have been released from mental hospitals and institutions for the retarded and placed into nursing homes. [1] Many of these facilities were not staffed or prepared to handle the developmental or psychiatric needs of the mentally disabled. Some did not meet safety or patient care standards. These facilities were frequently the only alternative to continued inpatient or residential care in a public institution rather than the most appropriate setting. Some were so large that, in effect, persons were moved from one institutional setting to another.

Current information is not available on the number of mentally disabled persons now in nursing homes who were released from public institutions. Information that is available, estimates that have been made, and the results of our review show that substantial numbers of mentally disabled persons have been placed into such facilities. It appears that more mentally ill persons reside in nursing homes than in public mental hospitals.

During 1974, HEW surveyed 288 SNFs throughout the country. From the results of the study, it was estimated that about 62,890, or 22 percent, of the 283,900 patients in

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[1] Nursing homes generally refer to skilled nursing facilities (SNFs) or intermediate care facilities (ICFs), but also include rest homes and homes for the aged.

the SNFs were under 65 years of age. One of every three patients in the facilities who were 65 or older had chronic brain disease and about one in 10 had a neurosis or psychosis. Of those patients under 65, 27 percent were mentally retarded and 20 percent were mentally ill.

Data from a survey completed in April 1974 by the National Center for Health Statistics, HEW, showed a 48-percent increase in the number of nursing home residents with mental disabilities since 1969--from 607,400 to 899,500. Of these, 72,700 were retarded, 200,300 were mentally ill, excluding those who were senile, and 626,500 were senile. Of the 114,200 residents under 65, at least 79,300, or 69 percent, were mentally disabled. Of these, mental illness or retardation was the primary diagnosis for 42,700, or about 37 percent.

According to National Institute of Mental Health (NIMH) estimates, nursing homes are the largest single place of care for the mentally ill. They represent 29.3 percent, or $4.2 billion, of the estimated total direct care costs for the mentally ill of $14.5 billion in 1974. In contrast, State, county, and other public mental hospitals accounted for 22.8 percent of the total direct care costs.

In addition, nursing homes housed about 2,350, or 26 percent, of the more than 9,000 mentally retarded persons released from 115 public institutions in 1974, as reported by the institutions in response to a survey conducted by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded.

From institution to nursing home

In January 1975, the Nebraska Medicaid agency identified about 900 mentally retarded and about 1,700 mentally ill persons in SNFs and ICFs. Many of these facilities had a large number of mentally disabled persons in relation to their total population. For example, one facility with 45 beds had 37 mentally disabled persons--23 mentally retarded and 14 mentally ill. Another 98-bed facility had 78 mentally disabled persons--53 mentally ill and 25 mentally retarded. Information on the ages of all the mentally disabled persons in SNFs and ICFs in Nebraska was not readily available, but at least 462 mentally retarded persons in such facilities were under 65.

A recent study conducted by the Massachusetts Department of Public Health showed that one-fifth of the residents in ICFs in the State were mentally disabled. The study included over 90 percent, or about 38,000, of the total number of nursing home beds in Massachusetts.

A Michigan study showed that there were an estimated 4,100 formerly institutionalized mentally disabled persons in nursing homes in the Detroit area alone. Michigan has established a special category of SNFs solely for retarded persons. SNFs that desire to care only for retarded persons must obtain special certification and must meet special requirements. As of December 1974, Michigan had placed about 750 mentally retarded persons in such facilities.

A study made by Oregon's Mental Health Division showed that about 250 retarded persons from institutions had been placed into nursing homes during the period from July 1969 to July 1974.

Mentally disabled persons have been placed into nursing homes because, among other reasons, (1) mental health agencies do not have all of the necessary funds for community care and therefore rely on other agencies, such as welfare departments, to provide funds; (2) Medicaid funds were available for SNF and ICF placement, but not for other types of community placements; (3) the Federal Government, with certain restrictions, shares the costs of SNF and ICF placements under Medicaid; (4) SNF and ICF placements are convenient because SNFs and, ICFs assume responsibility for the care of the people and therefore, less coordination among agencies is needed; and (5) other alternatives were not available. In addition, restrictions in the Supplemental Security Income program, such as the one which prohibited SSI payments to persons in publicly owned or operated facilities and the one which reduced SSI payments in cases when support was provided by State agencies, may have influenced the placement of persons into SNFs and ICFs because financial incentives to the State are greater under Medicaid than SSI. (See p. 130.)

The availability of Medicaid funds for nursing homes has significantly influenced the placement of many mentally disabled persons in nursing homes in Michigan. For example, one Department of Mental Health official in Michigan stated that many of these facilities were not prepared to handle or care for the mentally disabled. He called the placement of many of these persons into such facilities "regrettable". A Massachusetts official cited the availability of Medicaid funding for SNFs and ICFs as the reason that so many mentally disabled persons had been placed in these facilities.

Services not provided

Many mentally disabled persons were released from institutions and placed in nursing homes, including SNFs and ICFs, without provision being made for needed services. We found evidence of this practice in each of the five States in our review as well as in other States as reported by outside sources. Many of these persons were receiving only custodial care. In some cases, however, we noted that special efforts were being made to meet the special needs of the mentally disabled, particularly the retarded, in such facilities. Some examples follow.

Massachusetts

In June 1975, Massachusetts removed Medicaid certification from or issued warnings to 60, or about 10 percent, of the State's ICFs. These were nursing homes that failed to comply with the Life Safety Code or with minimum standards of patient care.

On a questionnaire we sent to the 60 nursing homes, we asked them how many of their residents were formerly in State institutions. Of the 46 homes that responded, nine said they did not have any mentally disabled. Thirty-one responded that an average of 28 percent of their beds were occupied by mentally disabled persons who were formerly in State institutions. Six nursing homes responded that they were out of business. The responses showed that 76 mentally disabled persons had been placed into 13 of these facilities after actions against the facility had been initiated.

Homes	Total beds	Mentally disabled patients	Beds occupied by mentally disabled patients (percent)
1	24	24	100
4	121	96	79
3	128	70	55
7	299	106	35
8	229	41	18
8	464	13	3
31	1,265	350	28

A State official told us that there was a general tendency to place formerly institutionalized persons in those nursing homes where the quality of care was poorer and safety standards not complied with as rigidly as in other nursing homes. He said that, generally speaking, the more ex-mental patients there were in a facility, the worse the conditions.

Michigan

We visited several nursing homes in Michigan where many mentally disabled persons had been placed. In general, the homes offered very few services other than custodial care, and were not prepared to provide the special services needed by the mentally disabled residents. For the most part, the residents were just sitting, watching television, or lying on their beds. An official in Wayne County told us that in the past, nursing homes served as a "dumping ground" for State institutions. Department of Social Services officials further stated that nursing homes were not helping persons to become self-sufficient but were, in fact, mini-institutions. Therefore, they were trying to place fewer persons in such facilities.

We visited one of the special nursing homes for the retarded in Wayne County. The facility housed 149 mentally retarded persons who had been released from a State institution for the retarded. Most of the retarded patients were children; all were Medicaid recipients. The facility was new and nicely furnished.

Developmental programming for the facility's patients was limited. The State had placed six employees at the facility to provide such programming for the patients in accordance with its policy to place one State employee at each special nursing home for the retarded for each 25 patients. However, the State employees could only provide 45 minutes to 1 hour of training to about 130 of the patients each day. The remaining patients were not receiving habilitation or training services except for some recreational activities.

During our tour of the facility, we noted that several patients were receiving such services as toilet training, self-feeding, and learning how to walk, but others were just sitting, or lying in their beds or on mats doing nothing. The facility did not have sufficient staff to provide needed services to the patients. It had only one part-time physical therapist and one full-time occupational therapist, but more patients needed these services than could be provided by the available staff. Sufficient staff was not available to dress all of the patients so that they could always attend the training classes that were provided.

We noted a strong urine odor in several wings. We were informed that the facility was also experiencing housekeeping problems, which accounted for the neglect in cleaning; however, steps were being taken to resolve these problems. All patients under 26 years of age had been evaluated for their educational needs according to the State's mandatory education law. The school system was in the process of arranging for educational programs for all except for about 35 of the facility's patients.

Two nursing homes we visited that were housing retarded persons served by the Macomb-Oakland Regional Center 1/ presented a different picture. One home had 85 retarded patients and the other had about 70 retarded children. The center and the school system were providing a variety of services to the patients. Services included language training, motor skills development, self-feeding and dressing, and academic subjects. At one home, the school system had placed 15 staff members, and the Center had placed staff members to provide programming. In addition, 43 participants in the Foster Grandparent program were at the facility 20 hours each week to help with training and recreation for the children. (See p. 34.)

Nebraska

Two nursing homes we visited in Nebraska had no special or developmental programming or services for those mentally retarded persons that we traced from the institution. A 1975 State interagency committee study of 18 mentally retarded persons in four nursing homes showed that formal individualized programs for the retarded did not exist. The committee's reports indicated that this lack of programming was typical of most nursing homes. The interagency committee developed a number of procedures to help resolve this problem. State officials told us that although they recognized that many mentally ill persons had also been placed into nursing homes, they had not taken action to solve this problem, but that they planned to do so in the future.

Oregon

In 1975 an Oregon task force reported that a typical day for a mentally ill person in a nursing home was sleeping, eating, watching television, smoking cigarettes, sitting in

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1/ A State-operated center in Michigan serving the mentally retarded in Macomb and Oakland counties.

groups in the largest room, or looking out the window; there was no evidence of an organized plan to meet their needs. A county service coordinator found that about 25 mentally retarded persons were transferred from institutions to nursing homes where they were receiving only custodial care even though about one-third of them were capable of participating in some kind of developmental program.

Deinstitutionalization or reinstitutionalization

Several HEW officials, including those in the Office of Long Term Care (OLTC), and the Developmental Disabilities Office (DDO), have questioned whether the placement of the mentally disabled into nursing homes is really deinstitutionalization or simply movement to another setting which is just as institutional in its size, structured living environment, and lack of privacy. The 1974 data obtained by the National Center for Health Statistics indicated that more than 50 percent of nursing home residents were in facilities with 100 or more beds and about 15 percent were in facilities with 200 or more beds. In Michigan, for example, thousands of mentally disabled have been placed in nursing homes. Of the nursing homes we visited, one used by the State for the mentally disabled had 440 beds while another had 330.

This view of reinstitutionalization as seen by the HEW officials appears to be supported by constitutional standards imposed on the States by Federal courts which state that mentally disabled persons have a right to treatment in the least restrictive environment commensurate with their needs. For example, judicially imposed standards in New York and Alabama provide that those States shall make every attempt to move residents of the designated State mental institution from (1) more to less structured living, (2) larger to smaller facilities, (3) larger to smaller living units, (4) group to individual residences, (5) places segregated from the community to places integrated with community living and programming, and (6) dependent to independent living. The standards imposed in New York went further in requiring that, with certain exceptions, community placement be a noninstitutional residence in the community of 15 or fewer beds for mildly retarded adults and 10 or fewer beds for all others, coupled with a program adequate to meet the residents' individual needs.

PLACEMENT IN GROUP HOMES, FOSTER CARE HOMES, AND OTHER RESIDENTIAL FACILITIES

Many mentally disabled persons have been released from institutions and placed into group homes, foster care homes, half-way houses, room and board facilities, and "welfare" hotels. Many were placed into decent, comfortable settings and were provided with a range of services to meet their needs. Others, however, were placed into overcrowded, substandard, and dirty facilities without provision being made for needed services. The only service provided to many mentally ill persons released to the community was medication.

The quality of community settings and services varied considerably among and within States. In general, it appeared that mentally disabled persons for whom the mental health system retained and exercised at least case management responsibility were provided with more services than those persons who were referred to other agencies or systems such as the welfare system.

Instances in which persons were released from State mental hospitals or insitutions for the retarded without provision for appropriate services occurred in all of the States we reviewed. Studies done by others also identified this problem in other States. Of the five States included in our review, we found both some of the worst and the best conditions in Michigan.

Michigan

In Detroit we visited 13 community residences operated under the supervision of the State Department of Social Services, where many mentally disabled persons had been placed from State institutions. State officials informed us that most of the residents of these homes received SSI. Eight homes we visited were clean and appeared to have adequate living conditions. Residents in five of the homes did not appear to be receiving any services. In several instances programming was limited to activities such as sitting and doing nothing or watching television.

In four homes, the floors, walls, and ceilings were extremely dirty; the bed linens were not only ragged but very soiled; and shower and toilet facilities were dirty and in disrepair. Conditions in these homes were so rundown that one agency stopped placing persons there until conditions improved. In two homes beds were located in what would ordinarily have been considered the living and dining rooms of the homes, which left little living space. Apparently because of overcrowding, kitchen and dining areas in these two homes were in the basements. One home had only one bathroom for its 19 residents, contrary to department standards which require one bathroom for every eight residents.

Many of the foster care homes serving the mentally disabled were in inner city areas with high crime rates, abandoned buildings, substandard housing, poor economic conditions, and little or no recreational opportunities. Of a total of 378 community placement residences in Detroit serving the mentally disabled, 165 were located in the inner city with 101 on one street. State officials attributed this to the availability of large homes at relatively low prices in the inner city and to restrictive zoning which limits aftercare homes to the older, rundown sections of the city. Although the number of mentally disabled in these facilities was not known, it has been estimated to be several thousand.

The only service being provided to many released mentally ill persons was medication. Studies done by others have revealed similar conditions. For example, the community mental health board in Wayne County, Michigan, found that as of June 1975, about 9,500 mentally ill clients needing aftercare services were being served while about 22,000 clients were expected to need such services during fiscal year 1976. Also, as of May 1975, about 1,200 persons in Wayne County known to be mentally retarded were on waiting lists for various community services, such as activity centers or sheltered workshops.

We visited 10 community residences in Detroit operated under contract with the State Department of Mental Health. In general these homes were nicely decorated, clean, and well-maintained. The clients in these homes generally received in-house programming, participated in activities, and frequently used community services, such as attending schools.

We also visited a variety of community residences where 15 retarded persons released from State institutions had been placed by the Macomb-Oakland Regional Center. These included family care training homes, group homes, and an apartment. Each was well-maintained and had adequate living, recreational, and sleeping areas, as well as an in-house learning program. Thirteen of the persons in our sample were engaged in some form of outside day activity, such as attending a school or a sheltered workshop. Of the remaining two persons, one was too medically impaired to participate in outside programs and the other was only 3 years old.

Oregon

In the three community residences we visited in this State, no provision for services had been made for persons placed there from a State mental hospital. For example, the managers of these facilities told us that available activities included watching television, listening to the radio, playing bingo, and reading. Of 36 persons we traced who were still receiving services from a mental health clinic in Oregon, 25 were receiving only medication.

Of the 25 mentally retarded persons we traced in Oregon, 19 had been placed in group homes. Services provided to these persons included social adjustment training, vocational rehabilitation, or supervision.

Nebraska

In Nebraska an unknown number of mentally disabled persons had been placed in room and board homes that did not provide adequate care. These homes had been licensed by the State Department of Agriculture. Complaints by citizen groups concerning the poor conditions in these homes led to the withdrawal of licenses from an estimated 320 of these homes, leaving them without State supervision or regulation. The State Health Department became responsible for regulating these homes in 1974, and in May 1975 a State interagency committee reported that stringent regulation of these room-and-board homes should solve the previously identified problems.

USE OF PUBLIC INSTITUTIONS BY PERSONS WHO COULD BE TREATED IN COMMUNITIES

Despite decreased resident populations and admissions at public institutions, many persons who could be treated in the communities still enter or remain in these institutions. The primary reason for this appears to be the lack of community-based facilities and services or lack of access to the same.

Mentally retarded

In a 1974 survey conducted by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, the superintendents of 130 public institutions for the retarded estimated that more than 50 percent of their residents, ranging from profound to borderline retarded, could be placed in the community if facilities and services appropriate to individual needs were available. By applying the estimate made by the 130 superintendents to the figure of 131,300 residents reported by the superintendents of 177 facilities, we estimated that about 71,600, or 54.5 percent, could be placed into the community. However, superintendents of 149 facilities reported that they planned to release only about 9,900, or about 10 percent, of their residents because of the lack of appropriate facilities and services in communities.

In all of the five States we visited there were many mentally retarded persons in institutions who could live in the community if they had access to appropriate community alternatives. For example:

--In Maryland a 1974 Mental Retardation Administration survey indicated that 2,240, or 80 percent of the aggregate population in five institutions, could be moved to the community by fiscal year 1980. Of those, 316 persons were ready for immediate placement and 797 could be placed if specialized services were provided. The remaining 1,127 persons required 2 to 5 years of training prior to release. Apartments, group homes, family or foster care, and a variety of services were needed to prepare these people for release. At one institution an estimated one-third to one-half (170 to 250) of the retarded children could function in the community if school or residential placements were available.

--A study completed in 1974 showed that nearly 1,200 mentally retarded persons in 2 of Oregon's 3 institutions could be placed in the community if adequate community facilities and services were available. For example, the study showed that at one institution, 223 persons could be placed within 1 year and 714 placed after 1 year. Group homes and nursing homes with ties to activity centers, sheltered workshops, and competitive employment were said to be needed. The superintendent of one institution told us that many persons were in a "holding pattern" waiting for living facilities, activity centers, workshops, and employment opportunities to be developed.

--Nearly 600 retarded persons in Michigan were ready to be placed in communities in Wayne County, but had to remain institutionalized because of the lack of group homes, foster homes, or semi-independent living arrangements. Waiting lists also existed for community services, such as vocational training, sheltered workshops, and activity centers.

During 1971 about 15,370 persons entered the Nation's public institutions for the retarded as compared to 15,150 in 1963. Data on total admissions to public institutions for the retarded after 1971 was not available at HEW. However, about 140, or 60 percent, of the 235 facilities operating during fiscal year 1974 reported about 10,800 total admissions during the year, of which about 7,800 were new admissions and 3,000 were readmissions. Approximately 2,880 of the new admissions were moderately, mildly, or borderline retarded while

4,920 were severely or profoundly retarded. About 67 percent of the new admissions were between the ages of 3 and 21. It would appear that many admissions could have been avoided if access to community alternatives had been available. In addition to those admitted to public institutions, 55 superintendents estimated that at least 50 percent of the 5,000 persons on their admission waiting lists could be treated in the community.

Readmissions

In 1963, 12 percent of the admissions to public institutions for the retarded were readmissions. By 1971, readmissions accounted for 27 percent. HEW discontinued collecting admission data from all of the States in 1972. The results of the 1974 survey conducted by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded indicated that 28 percent of the admissions in fiscal year 1974 were readmissions. In Massachusetts, readmissions consituted 3 percent of total admissions to State institutions for the retarded in fiscal year 1963 and 38 percent in fiscal year 1974.

In the 1974 survey, 135 facilities reported that the primary reason for readmissions was lack of community services such as living accomodations, comprehensive services, and followup. The failure to adjust to community living and community rejection were also cited as factors.

Mentally ill

Admissions to public mental hospitals continued to increase from 1950 to 1972. For example, admissions to such facilities increased form 178,000 in 1955 to a peak of 414,925 in 1971. Beginning in 1972, however, total admissions declined annually to 374,550 in 1974, the latest year for which national data was tabulated.

Although total admissions to public mental hospitals have been declining nationally since 1971, many persons continue to be placed in these facilities who could be treated in communities, as illustrated below.

--There were about 10,785 admissions to Massachusetts mental hospitals in 1974, compared to 12,306 in 1963. A 1973 study sponsored by the State Department of Mental Health showed that between 50 and 75 percent of the admissions to the State's mental hospitals could be avoided if adequate community services were available. The department's commissioner concurred by saying that about two-thirds of State mental hospital admissions could be eliminated if comprehensive services, such as 24-hour crisis intervention, were available. Patients had also been unable to leave the mental hospital we visited because of the lack of suitable housing. One patient, for instance, was ready to leave the hospital in July 1974, but had to remain there 8 months longer because there was no available space in a half-way house.

--There were about 12,500 admissions to Maryland mental hospitals in fiscal year 1974, compared to 7,300 in fiscal year 1963. The Commissioner of Maryland's Mental Hygiene Administration made a conservative estimate that 25 to 50 percent of the persons currently institutionalized could be treated in the community if funds specifically designated for mental health programs were available. Data provided by one mental hospital we visited indicated that about 70 percent of 800 persons admitted to one unit from January 1973 to December 1974 entered because community alternatives were unavailable. As of January 1975, 85 of 114 patients in this unit could have been released if services, such as day care, vocational training, transportation, employment, income assistance, and housing, were available.

--In Oregon, the officials at the State mental hospital we visited told us that about 25 percent of the persons admitted could have been treated in the community and that many of the patients who had been in the hospital for a long time could be placed in the community if appropriate facilities and services were available. The hospital had about 3,000 admissions in 1974.

Various other studies have also concluded that many persons who could be treated on the community level are instead served in State institutions. For example, a 1974 study sponsored by HEW of 1,800 patients in Texas mental institutions concluded that only 35.5 percent required continued psychiatric hospital care; and of the remaining 64.5 percent that could have been placed in the community, about 10 percent could live on the outside on their own.

Readmissions

Readmissions account for an increasingly large proportion of admissions to public mental hospitals. In 1969, 47 percent of those entering public mental hospitals had been in such facilities before, but by 1972, the percentage had increased to about 54 percent.

In Oregon, for example, about one-half of the more than 3,000 admissions to one mental hospital during 1974 were readmissions. The clinical director at the facility told us that the average patient there had been admitted to an institution two or three times. Of the 64 patients we traced from that facility to the community, 45 (70 percent) had been admitted to the hospital an average of four times.

In fiscal year 1963, about 43 percent of the 7,300 admissions to Maryland's mental hospitals were readmissions. By fiscal year 1974 about 70 percent of the 12,500 admissions were readmissions. In Massachusetts, readmissions to State mental hospitals increased from 35 percent of fiscal year 1963 admissions to 49 percent in fiscal year 1975.

Institution officials in Nebraska attributed frequent readmissions of the mentally ill to the inability of community mental health facilities to provide needed followup and aftercare services to persons released from the institutions.

On May 16, 1975, one community mental health clinic in Michigan reported:

> "In May 1975, thus far, there have been several readmissions and one suicide attempt of after care referrals due to their intake here not being soon enough (and information from referral agencies did not indicate such risks)."

FACTORS CONTRIBUTING TO PROBLEMS IN STATES

Many factors contributed to the problems the States have faced with deinstitutionalization. We issued reports to HEW on each of the States we reviewed, detailing the problems those States had. Those problems are described, in brief, below.

Responsibility for the mentally disabled in communities was generally fragmented and unclear. Mentally disabled persons, particularly those who are more severely disabled, often have a variety of needs--education, mental health services, habilitation, social services, medical and dental services, vocational rehabilitation and training, income support, housing, transportation, and employment.

When persons are patients or residents in public institutions, responsibility for their care is usually evident. Although several different agencies may provide funds or services to persons in public mental institutions, departments of mental health and retardation are responsible for overall case management, identification of needs, and arrangement for or provision of services.

When mentally disabled persons are released from institutions, however, responsibility for their care and support frequently becomes diffused among several agencies and levels of government, depending upon such factors as age, income, or disability. State and local governments have generally established separate agencies to develop and provide most of the resources to fill the aforementioned needs for general population groups, including the mentally disabled. The roles and responsibilities of these agencies and specific actions to be taken by them for deinstitutionalization, however, have frequently not been clearly defined, understood, or accepted.

Deinstitutionalization has not received the full and well-coordinated support of many State and local agencies administering programs that serve or can serve the mentally disabled. Moreover, agencies serving population groups that do or could include the mentally disabled have not included deinstitutionalization of the mentally disabled in their program plans nor have they made it a specific operating objective or priority. Furthermore, they have not provided financial or other support needed to help mentally disabled persons (1) avoid unnecessary admission or readmission to public institutions, (2) leave such facilities, or (3) receive appropriate help in communities.

This lack of support has led to further (1) difficulties in financing deinstitutionalization and (2) the lack of, or lack or access to, appropriate community facilities and services for the mentally disabled. Although the number of community services and facilities has increased, substantial shortages remain. Housing, mental health and developmental services, education, work training, activity programs, transportation, employment, and other services are needed.

Despite reductions in their institutional populations, State mental health and retardation agencies have had to devote the bulk of their resources to institutional care and therefore rely on other agencies for community placement efforts. These agencies have not, however, provided sufficient support. In some cases, these agencies have been reluctant to serve the mentally disabled or those who are more severely disabled at all. Other factors which have hindered the development and use of community resources are program eligibility requirements, controversy and confusion over program entitlements, the categorical nature of funding which sometimes impeded the ability to link services, incentives in certain programs which encourage institutional or nursing home placements, and the lack of funds for the large initial capital costs of community residences and funds for their continued operation.

Individual transitions to community living were not handled well in many instances. Planning for individual transitions was often fragmented and uncoordinated; specific and comprehensive needs were frequently not identified at the time of release; inappropriate community settings were being used; formal referrals were not always made; and followup was inadequate in the community.

The lack of a planned, well-managed, coordinated, and systematic approach to deinstitutionalization at the Federal level has caused or contributed to the aforementioned problems. A better planned, more coordinated, and more aggressive effort by the Federal Government could help facilitate deinstitutionalization and make sure that mentally disabled persons eligible for or receiving federally supported benefits receive appropriate services in the appropriate setting. The remainder of this report, therefore, deals with the actions that Federal agencies and the Congress can take to improve implementation of the deinstitutionalization objective.

CHAPTER 3

NEED FOR A FEDERAL STRATEGY AND MORE CONCERTED AND COORDINATED EFFORTS

Although deinstitutionalization of the mentally disabled has been a national goal since 1963, Federal agencies that do, should, or could have an impact on this goal had not yet developed a comprehensive, systematic, and clearly defined national strategy or plan to achieve the goal. They had not developed a management system to make sure that the goal was properly implemented and, for the most part, had not made a concerted effort to accomplish the deinstitutionalization goal.

HEW is the principal Federal agency concerned with the mentally disabled. Two HEW programs directly address deinstitutionalization -- the community mental health centers (CMHC) and developmental disabilities programs. These programs have had a positive impact but they (1) could have done more to help meet the goal, (2) have not yet had the impact they were expected to have, and (3) have not been able alone to provide all of the resources or coverage needed to achieve the deinstitutionalization goal.

Other potentially useful Federal programs have been identified but an overall implementation plan and management system have not been developed which (1) defines specific objectives and timeframes, (2) defines what constitutes acceptable community-based care, (3) sets forth specific steps needed to accomplish the goal, (4) defines roles and responsibilities of various agencies, (5) establishes accountability, and (6) provides central direction, guidance, coordination, and evaluation.

One of the basic problems at the Federal, State, and local levels is that those agencies having primary responsibility for the mentally disabled do not have all of the funds needed to develop adequate, comprehensive community-based care systems for the mentally disabled. In addition, they do not have all of the responsibility for regulating or monitoring the standards of care in communities. Therefore, they have approached deinstitutionalization by relying on the many social, welfare, and other programs that affect general population target groups, such as the poor, the aged, children, or the disabled, to accomplish deinstitutionalization without any central guidance, management, or focus.

In the absence of any national strategy or management system to implement deinstitutionalization, Federal officials responsible for these other programs that do or could have an impact on deinstitutionalization generally (1) were not aware of the national goal or had not received instructions on implementation, (2) had not implemented their programs to help achieve the goal, (3) had not undertaken substantive, sustained, joint efforts directed at deinstitutionalization, or (4) had not monitored or evaluated their programs' impact on deinstitutionalization of the mentally disabled.

With a few exceptions, the Federal agencies we contacted had not taken substantive action to assist in the deinstitutionalization effort. Officials administering programs in HUD, Labor, ACTION, and HEW that impact on deinstitutionalization generally were not aware of the national goal, did not view themselves as having responsibilities relating to deinstitutionalization, or had devoted little or no effort to assist in carrying out the goal. The Department of Justice, however, was taking substantive action in implementing the deinstitutionalization goal and in carrying out the 1971 Presidential mandate to help secure full legal rights for the retarded.

Even within HEW, deinstitutionalization of the mentally disabled was not a Secretarial or Department-wide objective in HEW's operational planning system until fiscal year 1976 when the development of a deinstitutionalization strategy for the mentally retarded became a formal operational objective to be monitored by the Secretary. Deinstitutionalization of the retarded was an operational objective in the Social and Rehabilitation Service (SRS) for fiscal year 1972, but it was not carried out then and has not been an SRS operational objective since then. The Developmental Disabilities Office has had deinstitutionalization as an operational objective since fiscal year 1972, but despite repeated attempts, has not been able to get other agencies, including its former parent organization, the Rehabilitation Services Administration (RSA), to establish or implement joint objectives or efforts. Although a number of attempts have been made by various agencies to develop joint operational objectives relating to deinstitutionalization, they were not implemented, primarily because problems arose both in getting agencies to cooperate and in obtaining support from SRS.

The need for a more concerted effort in the implementation of deinstitutionalization is illustrated by the fact that 11 major Federal departments and agencies administer at least 135 programs impacting on the mentally disabled. These programs provide funds for such activities as direct clinical care, education, rehabilitation, employment, housing, planning, and income support, or about all of the needs mentally disabled persons would have. For example, at least 11 different agencies administer 31 programs which provide direct clinical services for the mentally disabled, and at least five agencies administer rehabilitation programs affecting the mentally disabled.

The need for interagency coordination among Federal agencies has been expressed repeatedly over the last several years. In December 1971, the Director of DDO stated:

> "It would be helpful if the individual efforts of the several Federal agencies could be coordinated into one strategy which would support one another."

In commenting on the discharge planning and followup requirements in the then-proposed ICF requirements, the SRS Acting Administrator stated, in 1973, that the effective integration of services of various programs was critical to deinstitutionalization. In addition, the SRS long-range plan for fiscal years 1974-1978 contained the following comment:

> "There has been little experience within the Medicaid program with attempts to improve the conditions of care of the mentally retarded and to maintain or restore these individuals to states of independence or self-care. Activities in this area, more than in almost any other Medicaid program, will have to be conducted in close coordination with RSA, CSA [now PSA], and other organizational units with similar objectives concerning the mentally retarded."

In some instances, no mechanism existed to coordinate the efforts of various agencies in accomplishing the goal of deinstitutionalization. In other cases, such mechanisms did exist, but little effort was made to effectively use the mechanisms to coordinate a national effort. Three organizations have responsibilities relating to directing and coordinating Federal interagency efforts -- OMB, Federal regional councils, and the President's Committee on Mental Retardation (PCMR). OMB and Federal regional councils have not addressed or taken action on deinstitutionalization, while PCMR has only limited effectiveness in coordinating efforts of Federal agencies.

OFFICE OF MANAGEMENT AND BUDGET

OMB is responsible for insuring that Federal programs are properly coordinated. OMB is also responsible for overseeing the activities of Federal regional councils and for operating the Federal Management by Objectives (MBO) system. OMB, however, has not addressed deinstitutionalization, nor has it taken action to implement the President's 1971 directives to launch a national, coordinated effort to deinstitutionalize the mentally disabled.

Officials in OMB's management division told us that OMB has not addressed deinstitutionalization of the mentally disabled because it has not been raised as an issue requiring OMB's involvement. Furthermore, OMB informed us that since HEW was the principal agency concerned with the mentally disabled, it was up to HEW to take the lead role, develop a plan, identify the problems and the opportunities for other agency involvement, and come to OMB for support through the Federal regional council system, the MBO system, or other systems.

Management by Objectives system

MBO is a managerial approach for getting things done. It is a systematic method for controlling the implementation of policy, program, and budget decisions. MBO entails

--setting clear and precise objectives;

--defining specific steps, or actions, to accomplish the objectives;

--establishing roles, responsibilities, and accountability;

--setting time frames and budgets; and

--evaluating and controlling progress.

MBO was formally initiated on an interdepartmental basis within the Federal Government in April 1973, when the President directed 21 agencies to adopt this management approach. MBO provides a vehicle for (1) focusing attention on the administration's primary objectives, (2) measuring agency progress toward meeting those objectives, and (3) coordinating efforts. The Presidential MBO system is administered by OMB.

There were 144 presidential objectives as proposed by various agencies in fiscal year 1974 and 172 in fiscal year 1975. The objectives selected by the President were drawn by the agencies from such sources as Presidential statements, legislation, and longstanding agency policies. Deinstitutionalization of the mentally disabled was not a Presidential objective in the MBO system during fiscal years 1974 and 1975. HEW did not propose deinstitutionalization as an objective.

OMB officials told us that deinstitutionalization has not been a Presidential objective in the MBO system. These officials also said that OMB has not issued instructions or guidance to the agencies on deinstitutionalization, has not developed a plan to implement the deinstitutionalization objective, has not assigned agency roles and responsibilities, and has not monitored progress toward achieving the deinstitutionalization goals. OMB officials acknowledged that deinstitutionalization is a complex problem and that some central leadership is needed at the Federal level because there are so many Federal agencies involved.

FEDERAL REGIONAL COUNCILS

The Federal regional councils were established in 1972 in the 10 standard Federal regions to develop closer working relationships between Federal grantmaking agencies and State and local governments and to improve coordination of the Federal grant system. Regional councils were to

- --explain and facilitate the implementation of national policies,
- --coordinate Federal efforts at the regional level,
- --develop short- and long-term interagency and intergovernmental strategies to better respond to the needs of States and local communities, and
- --evaluate programs in which two or more member agencies participate.

The Under Secretaries Group for Regional Operations, under the direction of the Deputy Director, OMB, is responsible for the Federal regional council system, which includes establishing policy on council matters and providing guidance to councils. The Group includes the Under Secretaries of the Departments of Labor, HEW, HUD, Transportation, and Agriculture.

None of the Federal regional councils in the five regions included in our review had addressed deinstitutionalization of the mentally disabled. In general, council representatives told us that they had not addressed it because (1) they had not received headquarters instructions or guidance to do so from HEW, OMB, or the Under Secretaries Group, (2) deinstitutionalization has not been raised as an issue in need of council attention, or (3) deinstitutionalization was believed to be predominately an HEW concern.

Subsequent to our contacts, however, council representatives acknowledged that deinstitutionalization was an issue in need of interagency attention. The Director of HEW region V--a member of the Chicago regional council--stated that deinstitutionalization activities were so disorganized and scattered throughout HEW that it was difficult enough to deal with the problem in his own agency, without trying to organize and coordinate other Federal agencies activities in this area. In recognizing the importance of getting other Federal agencies to address deinstitutionalization, however, he stated:

> "The Housing and Community Development Act of 1974 is possibly one place to focus on the needs of the handicapped, especially the mentally handicapped, and their inclusion in state and local housing plans."

A HUD official in Region III suggested that to increase the responsiveness of HUD programs to the handicapped, HUD should enlist the aid of other Federal agencies through Federal regional council activities.

An official in OMB's management division told us that deinstitutionalization had not been considered as an issue to be addressed by Federal regional councils because none of the Under Secretaries had raised it as a matter for council consideration.

PRESIDENT's COMMITTEE ON MENTAL RETARDATION

PCMR was established by Executive Order 11280 in 1966 to (1) advise and assist the President in evaluating the national effort to combat mental retardation, coordinate Federal activities in the field, provide liaison between Federal activities and those of other public and private agencies, develop public information to reduce the incidence of mental retardation and ameliorate its effects, and (2) stimulate professional retardation activities. PCMR has 27 members, including the Secretary of HEW as Chairman, the Secretaries of HUD and Labor, the Attorney General, the

Directors of ACTION and the Office of Economic Opportunity (now Community Services Administration), and 21 other members appointed by the President. PCMR was preceded by the President's Panel on Mental Retardation and by the Office of the Special Assistant to the President for Mental Retardation.

Much of the work of PCMR is carried out by a full-time staff, which as of October 1975 consisted of eight support staff, nine professionals, and an executive director, who reports to the Assistant Secretary for Human Development, HEW.

In 1971, the President directed all executive departments and agencies, as the first step in the launching of a coordinated national effort, to put their full support behind PCMR efforts to help the mentally retarded return from institutions to the community and to evaluate their programs toward that end.

PCMR's responsibilities were increased by Executive Order 11776 in March 1974 to include identification of the potential of various Federal programs to achieve the Presidential goals in mental retardation, including deinstitutionalization. This Executive order also required each Federal agency to designate a mental retardation liaison with PCMR.

PCMR accomplishments

PCMR has done a great deal since it was established to promote public awareness of the needs of the mentally retarded, to identify problems in need of attention to help combat retardation, and to identify actions which could be taken to help solve or alleviate many of the problems confronting the retarded. PCMR's accomplishments include

--the issuance of several publications relating to community placement, legal rights, and employment of the retarded;

--the sponsorship of several symposiums, workshops, and meetings on the problems of mental retardation;

--the identification of 91 programs in 22 Federal departments and agencies that impact on the mentally retarded.

--the identification of actions that could be taken by various Federal agencies to help accomplish the deinstitutionalization goal; and

--the initiation of action to prevent two HEW agencies from taking a proposed action that would have had a substantial adverse impact on deinstitutionalization.

The PCMR staff was also instrumental in getting the Secretary to adopt deinstitutionalization of the retarded as a Secretarial objective in HEW's MBO system for fiscal year 1976. It was directing efforts within HEW to develop a deinstitutionalization strategy for the retarded by the end of fiscal year 1976 to achieve the November 1971 goal established by President Nixon.

Inability to mobilize and coordinate agencies' efforts

Despite PCMR's accomplishments, it has not been able to get Federal agencies outside of HEW to take any concerted action to assist in deinstitutionalization and was not even able to get HEW to take any coordinated and substantive action until 1975. This situation existed even though the Secretary of HEW is the Chairman of PCMR and the Secretaries of Labor and HUD and the Director of ACTION are members.

PCMR's effectiveness in mobilizing and directing a coordinated national effort among Federal agencies to accomplish the deinstitutionalization goal stems from a number of factors. These include:

--The lack of leadership from the Secretary of HEW, as Chairman of PCMR.

--The lack of involvement by OMB.

--The failure of other agencies to take an active role.

--The lack of clearly defined mandate by the heads of other Federal agencies to their program administrators to provide full support to PCMR.

--The lack of an unequivocal congressional mandate and a national strategy for deinstitutionalization setting forth specific steps that Federal agencies are to take, and a management system for implementing a deinstitutionalization strategy.

PCMR's inability to mobilize and coordinate other agencies' efforts was exemplified by the lack of results from a number of meetings sponsored by PCMR staff to bring Federal agencies together. Present at these meetings were representatives from constitutent HEW agencies and other Federal agencies. The PCMR staff also met with representatives of various agencies to discuss specific matters relating to their programs, such as Labor's effort to update a U.S. Employment Service handbook on employing the mentally retarded. These meetings served as means for exchanging information and frequently resulted in the issuance of publications. However, they did not generally result in specific, substantive efforts by the agencies. Agency personnel who did not attend were apparently not made aware of the meetings. Several HEW personnel who attended meetings sponsored by PCMR staff told us that they did not formally communicate the results of the meetings within their agencies and did not take any action as a result of the meetings. They said that they did not know what was expected of them.

ACTION

Some ACTION programs serve the mentally retarded. In fact, 63 percent of the Foster Grandparent program projects serve mentally retarded children. However, most of these are in institutional settings. ACTION's PCMR representative told us that he understood PCMR's policy concerning deinstitutionalization, but had not taken action to implement the objective because there was no mandate officially directing that steps be taken. The Director of Program Policy and Analysis for the Older Americans Volunteer Programs at ACTION told us that no one had contacted him concerning an emphasis on deinstitutionalization in ACTION programs. He said that with a mandate ACTION programs could provide greater assistance in the deinstitutionalization effort by providing more help to the mentally disabled in communities after they left the institutions. He later informed us that ACTION revised its program instructions for its Senior Companion Program to emphasize deinstitutionalization of adults.

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

With the exception of one of its area offices, HUD offices we contacted had taken no substantive, sustained action to assist in the deinstitutionalization effort. Almost all of the HUD regional and area office officials or specialists for the elderly and handicapped we contacted were not aware of the Presidential statements on mental retardation or the directives to HUD to assist in developing community-based housing for the retarded. HUD headquarters officials stated that HUD had the capability to effectively respond to deinstitutionalization and could do so if HUD had what it considered to be a valid mandate. (See p. 154.)

DEPARTMENT OF LABOR

Most of the labor officials we contacted had not taken any action directed at deinstitutionalization. Most stated that they had not been contacted concerning deinstitutionalization. Several told us that they believed their programs could be used to help implement deinstitutionalization if they had a specific mandate to do so. One Labor representative, for example, told us that he had attended one of the interagency meetings sponsored by the PCMR staff, but took no action as a result of the meeting because he did know what he was supposed to do. He stated that Labor's programs could be used more effectively to assist in the deinstitutionalization effort, but that a mandate from the Secretary of Labor or OMB would be needed before Labor could mobilize and direct its resources toward this goal. (See p. 165.)

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

HEW had not developed a comprehensive, consistent, or systematic approach to deinstitutionalization and with a few exceptions had not made a concerted effort to implement the national goal. Department-wide plans, goals, or objectives to accomplish deinstitutionalization had not been formulated or established. Guidance or instructions to HEW constituent agencies identifying specific steps to be taken had not been issued and no one organization in HEW had been given overall responsibility and authority for overseeing the implementation of the deinstitutionalization goal.

DDO and NIMH have undertaken the most substantive activities directed at deinstitutionalization. For the most part, other HEW agencies have not directed efforts toward deinstitutionalization of the mentally disabled, and those efforts that were made consisted of sponsoring research or demonstration projects. Officials in the five HEW regional offices included in our review had not taken concerted action to implement deinstitutionalization. Headquarters and regional officials attributed their lack of effort to (1) the absence of a specific mandate; (2) the lack of guidance, instruction, or support from top management or HEW headquarters for the regional offices, (3) a lack of staff, and (4) other priorities.

Other factors contributed to the lack of a systematic, concerted effort. One was the fragmented and piecemeal establishment of programs impacting on deinstitutionalization. Also, the two agencies primarily concerned with the mentally disabled, NIMH and DDO, (1) provided only a small portion of the funds needed and used for deinstitutionalization, (2) exerted only limited influence and no authority over other agencies, and (3) did not have the authority or responsibility for monitoring, evaluating, and enforcing standards and requirements under other programs which serve the mentally disabled.

Many attempts have been made by the staffs in several HEW constituent agencies and HEW regional offices to get top management to devote attention and effort to deinstitutionalization. These attempts were made both through the operational planning system and by other means, such as the establishment of task forces or committees. Although the Secretary recognized the importance of the issue, this recognition was not accompanied by sustained interest or followup. Although interagency attempts to help the retarded have been made, activities relating to deinstitutionalization of the mentally ill were, for the most part, limited to NIMH.

Intradepartmental coordination efforts

Since 1955 HEW has established offices, task forces, and committees to coordinate its programs which impact on the mentally disabled. Most of these efforts have related to the mentally retarded. The efforts have included:

- --The establishment of the Departmental Committee on Mental Retardation in HEW in 1955. It was renamed the Secretary's Committee on Mental Retardation in 1963 and replaced by a steering committee and the Mental Retardation Interagency Committee in 1972.

--The establishment of the Office of Mental Retardation Coordination in 1972. The name was changed to Office for the Handicapped in February 1974 and is currently called the Office for Handicapped Individuals.

--The establishment of the Task Force on Mental Retardation Institutions in 1973. The Task Force was combined with the Mental Retardation Interagency Committee in August 1974 to form the Interagency Committee on Mental Retardation.

--The establishment of the Disability Task Force in October 1973. In October 1975 we were informed that the Task Force had "faded away."

Although the responsibilities of these groups varied, they all appear to have had the common objectives of improving the coordination of existing programs and recommending actions HEW should take to improve the welfare of the mentally disabled. They served as a means for exchanging information but none appeared to have been effective in stimulating action specifically related to deinstitutionalization.

For example, the Task Force on Mental Retardation Institutions consisted of representatives from each HEW agency that administered a program related to mental retardation. The Director, DDO, was designated as the chairman. Its functions were to provide information, consultation, and technical assistance in deinstitutionalization efforts, and to recommend ways that departmental programs might be most effectively used to reduce the institutionalized mentally retarded population.

In October 1973, the findings of the task force were submitted to the Assistant Secretary for Human Development. The task force identified HEW programs which have actual or potential impact on deinstitutionalization and identified legislative changes that would remove some obstacles.

The task force did not identify specific improvements that could have been made in existing programs, such as more monitoring and evaluation of existing requirements, to help implement deinstitutionalization. The task force did not engage in any substantive activities after it completed its report, and according to the Deputy Assistant Secretary for Human Development, none of the task force recommendations but one were acted upon because they were not believed to be specific enough.

HEW planning process

In 1969 HEW implemented MBO through its operational planning system, which is part of the Department's overall planning system. HEW's planning system includes the following components:

--Issue analysis and policy development.

--Forward plans, which set the direction in which the Department is headed over the long-term (2 to 6 years).

--Operational objectives, which are immediate steps that the Department must take to accomplish long-range goals. According to HEW, operational objectives are statements of the most important results that the Secretary, agency heads, and regional officials intend to accomplish over a single year.

All HEW constituent agencies and regional offices participate in the planning system, which each year is initiated by the Secretary with the issuance of a planning guidance memorandum. This memorandum describes the initiatives the Secretary sees as important in upcoming years and instructs agencies on what they are to consider in their planning efforts. In developing this guidance, the Secretary draws on an analysis of issues confronting the regional offices, as described in papers submitted by them.

Each year the Secretary selects those agency objectives which he believes are most important and monitors progress through periodic reports and meetings with agency heads. In addition, agency heads and regional directors select objectives which they believe should be monitored.

The Secretary's planning guidance memorandums issued from 1971 through 1973 did not identify deinstitutionalization of the mentally disabled as an issue to be addressed. In March 1974, the Secretary's planning guidance memorandum called for an issue analysis of deinstitutionalization and asked the questions: (1) How can the Department best carry out a deinstitutionalization strategy? (2) What are the constraints and how can these be overcome? and (3) How can institutionalization be avoided?

A deinstitutionalization strategy was not developed, according to an HEW official in the office of the Assistant Secretary for Planning and Evaluation, because (1) no one had been assigned overall responsibility for developing the strategy, (2) the issue was so complex, (3) other work had priority, and (4) no one had followed up on the development of the strategy. He stated that both HEW and the States pushed for deinstitutionalization before fully considering (1) where the people would be released to, (2) who would provide services, and (3) who would pay for the services. To answer these questions, HEW developed research and demonstration projects to analyze the implications of deinstitutionalization and develop a strategy.

The Secretary's March 1975 planning guidance memorandum directed that an assessment be made of current deinstitutionalization efforts and that a strategy be developed to (1) prevent inappropriate institutionalization, (2) get people out of institutions when appropriate, and keep them out, (3) increase "normalization" for those remaining in institutions, and (4) increase community alternatives to institutionalization. During our review, a deinstitutionalization strategy objective was developed for fiscal year 1976 and is being monitored by the Secretary through PCMR.

Deinstitutionalization of the mentally disabled has generally not been an operational priority among HEW agencies. During fiscal year 1972, the Social and Rehabilitation Service had an operational objective directed at the mentally retarded which included reducing admissions to institutions by serving persons on waiting lists, and reducing institutional populations by providing a variety of community residential and supportive services. The objective called for the then Division of Developmental Disabilities to act as the lead agency and for such other agencies as the Rehabilitation Services Administration, the Community Services Administration 1/ and the Medical Services Administration (MSA) to provide support. The objective was not carried out, however, because the other agencies did not participate.

Deinstitutionalization had not been an operational objective at SRS since fiscal year 1972, but according to SRS officials, it was a research priority. The officials stated that SRS wanted to get more information on the implications of deinstitutionalization, such as cost-effective treatment modes, before becoming more involved in implementing it.

1/ HEW's Community Services Administration was renamed Public Services Administration (PSA) in February 1976.

Efforts of HEW constituent agencies and regional offices

Many HEW agencies and offices have responsibility for programs which have an impact on deinstitutionalization. The following sections explain the efforts, or lack of efforts, they have made to develop a deinstitutionalization strategy, coordinate their efforts, provide guidance to the regional offices, and otherwise assist in accomplishing the deinstitutionalization goal.

We contacted headquarters and regional officials of the following HEW agencies and offices concerning their role in deinstitutionalization, emphasis they had given to it, or assistance they had given to the States.

- Office of the Secretary
  - Special Assistant for Long Term Care
  - Assistant Secretary for Planning and Evaluation
  - Assistant Secretary for Administration and Management

- Office of Assistant Secretary for Health
  - Office of Long Term Care
  - National Institute of Mental Health
  - Health Resources Administration
  - Health Services Administration

- Office of Assistant Secretary for Human Development
  - Office for Handicapped Individuals
  - Administration on Aging
  - Office of Child Development
  - Office of Manpower
  - Rehabilitation Services Administration
  - Developmental Disabilities Office

- Social and Rehabilitation Service
  - Public Services Administration
  - Medical Services Administration

- Social Security Administration
  - Bureau of Health Insurance
  - Bureau of Supplemental Security Income

- Office of Education
  - Bureau of Education for the Handicapped

With some exceptions, these agencies had not taken concerted action to achieve deinstitutionalization of the mentally disabled. Regional offices cited the lack of a mandate from HEW headquarters, other priorities, and a lack of staff, as reasons for their inaction. For example, in January 1975 the Director of HEW Region VII told us:

> "I know of no formal written DI plan which is being executed in Region VII with States by HEW agencies, principally because Regional Agencies see a need to be responsive to their headquarters' programmatic guidance, which to date has not included DI as a top priority for planning and implementation. Agency headquarters agencies tend to require all or almost all regional manpower commitment and accountability tied to written MBO-type plans e.g., PHS aims at 100% accountability, which permits little flexibility for regional managers to respond to unique regional needs."

The efforts of HEW headquarters and regional agencies and offices discussed in the following sections were typical of the conditions throughout HEW. NIMH and DDO are included because of their primary responsibility.

Office of Assistant Secretary for Health

The Assistant Secretary for Health is responsible for several agencies with programs that could or did impact on deinstitutionalization, including NIMH, the Office of Long Term Care, and the Health Resources and Health Services Administrations. Except for NIMH, the officials we contacted in these agencies told us that they had not taken any specific action to achieve deinstitutionalization.

We were informed by officials in the office of the Assistant Secretary for Health that the Assistant Secretary had not:

--Formulated an overall policy or strategy for assisting in deinstitutionalization of the mentally disabled.

--Designated deinstitutionalization as a priority.

--Issued any instructions or guidance to component agencies on roles and responsibilities for deinstitutionalization. For example, no instructions or guidelines had been issued to comprehensive health planning agencies (now health systems agencies) concerning the role they could play in deinstitutionalization.

The Bureau of Health Planning and Resources Development in HEW's Health Resources Administration, however, believes that health systems agencies and State health planning and development agencies created by the National Health Planning and Resources Development Act of 1974 (42 U.S.C. 300k) could affect mental health services and expedite deinstitutionalization efforts. For example, State planning and development agencies could encourage the development of community alternatives to institutionalization through selective denial or granting of certificates of need, and health systems agencies could award grants for experimental or new community programs.

Office of Long Term Care

OLTC is HEW's focal point for long-term care and nursing home affairs. It is responsible for developing policies on long-term care activities throughout HEW, for stimulating needed long-term care activities, and for coordinating HEW's efforts in enforcing Federal standards for long-term care. OLTC has become involved in a number of efforts to improve the quality of care provided to persons in SNFs and ICFs and to expand home health care benefits under Medicare and Medicaid to provide alternatives to institutional care in general.

Among the problems associated with deinstitutionalization that OLTC can impact on are discharge planning at State institutions for the retarded participating in Medicaid and the placement of mentally disabled persons in skilled nursing and intermediate care facilities that are not capable of meeting their patients' or residents' needs. OLTC, however, had not instructed or requested the HEW regional Offices of Long-Term Care Standards Enforcement to emphasize these areas in their validation reviews of State survey and certification programs. However, since HEW approved deinstitutionalization as a Secretarial objective at the beginning of fiscal year 1976, OLTC has been involved in a number of activities aimed at this goal.

Some of the OLTC activities relating to deinstitutionalization were:

--Participation in efforts to develop community services and resources at State and local levels that will permit retarded persons to either remain in or return to the community.

--Working with SRS and others to identify ways to continue Medicaid health care support for deinstitutionalized persons placed in settings not classified as health institutions.

--Participating with several other HEW agencies to help States develop a technical assistance plan to encourage compliance with Medicaid regulations for institutions for the retarded. Some States, however, were having difficulties implementing the plan because of the lack of funds.

--Assessing the status of compliance of institutions for the retarded with Medicaid regulations and working with the States to insure that each facility had a plan to correct deficiencies.

OLTC officials stated that the presence of so many mentally disabled persons in SNFs and ICFs changes the character of the facilities and the types of services they must provide to meet the needs of the residents. They believe, however, that it would be very difficult for a surveyor to identify mentally disabled persons in SNFs and ICFs because the admitting diagnosis usually describes the person's physical rather than mental condition. To help overcome this problem, it is overseeing the development of a Patient Appraisal and Care Evaluation form to identify the needs of patients and to assist in planning care and evaluating services provided. As of August 1976, the form was being field tested.

OLTC has been given the lead role in HEW for coordinating and developing Federal policy on the use of home health care services under Medicare and Medicaid as an alternative to institutional care. Progress has been slow, however, and not much attention had been given to the needs of the mentally disabled in home health care policy development. The Director, OLTC, attributed slow progress to differences of opinion among the Assistant Secretary for Health, the Social Security Administration (SSA), and SRS on what the Federal Government should, would, and could pay for under home health care programs. As a result of these differences, the Secretary announced a series of public hearings in September and October 1976 to obtain citizen input to develop a uniform and consistent home health care policy. According to OLTC, the home health needs of the mentally disabled will be considered.

OLTC officials told us that they were aware of many of the problems associated with deinstitutionalization of the mentally disabled and have devoted efforts toward working with other HEW agencies with the goal of resolving some of the problems. They said, however, that a more vigorous and cooperative effort by HEW agencies is needed.

NIMH

NIMH is responsible for providing leadership at the national level in matters dealing with the care and treatment of the mentally ill. It administers a number of programs and activities relating to deinstitutionalization, the largest and most direct of which is the CMHC program.

NIMH officials told us that:

--There is a need for NIMH and interagency leadership, guidance, and strategy.

--There has been an "abrogation of professional leadership" at the Federal level in regard to deinstitutionalization.

--Deinstitutionalization has proceeded without establishing a framework of what constitutes acceptable community care. Although research and demonstrations have been carried out and models of community care concepts exist, the projects have not been pulled together.

According to NIMH, one of the biggest problems that must be overcome to successfully implement deinstitutionalization is the need for social support services for mentally disabled persons in communities, such as suitable living arrangements, income support, vocational training, employment, protective supervision, and other services. In a mental hospital, comprehensive services are easier to provide than in the community and can frequently be funded through third-party reimbursement. When a person is placed in the community, supportive services are more difficult to fund, obtain, and coordinate, and the quality of care provided is harder to monitor.

NIMH has had three task forces or special committees since 1970 which have focused on the problems associated with establishing community alternatives to mental hospitals.

These include the Task Force on Community Care which reported in April 1970 its findings on the need for alternate living arragements for the mentally ill. The task force reported that:

--Despite funding of 350 CMHCs, of which 200 were in operation, many persons entered, remained in, and reentered mental hospitals because there were no suitable alternate living arrangements available.

--Private financing that would guarantee rent or downpayments with mortgage payments for community facilities is difficult to obtain.

--There has been no major responsibility assigned to develop a well-organized support program for residential care on a national basis.

--NIMH reviews of mental hospital programs in a number of major States found that no provision had been made to assist personnel in foster homes and nursing homes to provide meaningful and therapeutic activity programs for residents.

The task force made recommendations that address these problems but, according to an NIMH official, the recommendations have not been implemented. Earlier, however, NIMH placed a higher priority for awarding project grants under the Hospital Improvement Program [1] for assisting State mental hospitals to develop more coordinated programs with communities. These projects resulted in moving a large number of hospital patients to communities. Other projects involved the establishment of precare or aftercare programs to prevent unnecessary admissions or readmissions by providing medication, therapy, casework services, crisis intervention, or other services in the community.

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[1] An NIMH project grant program established in 1963 to improve services in mental hospitals and to develop more cooperative relationships between hospitals and community programs.

In February 1971, the Task Force on Residential Care reported on (1) problems involved in placing mentally disabled persons in nursing homes and other residential facilities, (2) the lack of coordination at several different levels, and (3) service to some released mental patients by CMHCs but the lack of focus on this group.

The task force recommended a number of steps that would highlight residential care as a priority and expand coordinated efforts on its behalf, but recommended that no new legislative proposals be developed pending a more thorough assessment of the problems.

In January 1974, an NIMH community support work group was established to identify problems in providing community support to mentally ill persons and to develop ways to solve the problems. The work group has been charged with the responsibility for developing a strategy to increase the availability of adequate and accessible community mental health, social, and rehabilitation services.

Although the work group did not have operating funds of its own, it used contract funds from other programs and initiated efforts in fiscal year 1975 to develop a deinstitutionalization strategy, to establish relationships with other Federal agencies and organizations that have related concerns and responsibilities, and to identify barriers to deinstitutionalization. These efforts were continuing.

Although NIMH has primary responsibility within HEW for the mentally ill, it does not have the resources to meet many of their needs; therefore, NIMH must rely on the cooperation of agencies with the resources. NIMH has had problems getting that cooperation. NIMH was asked to provide input to regulations being formulated to implement the new social services program under Title XX of the Social Security Act. An NIMH official made the following statement regarding this request:

> "When we were reviewing and commenting on issue papers we found out that there were already draft regulations. When we were reviewing and commenting on draft regulations, we found out that regulations had already been published in the Federal Register."

DDO

Deinstitutionalization is a major goal of DDO. DDO developed a strategy for accomplishing this goal which entailed:

--developing and using standards for residential and community programs for the retarded;

--developing a handbook for use by the States which describes methods for helping to meet the needs of the retarded who are inappropriately placed or who are at risk of being inappropriately placed in institutions;

--providing funds to the States for development of institutional reform and deinstitutionalization action plans;

--promoting deinstitutionalization efforts by funding demonstration projects; and

--working with other Federal agencies to help implement deinstitutionalization.

DDO awarded grants to the Joint Commission on Accreditation of Hospitals (JCAH) to develop standards for residential and community programs for the retarded. Standards for residential facilities were published in 1971 and standards for community agencies were published in 1973. In 1973, DDO awarded additional funds to JCAH for a multi-year project to make accreditation surveys using its standards. As of January 1976, JCAH had conducted surveys at 104 residential facilities and 33 community agencies.

In 1973, DDO awarded about $1 million to the States to prepare institutional reform and deinstitutionalization plans to enhance their ability to meet the needs of those developmentally disabled persons in inappropriate institutional settings or those who risk being inappropriately institutionalized. These plans were to be completed during 1975.

Also in 1973, DDO awarded grants to 14 organizations to initiate pilot projects for demonstrating methods of reducing institutional populations. The information derived from these projects was to be incorporated into a handbook. DDO also initiated a technical assistance program in which a grantee provides needed assistance to State Developmental Disabilities Councils to help them carry out their responsibilities.

DDO directed its formula grant and project grant funds to deinstitutionalization. DDO issued guidelines to the States in 1974 for revising their State Developmental Disabilities plans. The guidelines indicated that the State programs should be consistent with the Federal goals and objectives to reduce the institutionalized mentally retarded population by one-third. In addition, HEW's regional offices were instructed to give first priority to projects relating to deinstitutionalization when considering applications for funding under the project grant programs administered by DDO regional representatives. These projects include those that (1) reduce inappropriate admissions, (2) reduce institutional populations, (3) reduce readmissions, and (4) bridge the transition from institutional to community life.

DDO has joined with other Federal agencies, such as (1) MSA to develop its regulations for the ICF program; (2) the Bureau of Education for the Handicapped to fund a project involving the National Center for Law and the Handicapped which was to perform legal research on and help secure the rights of the handicapped, as well as report to HEW on legal actions relating to deinstitutionalization; and (3) participating in a number of task forces and committees.

Despite repeated attempts, however, DDO has not been able to get other agencies to take substantive, sustained action toward the deinstitutionalization goal. DDO was not able to get PSA, MSA, or RSA to undertake specific action toward deinstitutionalization; the work of the Task Force on Mental Retardation Institutions did not result in substantive action; and an HEW-HUD task force was disbanded before its recommendations could be formally presented. DDO's attempts to stimulate joint efforts among HEW agencies and the reluctance of SRS to cooperate are illustrated by DDO's efforts to achieve coordinated action through the operational planning system.

DDO proposed an SRS deinstitutionalization objective for fiscal year 1973 that provided for joint Federal and State actions in:

--Planning and formulating an SRS interagency deinstitutionalization plan and Federal interagency coordination.

--Assisting States to develop, complete, and initiate implementation of statewide deinstitutionalization plans.

--Enabling 10 States to screen persons who are in institutions or who risk institutionalization, as well as place 2,000 persons in the community and provide them with support services.

The proposed objective would have required cooperative efforts from all SRS agencies. For example, MSA's early and periodic screening, diagnosis, and treatment program would have been used to screen and provide services to persons on institutional waiting lists; PSA would have been expected to provide social services to the persons placed in the community; and RSA would have been expected to provide vocational rehabilitation services. This deinstitutionalization objective was not accepted by SRS.

DDO proposed another SRS/Secretarial objective for deinstitutionalization for fiscal year 1975. This objective was supported by RSA and would have provided for joint RSA and DDO sponsorship of demonstration projects in 10 institutions aimed at reducing each institution's population by providing vocational rehabilitation and other support services. SRS, however, rejected the objective because it did not believe it was substantive enough.

The Director of DDO attributed his agency's inability to generate substantive action by other agencies to its prior relatively low position in HEW's organization, as well as to the lack of a mandate to other agencies to work with DDO in implementing the deinstitutionalization goal.

Regional offices

None of the five HEW regional offices included in our review had taken comprehensive, systematic, or concerted action directed at deinstitutionalization; some limited activities focusing on deinstitutionalization, however, have been undertaken.

In fiscal year 1975, region I established deinstitutionalization as a priority objective and set up a committee to identify deinstitutionalization barriers in policy, regulations, and legislation. The committee also contacted the States in the region to initiate joint efforts with them.

The committee identified a number of barriers to deinstitutionalization, and in recommending to HEW headquarters that deinstitutionalization be established as a Secretarial objective in the Department's MBO system, the region stated:

> "* * * to date, the Department has not pushed for clear, consistent State-local action plans, and has not itself developed a coherent, forceful strategy to support constructive State and local efforts* * *."

Joint efforts between region I and the States did not occur although liaison was established with two States in the region.

The committee did not address actions that HEW region I could take within existing programs, and little emphasis, coordination, monitoring, or evaluation was evident in regard to program impact on deinstitutionalization in the region.

During our review, SRS in region X conducted a study of the impact of Federal programs on deinstitutionalization in Oregon. Although the study identified aspects of Federal programs that were adversely affecting deinstitutionalization, region officials took no action as a result of the study because they believed that there was nothing they could do to resolve the problems which were identified.

In general, HEW agencies had done little or no monitoring or enforcing of the program requirements relating to deinstitutionalization and had not coordinated regionwide efforts to use existing programs to implement deinstitutionalization. For the most part, regional officials and staffs did not believe that they had responsibilities relating to deinstitutionalization and attributed their lack of effort in this area to other priorities and the lack of a specific mandate from HEW headquarters. For example, RSA officials told us that deinstitutionalization was not a required goal or objective of the vocational rehabilitation program, and therefore, they had no mandate to evaluate how well States were helping the more severely mentally disabled return to communities. The representatives for the Office for Handicapped Individuals in four of the five regional offices were uncertain of their authority or responsibility and had not taken any action to coordinate regional efforts for deinstitutionalization. One region had not designated anyone to represent the office.

In an April 1975 memorandum to HEW headquarters, the region V director stated:

"We are painfully aware that much is wrong with placement of the mentally ill and mentally retarded in Michigan and in most other places throughout the country. We are also aware of the reasons why there are so many problems and problem situations in the placement of these people.

"The mentally retarded and the chronic mentally ill person requires supportive care. This means a decent place to live, adequate rehabilitation work programs, and opportunities for meaningful participation in some form of community activities. Work, play, and love are needs of all people, but it appears none of these are actually available to the deinstitutionalized persons. The need for adequate and acceptable mental health services, as well as social and rehabilitative services seems to be fragmented among the following Federal agencies:

Rehabilitation Services Administration
Medical Services Administration
Community [Public] Services Administration-SRS
Health Resources Administration-Long Term Care
    Division
Housing and Urban Development
OS - Office of Nursing Home Affairs
Social Security Administration
Administration on Aging
Department of Labor
Others"

* * * * *

"In may respects, the problems in the placement of these "hard-to-place" groups is similar to, but more difficult than, the long term and nursing home problems of the elderly - with which we are now dealing on a Regional basis.

"It is my suggestion that we begin to give this some serious thought on a national basis, as we have given to the long term care problems of the elderly. The Regional Director's Office, with some support from Washington, could assume a leadership role in tackling this problem."

Similarly, the HEW Region VII SRS Commissioner told us that:

> "As you are probably aware, each fiscal year, the Regional Director requests Region VII HEW agencies to develop interagency priority objectives. One of the objectives which SRS developed for FY 1975 was an objective on deinstitutionalization. This objective involved primarily Rehabilitation Services/ Developmental Disabilities, Rehabilitation Services, and Community Services in SRS, Public Health Service, Office of Education, and the Office of Human Development. This objective had as its initial and central purpose, the development of a common system for monitoring and planning deinstitutionalization programs in State agencies.
>
> The objective was never implemented. The participating DHEW agencies could not arrive at a common objective and strategy which complemented and enhanced whatever deinstitutionalization activities each agency had underway. SRS encountered serious and genuine differences among the participating DHEW agencies on deinstitutionalization philosophy and definitions. Additionally, some agencies considered themselves unable to assign to the objective the amount of staff necessary to implement it. Essentially, for these reasons, the Regional Director has now established a committee to ascertain the critical reasons which inhibited the operationalization of a deinstitutionalization objective in FY 1975 and to determine whether a deinstitutionalization objective is viable for FY 1976."

Both HEW Regions V and VII established deinstitutionalization objectives for fiscal year 1976. Region V established a task force on alternatives to institutional care. In October 1975, Region VII sponsored a symposium on deinstitutionalization.

CHAPTER 4

MORE EFFECTIVE USE OF THE DEVELOPMENTAL DISABILITIES PROGRAM POSSIBLE

The developmental disabilities programs in the the five States included in our review had a positive, but limited, impact on deinstitutionalization. 1/ They provided funds to develop and expand needed community resources and had some success in stimulating, influencing, coordinating, and monitoring other agencies' activities. However, their successes were not commensurate with the needs; their authority did not match their responsibilities; their stimulating, influencing, coordinating, monitoring, and evaluating roles needed to be strengthened; and their efforts in these areas needed to be intensified.

HOW THE PROGRAM IS ADMINISTERED

The developmental disabilities program is directed at the State level by a State council, which must include representatives from at least the following State programs: special education, vocational rehabilitation, residential services for the mentally retarded, social services, crippled children's services, health services or long-term care programs, and medical assistance. The council must also have adequate staff to carry out its functions, including at least one planner.

Each State is required to designate a responsible agency, or agencies, for administering the program. The program was administered by the State health departments in Michigan and Nebraska, by the Department of Human Resources in Oregon, by Maryland's Department of Health and Mental Hygiene, and by the Executive Office for Administration and Finance, Office of the Governor, in Massachusetts.

1/ Developmental disabilities are those which are attributable to mental retardation, cerebral palsy, epilepsy, autism, conditions closely related to mental retardation, or dyslexia. They originate before a person becomes 18 years old, can be expected to continue indefinitely, and constitute a substantial handicap to a person's ability to function normally in society.

Under the program, HEW provides formula grant funds to the States for their use in planning, administering, and evaluating programs for the developmentally disabled and for providing services to them. To a limited extent, the funds can also be used for constructing facilities. HEW regulations allow the States, with their grant funds, to provide a variety of services to the developmentally disabled, including housing, training, followup, education, day care, and sheltered employment (a controlled work environment).

During fiscal year 1975, the States received about $28 million in developmental disabilities formula grant funds. 1/ According to their financial plans, the five States included in our review intended to use about 84 percent of their fiscal year 1975 formula grant funds for services and the remaining 16 percent for planning and administration costs. None of the five States reported using formula grant funds for construction. The five States we reviewed received a total of $2.7 million in developmental disabilities formula grant funds as shown below.

State	Amount
Michigan	$1,107,920
Maryland	444,380
Oregon	285,910
Nebraska	214,560
Massachusetts	692,915
	$2,745,685

PROGRAM OBJECTIVES

The developmental disabilities program was established in 1970 to (1) identify needs of the developmentally disabled and develop comprehensive plans to meet these needs, (2) stimulate and coordinate other agencies to take specific actions to provide services to the retarded, and (3) fill gaps in services and facilities. Deinstitutionalization is a major goal of the program.

1/The Federal Government provides up to 75 percent of allowable costs under the program.

According to HEW regulations, States receiving formula grants under the developmental disabilities program were responsible for

- --identifying, reviewing, and evaluating all major programs, services, and facilities in the States for the developmentally disabled;
- --coordinating and, where possible, stimulating the development of planning efforts on behalf of the devellopmentally disabled by State agencies and at the local level throughout the State;
- --developing and expanding (filling gaps in) community-based facilities and services;
- --assuring the effective coordination of other major activities and programs in the State for the developmentally disabled; and
- --describing the quality, extent, and scope of services being provided or planned to be provided to the developmentally disabled under nine specifically cited federally assisted programs, as well as under other related programs.

ACCOMPLISHMENTS AND PROBLEMS

The developmental disabilities programs in the five States included in our review have identified weaknesses in services and facilities, and developed plans and provided funds to fill some of the gaps. However, their success in stimulating and coordinating other agencies' deinstitutionalization efforts was generally limited. In addition, the gaps in community-based facilities and services far exceeded the funds available under the program. 1/

Although State developmental disabilities programs have been given broad responsibilities, they did not have authority commensurate with their responsibilities. The did not have the authority to require other State agencies to cooperate with the councils or the developmental disabilities agencies. As a result, attempts by developmental disabilities councils or agencies to identify and resolve problems were not always

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1/ The developmental disabilities program replaced a mental retardation facilities construction and staffing project grant program.

successful. In addition, councils or agencies often did not evaluate or attempt to coordinate or influence other agencies' activities that affected deinstitutionalization.

Identifying and filling gaps

All five State developmental disabilities agencies in our review identified gaps in community-based facilities and services that presented obstacles to deinstitutionalization. They identified shortages in community-based housing, sheltered employment, transportation, followup, information and referral services, and other services. They also provided funds to help alleviate some of the shortages.

Massachusetts and Oregon programs, for example, provided for the operation of group homes or community residences. Nebraska identified information and referral services as a major gap and, therefore, devoted much of its funds for such services. The Maryland program provided funds for group homes, sheltered employment, and activity centers. The Michigan program provided funds to help a regional center place mentally retarded persons in the community, and also provided funds for the operation of sheltered workshops, activities centers, and other projects.

As indicated on page 54, the developmental disabilities agencies planned to use about 84 percent of their formula grant funds for the provision of services. However, the amount of funds needed to fill the gaps in community facilities and services far exceeded the funds available under the program and the funds provided by other agencies. Therefore, the weaknesses were reduced but many still remain.

One of the principal reasons for the gaps in community-based facilities and services is that the bulk of State mental retardation agency budgets are generally used to support the care of persons in institutions. For example, about 19 percent, or $6.8 million, of Maryland's Mental Retardation Administration's budget for fiscal year 1975 was for community services, while about 80 percent, or $29.2 million, was for institutional programs. Mental retardation agencies must rely on other agencies to provide funds to help achieve deinstitutionalization objectives.

Stimulating and influencing other agencies

State developmental disabilities councils and agencies have had limited success in stimulating and influencing various State and local agencies to take specific action toward deinstitutionalization. Many State and local agencies that were responsible for providing facilities and services to general population groups--among which many retarded are included--had not adopted deinstitutionalization as a program goal or priority; nor had they taken substantive action to assist in the deinstitutionalization effort.

In Oregon, for example, State agency officials indicated that few, if any, specific actions to emphasize the mentally retarded have been initiated as a result of the council's efforts. The Director of Oregon's developmental disabilities program and the Executive Director of the Oregon Association for Retarded Citizens, both members of the council, said that the program has not effectively influenced other agencies to emphasize care for the mentally retarded. The developmental disabilities director said the council did not have the funds to effectively cause other service agencies to shift more attention to the mentally retarded.

The executive director of the Oregon Association for Retarded Citizens said the council could not effectively influence changes in State agencies because the council is an "insystem advocate." He said that the agency representatives on the council were not in policymaking positions in their own organizations.

In Maryland, we contacted State agencies responsible for mental retardation, crippled children's services, education, vocational rehabilitation, social and employment services, and comprehensive health planning to determine what actions they had taken as a result of the council's influence. Three of the agencies either had taken no action or were not aware of actions taken as a result of requests by the council; one agency had not been contacted concerning an identified problem for which it had responsibility; one agency thought coordination was needed at the local level rather that at the headquarters level; and the director of one agency thought that the council had not met its mandate because it awarded numerous grants of small amounts (average of $19,000 per grant in fiscal year 1975) rather than fewer but larger grants of a more continuing nature. The State Medicaid agency was not represented on the council.

Although the Maryland council was slow in getting started, it has established deinstitutionalization and institutional reform as its only priority in fiscal year 1976 and had initiated an effort to obtain support from other State and local agencies. For example, the Employment Security Administration was added to the council in 1975.

The Michigan Developmental Disabilities Council has had some success in influencing other State agencies to assist in deinstitutionalization. For example, it prompted the Department of Social Services to provide funds for transporting eligible mentally retarded persons from their residences to sheltered workshops or activity centers. On the other hand, a State Department of Public Health official said that the council has not been able to influence other agencies to take actions to the extent needed to successfully implement deinstitutionalization.

More concerted efforts needed

One objective of the developmental disabilities program is to coordinate and, where possible, stimulate efforts on behalf of the developmentally disabled at local levels throughout the State. Although housing has been identified as a critical need for deinstitutionalization, local housing agencies we contacted had not, with one exception, included the needs of the developmentally disabled in their housing assistance plans. State developmental disabilities agencies either had not attempted at all or had not succeeded in an attempt to influence local housing authorities.

According to the President of the National Conference on Developmental Disabilities, in a 1975 survey of 33 State councils by the Conference, 24 reported that local housing authorities were not involved in providing community-based housing for the retarded. Nine reported that negotiations or discussions with local housing authorities were underway.

In addition, in April 1976, the Consortium Concerned with the Developmentally Disabled, a coalition of 22 national organizations, reported on the results of a survey by some of its member organizations at the State and local levels with regard to the Housing and Community Development Act of 1974. Some successes in obtaining HUD housing assistance payments for the developmentally disabled were reported. However, of 130 respondents to the survey, 84 reported that their communities either failed to include the needs of the developmentally disabled in their housing assistance plan or had submitted a plan which they believed inadequately addressed the needs of this population. Also, 36 respondents reported that their local housing authorities were unaware of the applicability of the act to the developmentally disabled, and the same number believed that their local housing authorities were insensitive to the housing needs of the developmentally disabled.

Although community-based housing had been identified as a critical need by the Oregon State Developmental Disabilities Council, the council had apparently not influenced local housing authorities to assist in the deinstitutionalization effort. For example:

--Only one of four communities we contacted that were receiving Federal housing assistance funds had assessed the needs of the mentally retarded residing in or expected to reside in the community and had included the housing needs of the mentally retarded in its housing assistance plan required by HUD.

--The housing programs manager in Portland, Oregon's largest city, said that his agency had not included the needs of the retarded in its housing assistance plan because no one had contacted the planning staff to suggest that deinstitutionalization be considered and the staff had not thought themselves to consider the needs for community-based housing.

--The Salem Housing Authority, on its own initiative, was planning to develop housing units for the retarded because it was aware of a number of retarded people being released in the community. The State's largest institution for the retarded is in Salem. Contact had not been made by the Mental Health Division or the Developmental Disabilities Council. The director of the Housing Authority was not aware of the Developmental Disabilities Council. The director said that after the decision was made to develop special housing units for the retarded, they found themselves embroiled in a "bottomless pit of regulations and requirements" and were having considerable difficulties starting the program.

We also contacted other State agencies that administer programs affecting deinstitutionalization that had not been considered by the councils. For example, an employment agency representative in Oregon told us that her agency could do more to assist in deinstitutionalization if its role were more clearly defined and if better communication existed between employment offices and State institutions. Similarly, an employment agency representative from Nebraska stated that more could be done to help find employment for the mentally disabled if there were more cooperative efforts among agencies.

Coordination

Coordination among State agencies, particularly those involved in mental health, retardation, public welfare, and social services, was a major problem in all of the five States we reviewed. Roles and responsibilities for the deinstitutionalization of the mentally retarded were generally not clearly defined, accepted, or understood. State Developmental Disabilities Council members or staff in each of the five States, however, told us that they did not have the authority to require other agencies to coordinate or cooperate.

The Massachusetts developmental disabilities agency planned, initiated, and managed a multiagency effort to upgrade the State's institutions for the retarded so that they could participate in the Medicaid program. The agency has also initiated efforts to develop a client information and evaluation system involving several agencies which would better enable followup, identification of need, and the matching of need with program eligibility.

On the other hand, the Director of the Massachusetts developmental disabilities agency informed the Governor in 1975 that coordination was a significant problem in the State's deinstitutionalization efforts. She told us that although her agency had identified this problem, neither it nor the council had the authority to require agencies to cooperate or improve their programs.

The need for greater coordination was illustrated by the lack of communication among the Departments of Mental Health, Public Health, and Public Welfare. The Department of Mental Health was placing persons into nursing homes that the Department of Public Health had found to be substandard, and neither the Department of Mental Health nor the Department of Public Welfare had taken prompt action to see that no more mentally disabled persons were placed in such facilities until deficiencies were corrected. One Department of Mental Health official told us that he occasionally learned of an action taken against a nursing home by reading about it in the newspaper.

Coordination at the State and local levels was also a major problem in Michigan. In Wayne County, for example, there was no coordination among several organizations involved in the community placement process. Responsibilities among agencies were not clearly delineated. No State agency had been assigned overall responsibility for sponsoring work activity services for those mentally disabled persons over 25 years of age in the community. A State Department of

Public Health official told us that problems were encountered because laws, rules, and regulations did not spell out each State agencies' responsibilities for retarded persons and the Developmental Disabilities Council could not require agencies to cooperate.

In Maryland, programs relating to the mentally retarded were divided among many agencies. Responsibilities for serving the retarded in the community had not been clearly defined. The majority of local health departments, CMHCs, and clinics had no office, position, or focal point for coordinating, planning services for, or serving the mentally retarded. Particular problems existed with respect to filling the mental health needs of the retarded and the operation of two separate social service systems.

The Oregon Council recognized the need for service coordination at the local level and used a substantial portion of its fiscal year 1974 Federal formula grant ($109,000 of $280,000) to establish and support service coordinators in local areas in the State. In fiscal year 1975, service coordinators served 23 or Oregon's 36 counties. As discussed on p. 96, these service coordinator positions have helped, but have not been able to provide followup for many retarded persons released to their counties.

Monitoring and evaluation

HEW regulations require State developmental disabilities councils or agencies to describe the quality, extent, and scope of services provided to the developmentally disabled under several specified programs and other related programs. Medicaid and public welfare are two specified programs.

Although many mentally retarded persons have been placed into SNFs and ICFs under Medicaid and others have been placed into such community-based facilities as room and board homes or foster homes using SSI or other welfare resources, information was usually not available on the extent, quality, and scope of services provided at these facilities.

More monitoring and evaluation needed

States need to increase their monitoring and evaluation of the quality of services provided to the developmentally disabled by other State and local agencies, and the effectiveness of State interagency coordination.

In Massachusetts, for example, the State Departments of Mental Health and Public Welfare have agreed on their responsibilities for placing mentally disabled persons in the community from State institutions. The discharge planning and followup provisions of this agreement were not being implemented for the persons released from the institutions included in our review. The Department of Mental Health and Division of Employment Security also had an agreement that local employment offices would participate in the discharge planning process at State institutions This agreement also was not being implemented.

We discussed these problems with the Director of the Massachusetts developmental disabilities program. She informed us that her agency's activities have centered around fostering such agreements and informing people of them. She said, however, that her agency has not evaluated either the implementation of such agreements or the effectiveness of various programs because it did not have enough funds for such an evaluation. However, she said that in the future, more monitoring and evaluation will be done.

As described in chapter 6, the release planning and followup procedures of various agencies for the retarded that are being placed in the community need improvement. It appears that State developmental disabilities councils or agencies could become more involved in monitoring and evaluating such procedures and recommending improvements when needed.

More involvement in the utilization control process possible

As noted in chapter 7, several improvements are needed in State programs to control the utilization of medical services covered by Medicaid. As part of their monitoring and evaluation efforts, State developmental disabilities councils or agencies could become more involved in the utilization control process. The Executive Director of the Maryland Council, for example, told us that the Council had not been involved in the utilization control process in the past, but it would become more involved in the future.

State developmental disabilities councils or agencies could, in conjunction with State Medicaid agencies, be responsible for

--making certain that utilization controls properly identify mentally retarded persons who are inappropriately placed in public institutions, SNFs, and ICFs or who are not receiving needed services in such facilities.

--including (1) in State developmental disabilities plans, the results of independent reviews as they relate to the retarded, (2) a multi-agency action plan to develop, or obtain, appropriate facilities or services for those persons identified as inappropriately placed or not receiving needed services, and (3) a progress report; and

--providing assistance to State Medicaid agencies in implementing utilization controls as they relate to the developmentally disabled.

ACTION NEEDED BY FEDERAL AGENCIES

Federal agencies, particularly HEW, can improve the effectiveness of the State developmental disabilities programs by

--more specifically delineating State council or agency responsibilities relating to State and local programs supported by HEW and other Federal agencies;

--providing guidance or instructions to federally supported State and local agencies on how they can cooperate with developmental disabilities councils or agencies;

--emphasizing to a larger extent, (1) the responsibilities of the council or agency with regard to monitoring and evaluating other agencies' activities as they relate to the mentally retarded and (2) coordination at the local level.

Need for clarification by HEW of developmental disabilities responsibilities relating to federally supported programs

HEW regulations require that State developmental disabilities councils consist of representatives from several specified State programs. The regulations require the States to describe the extent, quality, and scope of services provided or to be provided by nine programs to the developmentally disabled. The regulations, however, need to more clearly identify the responsibilities of the State developmental disabilities programs for stimulating, influencing, coordinating, or monitoring federally assisted State and local programs supported by HEW and other Federal agencies.

Guidance needed from Federal agencies on how the States are to cooperate with developmental disabilities

Some State or local agencies administering federally supported programs were required by Federal regulations to coordinate or cooperate with the State developmental disabilities council or agency; others, however, were not. For example, HEW regulations under the Rehabilitation Act of 1973 require a State vocational rehabilitation agency to enter into cooperative arrangements with other State agencies, such as developmental disabilities. On the other hand, HEW regulations do not require State Medicaid agencies to cooperate or coordinate with developmental disabilities councils or agencies.

State agency responsibilities need emphasis

Each year HEW requires States to prepare plans for using their developmental disabilities formula grant funds. States are required to estimate their expenditures for planning, administration, services, and construction. HEW did not, however, require the States to identify how much would be used for monitoring or evaluating the quality of services provided to the developmentally disabled under other programs.

More emphasis on coordination at the local level

Deinstitutionalization seems to be more successful when overall responsibility and accountability for mentally retarded persons in the community is pinpointed and clearly assigned to one organization, such as at the Macomb-Oakland Regional Center in Michigan and the Eastern Nebraska Community Office of Retardation. Inasmuch as coordination is a principal objective of the developmental disabilities program, HEW should consider requiring States to devote more effort and possibly more of their developmental disabilities funds to coordinate at the local level when it is needed.

IMPLICATIONS OF NEW LEGISLATION

In 1975, the Congress strengthened the developmental disabilities program by enacting the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. 6001). This act required that:

--At least 10 percent of the formula grant funds in fiscal year 1976 be used to assist in developing and implementing plans for eliminating inappropriate institutional placement and that 30 percent of such grant funds be used for this purpose in fiscal years 1977 and 1978.

--State plans be designed to eliminate inappropriate institutional placement and improve the quality of care for persons requiring institutional care.

--The State plan support the establishment of community programs as alternatives to institutions with full assistance of and in full coordination with other community programs.

--The State Planning Council, to the maximum extent feasible, review and comment on all State plans which relate to programs affecting developmental disabilities.

--States, in order to receive formula grant funds under the act after September 30, 1976, provide assurances that each program (including programs of any agency, facility, or project) which receives funds under the grant has, in effect for each developmentally disabled person who receives services from or under the program, a habilitation plan meeting specified requirements, including (1) the specific goals and objectives, (2) identification of a program coordinator responsible for the implementation of the plan, (3) specification of the role and objectives of all parties to the implementation of the plan, and (4) periodic review.

--The National Advisory Council on Services and Facilities for the Developmentally Disabled include representatives from various HEW agencies, such as RSA and SRS.

--States receiving formula grants under the program establish a system which protects the rights of and advocates for developmentally disabled persons.

Section 204 of the act requires the Secretary of HEW to conduct or arrange for the conduct of a review and evaluation of the standards and quality assurance mechanisms applicable to residential facilities and community agencies under Federal laws he administers. This study is to include an assessment of (1) their effectiveness in insuring that services rendered to persons with developmental disabilities are consistent with current concepts of quality care concerning treatment, services, and habilitation; (2) the relative effectiveness of their enforcement; and (3) the degree and extent of their effectiveness. From the results of this study, the Secretary is further required to develop recommendations for change in the Federal laws and regulations he administers and to report his findings and recommendations to the House Committee on Interstate and Foreign Commerce and the Senate Committee on Labor and Public Welfare by March 1977.

This report and the five reports to HEW regional directors address both the effectiveness of several HEW programs in insuring that the developmentally disabled receive appropriate care and services, and the extent to which program requirements were enforced.

DISCUSSION WITH DDO OFFICIALS

We met with the DDO officials to discuss our findings and what actions needed to be taken to resolve the problems identified in our review. DDO officials generally agreed with our suggestions and stated that, to the extent they could, they would strengthen the regulations for implementing the new act to resolve the problems we identified. For example, they said they would try to include local housing agencies among those specified agencies that State developmental disabilities councils were to coordinate with.

CHAPTER 5

IMPACT OF COMMUNITY MENTAL HEALTH CENTERS AND CLINICS ON DEINSTITUTIONALIZATION

The Community Mental Health Center program was enacted in 1963 to enable most mentally ill persons to be treated in their own communities. Two of the program's major objectives were to decrease the use of State mental hospitals and improve the organization and delivery of community mental health services by developing a coordinated system.

In August 1974 we issued "Need for More Effective Management of Community Mental Health Centers Program" (B-164031(5), Aug. 27, 1974). We reported that the centers had increased the accessibility, quantity, and type of community services available and have enhanced the responsiveness of mental health services to individual needs. However, that report, other studies, and information obtained during this review show that the CMHC program had not been fully effective in preventing unnecessary admissions to public mental hospitals, providing care and followup treatment to persons released from such facilities, or developing a coordinated system of care for the mentally ill. It appears that, in some cases, psychotropic drugs and other Federal programs, such as Medicaid and other public assistance programs, have had more of a direct impact on the reduction of mental hospital populations than the CMHC program.

Recognizing that improvements were needed, the Congress enacted legislation--the Special Health Revenue Sharing Act of 1975 (42 U.S.C. 246) and the Community Mental Health Centers Amendments of 1975 (42 U.S.C. 2689)--imposing more stringent requirements on CMHCs and the States to insure that the intent of the CMHC program was met.

State and local governments, as well as private organizations, have also established or supported mental health clinics which have not received construction or staffing grants from the National Institute of Mental Health. These clinics provide such services as day treatment, medication, and psychiatric therapy to the mentally ill.

In this report, therefore, CMHCs refer to facilities which received construction or staffing grants from NIMH. Mental health clinics refer to facilities not receiving such grants. However, some of these clinics received Federal funds from other sources, such as from the Medicaid or Comprehensive Public Health Services programs.

STATUS AND OPERATION OF CMHC PROGRAM

As of July 1975 NIMH had awarded construction and/or staffing grants of $1.2 billion to 603 CMHCs. When all 603 CMHCs become operational, they will serve areas covering about 41 percent of the U.S. population. As of July 1975, 507 CMHCs were in operation

Construction grants were for as much as 66-2/3 percent of construction costs for centers in nonpoverty areas and as much as 90 percent for centers in poverty areas. In general, staffing grants were awarded on a declining basis over 8 years, ranging between 75 and 30 percent for centers in nonpoverty areas and between 90 and 70 percent for centers in poverty areas.

CMHCs are established under a catchment-area concept, with each CMHC responsible for assuring that mental health services are available to the population in its area. Under NIMH regulations, each catchment area was generally required to have a population range of 75,000 to 200,000, with only one CMHC in each catchment area. NIMH estimates that it would take about 1,500 CMHCs to provide a nationwide network. According to NIMH, it awarded CMHC staffing and/or constru-tion grants to the five States in our review as shown below through fiscal year 1975.

State	Number of centers	Grant funds (millions)
Maryland	10	$13.4
Massachusetts	17	38.0
Michigan	21	29.5
Nebraska	7	9.8
Oregon	2	5.1

Before the 1975 amendments to the CMHC authorizing legislation, each CMHC was required to provide at least five basic services: inpatient, outpatient, partial hospitalization, emergency, and consultation and education. The 1975 amendments, effective July 1, 1975, require CMHCs to provide additional services. (See p. 79.)

EFFECTIVENESS IN PREVENTING UNNECESSARY ADMISSIONS, PROVIDING AFTERCARE AND FOLLOWUP, AND ACHIEVING COORDINATION

Both CMHCs and mental health clinics have had a positive, but limited impact on preventing unnecessary admissions to public mental hospitals or in providing aftercare or followup treatment to released patients. The resident population of State mental hospitals had been substantially reduced before many CMHCs became operational. In the August 1974 report, based on a review of 12 CMHCs in 7 States, we showed that CMHCs had not been fully effective in (1) screening persons wanting to enter, or who had been referred to public mental hospitals, to avoid unnecessary admissions. (2) providing services or followup to persons released from mental hospitals, or (3) coordinating services for the mentally ill in the community.

Data available from various studies indicate that the CMHC program has helped reduce admissions to State mental hospitals, but has generally not had a significant impact on helping persons to return to communities from mental hospitals. For example, a November 1973 report by an NIMH contractor who compared mental hospital admission and resident rates in areas with CMHCs to those areas not having CMHCs found that while CMHCs had an impact on reducing admissions to State mental hospitals, there was no large consistent relationship between the opening of CMHCs and State hospital resident rates.

NIMH data on sources of referrals to CMHCs also indicate that the CMHC program was having only a limited impact on reducing public mental hospital populations. For example, for 1974 NIMH reported that about 29,300, or about 3.8 percent of the 780,400 additions to CMHCs during the year, were referred by public mental hospitals. Public mental hospitals accounted for fewer referrals to CMHCs than any other referral source reported, except for the clergy.

Other indicators of the impact of CMHCs, as well as mental health clinics, on shifting the emphasis of care from public mental hospitals are admissions and readmissions to such facilities. Although total admissions to public mental hospitals have been decreasing overall in recent years, inpatient admissions to public mental hospitals increased in 21 States and the District of Columbia during fiscal year 1974. As shown in chapter 2, readmissions constitute a significant portion of admissions to public mental hospitals.

One factor contributing to the high readmission rate was the lack of appropriate facilities and services in the community. NIMH officials stated that the high readmission rate indicates that many released patients are not receiving needed services in the community. However, they stated that all readmissions do not necessarily indicate that the "system" has failed. They pointed out that mentally ill persons, like physically ill persons, have relapses requiring rehospitalization without necessarily meaning that insufficient care had been received.

NIMH officials further stated that it is not always the lack of mental health services that contributes toward the high readmission rate. The lack of support services, such as housing, medical care, income support, social services, vocational training, or employment, are also factors. For example, an NIMH-sponsored study in Maryland showed that, of 31 persons participating in a deinstitutionalization project who were readmitted to a State mental hospital, 10 were readmitted primarily because of insufficient housing in the community.

Community mental health centers

CMHCs we visited generally did not have data on their effectiveness in screening admissions to public mental hospitals or in providing services or followup to persons released from mental hospitals. Some data was available, however.

Maryland

A study involving one Maryland CMHC indicated that several persons were needlessly being referred to a State hospital because they were not being screened or evaluated by the CMHC before their admission.

Nebraska

CMHCs developed at a much slower rate in Nebraska than envisioned and most of the State's centers did not become operational until 1974 and 1975 after the State mental hospital population had been substantially reduced. Staff from the Nebraska CMHC we visited, however, did discuss the needs of persons who were to be referred to them with the staff at the State mental hospital serving its catchment area. This arrangement helped to make sure that persons referred to the center by the mental hospital were provided services after their release from the hospital.

An official at the CMHC said that there had been no formal cooperative efforts among agencies to determine how to comprehensively meet the needs of the mentally ill. He further stated that his center lacked the trained staff and resources to fulfill its responsibilities. Particular needs included halfway houses for adults and related programs for adolescents.

Massachusetts

Massachusetts State mental hospitals could provide medication to persons at no cost while CMHCs did not have the funds to do this. Accordingly, some persons released from mental hospitals were returning to receive medication rather than going to closer CMHCs. Thus, the CMHCs were unable to fulfill one of the program's main objectives. In addition, a March 1975 study at one State mental hospital showed that nearly 50 percent of inpatient admissions were made during evenings and weekends when the CMHC serving the catchment area was closed.

District of Columbia

The District of Columbia's public mental hospital reported more than 3,600 inpatient admissions during fiscal year 1974. We asked the Central Admissions Service of the public mental hospital which serves the District--Saint Elizabeths Hospital--to determine how many persons admitted during a 1-month period could have been treated at a CMHC or other alternative to Saint Elizabeths.

Saint Elizabeths is administered by NIMH and serves District residents, visitors, and others. The District of Columbia is divided into four catchment areas, each with a CMHC. The CMHC for one area is on the grounds of Saint Elizabeths; thus we excluded those admissions from our findings. We also excluded non-District resident admissions.

The Central Admissions Service determined that 90 of the 100 persons admitted to the hospital as inpatients from the other 3 areas from February 14 - March 15, 1975, could have been treated just as well in an alternate facility--primarily CMHCs. Fifty-one, or 56.7 percent, of the 90 persons who were unnecessarily admitted were referred to Saint Elizabeths by the CMHCs in the 3 areas. The other 39 persons were referred by the police, courts, or entered in another manner. According to the Central Admissions Service, the 90 persons were not treated in the CMHCs in their catchment areas primarily because beds were not available or the CMHCs could not handle the additional workload.

The following table shows where the 90 persons could have been treated.

Location or type of treatment	Number of persons
Inpatient CMHC hospitalization	70
Short-term residential	11
Crisis intervention and short-term residential or outpatient care	8
Outpatient	1
Total	90

Development of CMHCs apart from mental hospital system

In general, the CMHC program has developed apart from the public hospital system. Many CMHCs did not view reducing the use of State mental hospitals as a primary goal and therefore did not direct much effort toward this goal. The lack of a formal link between the CMHCs and the public mental hospitals helped fragment responsibility for the mentally ill released from mental hospitals. It also appears to have hindered the accomplishment of two CMHC program goals--reducing the use of mental hospitals and providing a coordinated system of care for the mentally ill.

According to NIMH, as of 1974 mental hospitals received only about 3 percent of the grant funds for CMHCs. Local governments, charity groups, general hospitals, and other organizations received most of the funds. Therefore, a situation developed in which (1) the mental hospitals were generally accountable to the State for persons who are inpatients or released on leave while (2) CMHCs were generally accountable to NIMH, other governmental units, or private organizations for groups of persons that may not have included those seeking admission to or being released from mental hospitals.

This problem was discussed in our August 1974 report on the CMHC program: public mental hospital and CMHC officials had different views on CMHC responsibilities for screening persons before their admission to mental hospitals and providing services to persons released from such facilities. This problem was also identified in an August 1972 report by an NIMH contractor. The contractor asked CMHCs to rank order 10 goals of the CMHC program. Of the 175 CMHCs that responded, the goal of decreasing State mental hospital utilization was ranked next to last.

Another factor complicating the relationship between CMHCs and public mental hospitals was the different characteristics of the population they often served. For example, one reason cited by an NIMH contractor in its November 1973 report for the limited impact of CMHCs on reducing mental hospital rates was that CMHCs attracted a new type of patient who was not very ill and not a candidate for hospitalization in a State institution.

In commenting on these problems, NIMH told us that in States such as Utah where the State has taken leadership in involving community programs in discharge planning, many of the problems of patients returning to the community are lessened and recidivism reduced. NIMH believes that State mental health department leadership in assuring screening and aftercare seems to be the essential factor.

Mental health clinics

A national network of CMHCs has not been established; however, State and local governments and other organizations have established many community mental health clinics. Most of the clinics we visited did not offer the range of services that CMHCs are required to provide. As discussed in chapter 2, they often (1) could not provide needed services or followup treatment to released patients or (2) prevent unnecessary institutionalization.

Maryland

Mental health clinics we visited in Maryland did not, nor were they required to, screen all prospective admissions to State mental hospitals. Services available to the mentally ill were often limited because there were few CMHCs and most mental health clinics did not offer a full range of mental health services. Only 8 of the 32 State-supported mental health clinics offered the 5 services (see p. 68) required of CMHCs. Of the remaining 24 clinics, 7 offered 3 of the services and 17 offered 2. In March 1975 a Mental Health Advisory Committee for one Maryland county observed the following about that county's clinic:

--Services were provided only 4 hours a week.

--Increasing present hours of service twofold would provide only minimal service to about one-quarter of those estimated to need it.

--Part-time clinic operation, even substantially expanded, would force persons needing immediate help to wait anywhere from a week to a month before they could be seen by a local mental health professional.

Michigan

Several community mental health clinics in Michigan served primarily as medication-dispensing facilities. At two clinics we were told that they had large patient loads and little time for therapy. Officials at a State hospital and a Community Mental Health Board said that one reason the psychiatrists did not provide therapy was because they were foreign medical graduates who could not communicate with the patients. Our review of case files at the two clinics indicated that medication was the only service provided.

Reports submitted to the Community Mental Health Board by four other mental health clinics indicated that their primary function was giving medication. The reports indicated that the clinics did not provide enough psychiatric time for therapy and counseling. The 4 clinics had about 250 persons on waiting lists.

Oregon

Alternative services which could divert people from admission to State mental hospitals are the least developed elements of Oregon's mental health services. Service for former hospital patients has been generally limited to medication followup and, as a result, people use State hospitals to receive services that could be given in the community.

Almost half of Oregon's communities could not place a patient in a local treatment program after evaluation without a long waiting period. For example, a Mental Health Division review of the Multnomah County program showed that admissions at two of the county's four clinics was closed and a third had a 4- to 6-week waiting list. Over 1,800 persons from the county are admitted to 1 State mental hospital annually; many are readmissions.

Few communities had the range of services needed to prevent State hospitalization or provide a full range of mental health services. Only 5 of Oregon's 30 county mental health programs offered a complete range of alternatives to State hospitalization and less than half the counties offered the services Oregon's Mental Health Division considered essential to avoid hospitalization. These essential services are day or night treatment, emergency services, community residential care, and local inpatient treatment.

Massachusetts

Only 13 of the State's 39 catchment areas 1/ had all 5 services that CMHCs were required to provide; 10 had most of the services, and the remaining 16 had very limited services. State officials said that partial hospitalization and 24-hour crisis intervention services were the greatest needs.

PROBLEMS IN FUNDING CMHCs AND CLINICS

States have had difficulties funding CMHCs and clinics. Factors contributing to these problems included:

--Uncertainties regarding Federal funds and anticipated difficulties in future funding of CMHCs as the Federal staffing grants decline or are discontinued.

--Rising costs of mental hospital care, thereby hindering the States' ability to make sufficient funds available for community-based services.

--Limited reimbursements for CMHCs and health clinics under Medicaid and Medicare.

Uncertainty of Federal funding and funding sources after the CMHC grants expire

Contrary to congressional desires, the President has proposed phasing out Federal funding of the CMHC program because he believed that the CMHC concept has been adequately demonstrated. The uncertainty surrounding the program's future and anticipated difficulty in funding CMHCs after the Federal staffing grants lapse have impeded the program's growth in some States. Officials in three States we reviewed provided the following comments.

Maryland

Federal cutbacks in program funds earmarked for CMHCs in favor of relying on third-party payments, such as Medicaid, Medicare, and insurance, will have an adverse impact on the continuity of care available to mentally ill persons because collections from third-party payers may not necessarily be reinvested in mental health care.

1/In April 1976, the Massachusetts Secretary of Human Services told us that the number of catchment areas had been increased to 40.

Methods for continued funding for CMHCs as Federal support declines and ultimately ends had not been established and may prove to be a difficult problem unless third-party payments increase in the future.

Oregon

Oregon's Department of Human Resources would like to establish a balance between having a statewide deinstitutionalization plan which is substantially federally funded and a program that State and local governments can maintain if there is a change in Federal fiscal priorities. For example, the Mental Health Division asked the State legislature for matching funds to establish two additional CMHCs (one in Portland) in its 1973-75 budget request, but the legislature denied the request because of the uncertainty of the continued availability of Federal funding.

Federal requirements associated with the CMHC program are too inflexible. For example, the services that CMHCs must provide are usually more than local communities are willing to develop to meet their needs.

Local communities can use State grants they receive as part of the matching funds needed for the CMHC program, but they have not shown interest in the CMHC program because they do not have the additional funds needed to participate in the program.

Nebraska

The director of one mental health clinic that was not federally funded told us that the county commissioners were afraid that they would not be able to finance the entire cost of a CMHC after the Federal funds were no longer available and therefore did not participate in the program.

Growth in mental hospital budgets

Although mental hospital resident populations have declined by more than half since 1963, admissions have increased as have State expenditures for mental hospitals. Nationally, expenditures for State mental hospitals as reported by NIMH increased from about $1.7 billion in 1968 to about $2.8 billion in 1974. Although State mental health departments have increased their expenditures for community mental health services, State institutions still generally account for the bulk of State mental health budgets. [1] For example, both Maryland and Michigan allocated 16 percent of their mental health budgets for community care in fiscal year 1974.

Faced with inflation, imposition of standards on mental hospitals, and increased admissions, States found themselves having to support increased costs at mental hospitals as well as the development of community-based programs. Although Federal funds, such as Medicaid, CMHC grants, and Comprehensive Public Health Services funds, helped, they were not enough to support both improved institutional care and development of a comprehensive system of community mental health services.

Limited coverage under Medicaid and Medicare

As explained in chapter 6, alternatives to inpatient care, such as day treatment or partial hospitalization, have just become covered under State Medicaid programs, are not covered, or were limited. In general, mental health clinics not affiliated with a general hospital have difficulty in qualifying for Medicare and Medicaid reimbursements. Outpatient services provided by mental health workers in individual and group sessions without direct supervision by a physician or psychiatrist are generally not eligible for reimbursement. According to 1975 NIMH data, less than 6 percent of the CMHCs staff were psychiatrists. NIMH believes that the maldistribution of psychiatrists among CMHCs is another hindrance to increased Medicaid funding.

As discussed in chapter 8, Medicare provides only limited coverage of outpatient services for the mentally ill.

Although Medicaid expenditures for CMHCs have been increasing, they still represent only a small portion of their funding sources. According to 1974 NIMH data, CMHC Medicaid receipts amounted to $53.6 million, or 9 percent of total receipts. This compares to about $19.7 million, or 5.7 percent, in 1972, and $8.9 million, or 3.8 percent, in 1970.

State Medicaid officials in Michigan, Maryland, and Nebraska had no current information on Medicaid expenditures for CMHCs or clinics. Oregon officials estimated that mental

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[1] This does not mean that such funds were not needed at mental hospitals to care for the patients, but only shows how the funds were used.

health clinic service costs under Medicaid amounted to $849,000 in fiscal year 1975. Massachusetts officials estimated that fiscal year 1976 Medicaid expenditures for mental health clinic services would be about $1 million.

IMPLICATIONS OF 1975 MENTAL HEALTH LEGISLATION

The Special Health Revenue Sharing Act of 1975 and the Community Mental Health Centers Amendments of 1975 strengthened the requirements of the Comprehensive Public Health Services and CMHC programs as they relate to deinstitutionalization. Implementation of this legislation should help alleviate many of the problems we identified. However, shortages of funds may severely hinder the States' abilities to meet the objectives and requirements of this legislation.

Special Health Revenue Sharing Act of 1975

This act requires States to establish and implement a plan to:

- --Eliminate inappropriate placement of persons with mental health problems in institutions, insure the availability of appropriate noninstitutional services for such persons, and improve the quality of care for those persons for whom institutional care is appropriate.

- --Assist the courts and other public and appropriate private agencies to facilitate (1) screening by CMHCs, or other appropriate entities, of State residents who are being considered for inpatient care in a mental health facility to determine if such care is necessary and (2) the provision of followup care by CMHCs or other appropriate entities for persons discharged from mental health facilities.

As required in previous legislation, the act provides that at least 15 percent of each State's allotment for comprehensive public health services be used only for the provision of mental health services and that at least 70 percent of such funds be made available for the provision of community services. During fiscal year 1975, $90 million was appropriated for comprehensive public health services. Therefore, at least $13.5 million was required to be used for mental health programs and of this amount, about $9.5 million was required to be used for community-based mental health services. However, the amount of funds available to States under this program was insufficient in relation to the State mental health budgets and to actual needs. In fiscal year 1974, for example, Maryland used $237,000 of its Comprehensive Public Health Service funds for mental health, while the State's Mental Hygiene Administration budget was $65.1 million.

Community Mental Health Centers Amendments of 1975

These amendments require CMHCs to provide seven new services in addition to the five previously required. Three of the newly required services are screening, transitional halfway house services, and followup care for residents of their catchment areas who have been discharged from a mental health facility.

CMHCs must help courts and other public agencies screen residents of the center's catchment area who are being considered for referral to a State mental health facility for inpatient treatment. They must also provide, where appropriate, treatment at the center as an alternative to inpatient treatment at the State facility. Transitional halfway house services are to include services for both those who have been discharged from a mental health facility or who would, without such services, require inpatient care in such a facility. CMHCs must also coordinate their services with those provided by other health and social service agencies.

Potential complications in funding halfway house services

One potential problem facing CMHCs in implementing the 1975 amendments is restrictions relating to the use of Medicaid and SSI funds to help provide the newly mandated transitional halfway house services for the mentally ill.

HEW regulations generally prohibit payment of SSI to persons in publicly operated institutions. 1/ Of the 603 CMHCs funded as of November 1975, 283, or 47 percent, were publicly sponsored. Therefore, these 283 CMHCs would have to contract with a private organization to run their halfway houses so that their residents could be entitled to SSI. Also, to be eligible for SSI, persons who are not 65 or older must have a total disability expected to last at least 1 year. Therefore, mentally ill persons who have disabilities that are not total and not expected to last 1 year are not entitled to SSI.

1/If a least 50 percent of the cost of a person's care in a public institution is supported by Medicaid, he or she can receive up to $25 each month under SSI. In October 1976, SSI was authorized for persons in certain public facilities. (See p. 132.)

Mentally ill persons under 65 are not eligible for Medicaid in institutions for mental diseases, except for those persons under 21 in accredited psychiatric facilities. Since a halfway house for the mentally ill would be considered an institution for mental diseases under HEW regulations, mentally ill persons under 65 would not be entitled to Medicaid in such facilities. Such persons, however, might qualify for Medicaid reimbursement if they were in an SNF or ICF in which less than half of the patients or residents were mentally ill.

CHAPTER 6

IMPACT OF MEDICAID ON DEINSTITUTIONALIZATION

Medicaid is one of the largest single purchasers of mental health care and the principal Federal program funding the long-term care of the mentally disabled. According to the Medical Services Administration, more than $1 billion annually is spent under Medicaid for the care of mentally disabled persons. It appears to have been the most important federally sponsored program affecting deinstitutionalization.

Medicaid has had a positive impact on the care of the mentally disabled by imposing minimum requirements on the quality of care provided in mental institutions and skilled nursing and intermediate care facilities and requiring that such facilities take steps to make sure that arrangements were made for postrelease care. Federal reimbursements under Medicaid have also made additional funds available to the States to improve the quality of care and to develop community alternatives to institutional care.

On the other hand, the funding available under Medicaid for SNF and ICF care, coupled with the lack of alternatives, has heavily influenced the placement of the mentally disabled into such facilities. In many instances, SNFs and ICFs were not prepared to meet the special needs of the mentally disabled or were not the most appropriate setting for the persons placed. Persons were also being released from mental hospitals and institutions for the retarded to SNFs and ICFs, and to other settings, without any release plan, with an incomplete plan, or without adequate provision for followup services.

HEW has initiated a major effort to upgrade SNFs and ICFs and the quality of care they provide. HEW's efforts, however, have generally not addressed the special needs of the mentally disabled in these facilities. HEW officials said that additional efforts aimed at the mentally disabled were needed. HEW can help solve some of the problems by emphasizing and more systematically monitoring, evaluating, and enforcing Medicaid requirements relating to deinstitutionalization and by integrating related requirements in Medicaid and in other programs. Specifically, HEW should make certain that (1) States covering persons 65 years of age of older in mental hospitals under Medicaid develop and effectively implement comprehensive mental health programs for persons of all ages, (2) SNFs and ICFs with mentally disabled persons are capable of providing for their specialized needs, (3) States effectively implement utilization control programs (see ch. 7), (4) discharge planning and other continuity of care requirements for mental hospitals and institutions for the retarded are sufficient, clear, consistent, and met, and (5) interagency agreements required by Medicaid regulations between such agencies as mental health, public health, vocational rehabilitation, and public welfare adequately address deinstitutionalization and are effectively implemented.

HEW needs to assess how its standards for institutions for the mentally retarded participating in Medicaid affect States' ability to continue to develop community resources for persons inappropriately placed in such facilities or who risk being admitted therein. Facilities must fully comply with these standards by March 18, 1977. The cost to attain compliance is estimated to be substantial. National policy decisions may have to be made regarding how to allocate funds between improving public institutions versus developing community alternatives when legislation and courts are mandating community-based care and when superintendents of public institutions believe that many residents in such facilities could be treated in the community if appropriate resources existed.

THE MEDICAID PROGRAM

Medicaid is a federally sponsored program which assists States financially to help them provide health and rehabilitative services to the needy, including the mentally disabled. Under Medicaid, the Government reimburses the States for between 50 and 78 percent [1] of allowable costs of providing such services to eligible persons. Within certain limits, each State may define the extent of benefits it will provide under its Medicaid program and to whom it will provide various services.

Coverage of the mentally disabled

Inpatient mental hospital and residential care in institutions for the retarded are optional services under Medicaid. The Congress authorized such care to improve the quality of care in such facilities to help mentally disabled persons attain their maximum potential and, in particular, to help them return to the community.

Medicaid coverage for the mentally disabled has expanded considerably. For example, in 1965, when Medicaid

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[1] Effective July 1, 1975, the maximum rate decreased from 81 percent.

was enacted, the Congress authorized Federal reimbursements for inpatient mental hospital care for persons 65 or older. In 1971 the Congress authorized Medicaid to cover ICF services, including services in institutions for retarded persons. In 1972 States were authorized to receive Federal assistance for inpatient mental hospital care for persons under 21.

As of August 1, 1975, State Medicaid programs (including the District of Columbia's) covered the following:

Services	No. of States
Inpatient care in institutions for mental diseases--persons 65 or older	42
Inpatient care in psychiatric facilities--persons under 21	27
ICF--institutions for the mentally retarded	38
Mental health clinic	Not available
Prescribed drugs	48

Medicaid legislation limits inpatient care in mental hospitals to persons 65 or older or under 21. All eligible persons, including those between 21 and 65, can receive inpatient psychiatric services in general hospitals.

No federally imposed age restrictions apply to Medicaid coverage of persons in public institutions for the retarded. SNF and ICF services in institutions for mental diseases are limited to persons 65 or older.

Administration by HEW

At the Federal level, the Social and Rehabilitation Service is responsible for administering the Medicaid program. Within SRS, MSA is the principal organization involved in the program's daily operation. However, as shown below, other agencies have key responsibilities relating to the Medicaid program.

--The Office of Long Term care is HEW's focal point for long-term care. It provides policy direction and coordinates HEW's standards enforcement activities in SNFs and ICFs, including institutions for the retarded, but not mental hospitals.

--Offices of Long-Term Care Standards Enforcement in HEW's regional offices are responsible for monitoring State agencies' approval and certification of SNFs and ICFs to participate in Medicaid. This includes institutions for the retarded, but not mental hospitals.

--Special initiatives units in HEW's regional offices were responsible for onsite evaluations and otherwise monitoring State utilization control programs for mental hospitals, SNFs, and ICFs, including institutions for the retarded. (During our review, MSA assumed this responsibility.)

--The Bureau of Health Insurance (BHI), Social Security Administration, is responsible for administering the Medicare program. To participate in Medicaid, mental hospitals serving persons 65 or older must meet Medicare requirements as well as special Medicaid requirements. BHI has certain responsibilities for monitoring State agencies which survey and certify providers of care under Medicare.

--NIMH is responsible for providing leadership in the mental health field. This includes helping BHI and MSA develop standards for mental health care under Medicare and Medicaid.

--The Bureau of Quality Assurance, Health Services Administration, is responsible for (1) providing national leadership to assure that health services under Medicare and Medicaid are medically necessary and furnished as economically as possible, (2) developing quality assurance standards and policies and coordinating and evaluating their implementation, and (3) developing conditions and standards of participation relating to quality of care for service providers under Medicare and Medicaid.

--The Developmental Disabilities Office provides technical assistance on matters dealing with the mentally retarded, such as the development and enforcement of standards for institutions for the mentally retarded.

DEVELOPMENT OF ALTERNATIVES TO MENTAL INSTITUTIONS UNDER MEDICAID

HEW regulations require States providing inpatient mental hospital care to persons 65 or older under Medicaid to show that they are making satisfactory progress toward developing and implementing a comprehensive mental health program for persons of all ages through use of appropriate mental health and public welfare resources, including CMHCs, nursing homes, and other alternatives to care in public institutions. These States must submit annual progress reports to HEW. States have not been submitting these reports, however, because HEW has not been enforcing the requirements.

Similar requirements do not apply for those retarded in institutions who are covered by Medicaid. However, HEW regulations require that States document the unavailability of community resources and initiate plans for actively exploring alternatives when persons whose needs might be met through alternative services unavailable at placement are placed in ICFs, including those for the retarded.

The principal alternatives to institutional care developed under the Medicaid programs have been SNFs and ICFs. (See ch. 2.) Many mentally disabled persons have been placed in these facilities without provision for needed services and because they were the only available alternatives, although they were frequently not the most appropriate. Development of alternatives to public institutional care has been limited.

Mental health clinic services

Current information on the extent to which States included mental health clinic services in their Medicaid programs was not available at MSA. Although all five States we reviewed included such services under their Medicaid programs, the extent of coverage was limited.

Generally, mental health clinic services under Medicaid were not available in the States we reviewed until recently. Also, coverage under Medicaid was generally limited to a relatively small number of providers. For example, only 3 of Maryland's 32 mental health clinics and 3 of its 6 CMHCs with Federal staffing grants were providers under Medicaid. Only 4 of Nebraska's 12 mental health centers were providers under Medicaid.

Day care

None of the five States funded nonmedical day care for the retarded under Medicaid. Three States included day care for the mentally ill under Medicaid; however, coverage was limited. In Nebraska and Michigan, for example, day care for the mentally ill was covered only in clinics affiliated with hospitals. Officials in the three States including day care in their Medicaid programs said that funding for such care was not substantial.

Nebraska's coverage of day care under Medicaid appeared to provide some incentives for outpatient care, even though such coverage was limited. Day care for the mentally ill was available under Medicaid only when provided in a hospital under the supervision of a physician or psychiatrist. Day care (or night care) could be provided for up to 60 days in any 12-month period. However, Nebraska limited inpatient care and day or night care to a maximum of 30 days in any 12-month period. Two days of day or night care are counted as 1 day of inpatient care. Therefore, a person could receive up to 60 days of day or night care. 30 days of inpatient hospital care, or any combination of these as long as the total number of days did not exceed the equivalent of 30 days of inpatient care.

MSA has informed us that Nebraska's limitations on inpatient and outpatient hospital psychiatric care under Medicaid are contrary to HEW regulations. These regulations prohibit the arbitrary denial or reduction in the amount, duration, or scope of required services to eligible persons solely because of their diagnosis, type of illness, or condition. MSA said that it was taking action to make certain that the State complies with this prohibition.

Officials in Oregon and Maryland--two States not covering day care--told us they believed day care was important to deinstitutionalization. Maryland Medicaid and Mental Health Administration officials said day care services were not covered because State matching funds were not available. However, Mental Health Administration officials believed it was necessary to develop a statewide system of health-related day care programs if the State's deinstitutionalization efforts were to be successful. Moreover, they stated that they were developing day care regulations that would qualify under Medicaid.

Oregon's Mental Health Division identified day treatment as one of the highest priority service alternatives to State hospitals. Public welfare officials noted that the coverage of day care in hospitals and clinics was requested in the agency's 1973-75 biennium budget, but was not approved. The Administrator for Public Welfare noted in a justification for the request that many other programs could fail without additional day-treatment support, resulting in increased hospitalization costs. The mental health liaison official in public welfare stated that additional day care programs were crucial for moving ahead with deinstitutionalization of the severely mentally disabled.

Small residential facilities

HEW's ICF regulations include a number of incentives to encourage participation by small, community-based group homes as an alternative to institutional care, particularly for the retarded. For example, ICFs of 15 beds or less can apply the less stringent residential, rather than the institutional, requirements of the Life Safety Code. In addition, regulations allow for a modified nursing personnel requirement and allow ICFs to obtain health and rehabilitation services for residents through community resources rather than requiring them to provide all such services within the facility.

Officials in the 5 States we reviewed said that ICFs of 15 beds or less for the retarded had not been developed in their States despite the availability of Federal matching funds. 1/ The reasons they gave for this are that the (1) requirements were too medically oriented in relation to the needs of many retarded persons and would not provide a normal living environment, (2) regulations were confusing and they did not understand the requirements, or (3) overhead costs of operating a facility with less than 16 persons that would meet all the requirements would be too high.

HEW regulations define an ICF as a facility providing health-related services on a regular basis to persons who, because of their physical or mental condition, require services above the level of room and board, but below the level of care and treatment hospitals or SNFs can provide The regulations further provide that ICF services may include services in public institutions for the retarded if, among other factors, the primary purpose of the institution is to provide health or rehabilitative services to the retarded that meet standards prescribed by the Secretary.

We did not evaluate in detail the impact HEW's ICF regulations had on the establishment or use of small, community-based ICFs as an alternative to large, public institutional or nursing home care. However, the MSA Commissioner stated that (1) Medicaid was a "medical assistance" program, (2) the requirements for the small ICFs should be medically oriented, and (3) those persons who do not need "medical" care or supervision should not be covered under the program. Thus, he believed that the regulatory requirements were not too stringent or too medically oriented.

A Developmental Disabilities Office official informed us that she agreed with the States' contentions concerning the

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1/Subsequently, we noted that Maryland had 1 ICF for the retarded with less than 15 beds.

regulations' complexity and could understand how they could be confused about the requirements. She believed that if State officials fully understood the requirements, they might not have been so reluctant to develop ICFs of 15 beds or less for the retarded. She also agreed that HEW needed to clarify the requirements for the States. The Special Assistant to the Secretary for Long-Term Care also agreed that the regulations pertaining to ICFs of 15 beds or less are confusing and need to be clarified.

Home health care

In July 1974 we reported to the Congress on problems associated with the use of home health care benefits under Medicare and Medicaid as alternatives to institutional care. 1/ In general, home health care was not an effective alternative to institutional care because of low reimbursement rates, program restrictions, limited usage, ambiguities in regulations, and other reasons. A detailed assessment of home health care benefits under Medicaid and Medicare was not included in this review. However, we do discuss the impact of home health care benefits on the mentally disabled.

Home health care services under Medicare and Medicaid appear to be more oriented toward persons with physical impairments than mental illness or retardation. Some States were applying eligibility criteria under the Medicare program to persons in the Medicaid program. Under Medicare, home health services are limited to persons confined to their homes and needing skilled nursing care, or physical or speech therapy, on a part-time or intermittent basis. Inasmuch as mentally disabled persons without physical impairments would not necessarily be confined to their homes, they would not be entitled to home health services in those States which applied Medicare criteria under their Medicaid programs.

In August 1975 HEW published proposed regulations for home health services under Medicaid to remove certain restrictions and ambiguities which had prevented full realization of the benefits of home health services. The proposed regulations would require States to make nursing and home health aide services and medical supplies and equipment available under Medicaid and would allow them to cover speech therapy as optional home health services. As of September 1976, final regulations had not been published.

1/ "Home Health Care Benefits Under Medicare and Medicaid," B-164031(3), July 9, 1974.

PROBLEMS WITH SNF AND ICF PLACEMENTS

HEW's regulations provide that ICFs can accept only those persons whose needs they can meet either directly or in cooperation with community resources or other providers of care. In addition to rehabilitative nursing services, HEW's regulations require SNFs to provide, or arrange for, specialized rehabilitative services as needed by their patients to improve and maintain functioning. In August 1974 MSA distributed a memorandum to State Medicaid agencies and to HEW regional offices concerning the placement of retarded persons in ICFs and SNFs.

This memorandum stated that:

--Some States were beginning to transfer residents of State institutions for retarded persons to ICFs which primarily serve the elderly.

--Mentally retarded persons must be carefully evaluated before being admitted to an ICF, and placement of a mentally retarded person in an ICF geared to provide care primarily for the aged will nearly always violate regulations, jeopardizing the facility's certification.

--The importance of carefully examining the placement of the mentally retarded in ICFs should be communicated to State survey agencies and proper implementation of requirements for an onsite inspection by an independent review team at least annually should assure that a person's health and rehabilitation needs can be adequately met by the ICF.

--Mentally retarded persons have sometimes been placed in SNFs where their special needs, other than for nursing services, were overlooked.

As illustrated in chapter 2, many mentally disabled persons have been placed in substandard SNFs or ICFs or without provision for needed services. Although HEW cautioned the States about this practice, it had not systematically monitored or enforced its requirements relating to the placement of mentally disabled persons in SNFs and ICFs.

Taking beds needed by others

Placing large numbers of formerly institutionalized mentally disabled persons in nursing homes precludes other persons needing care in such facilities from being admitted.

For example, in Massachusetts we noted that physically ill persons have had to remain hospitalized longer than necessary because beds in nursing homes were not available. Thus, greater amounts of Medicaid funds have been expended than would otherwise be necessary had the persons been placed in such facilities sooner.

The nursing home ombudsman in Oregon told us that a similar problem existed there. She said there was a shortage of nursing home beds and that many mentally disabled persons had been placed in facilities which were not equipped to handle their special needs. As a result, other persons needing care in such facilities could not get in.

Potential violation of Medicaid restrictions

We did not make a detailed assessment of the requirements for such placements. However, we found that some mentally ill persons under 65 had been placed in ICFs or SNFs in which more than 50 percent of the patients or residents were mentally ill. Federal Medicaid funds may have been improperly claimed for some of these persons.

Federal legislation and HEW's regulations prohibit use of Federal Medicaid funds for any person under 65 in an institution for mental diseases, except for those persons under 21 in accredited psychiatric facilities. HEW regulations define an institution for mental diseases as a facility which is "primarily" engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services. MSA has defined institutions "primarily" providing care for persons with mental diseases as those which (1) are so licensed, (2) advertise as such, or (3) have more than 50 percent of their residents or patients with mental diseases. MSA has also stated that, in some cases, facilities with less than 50 percent of their patients mentally ill could be considered institutions for mental diseases.

Sixty percent of the residents of 1 ICF we visited in Maryland were diagnosed as mentally ill and 59 of these mentally ill residents were under 65. The facility may therefore not have been entitled to Federal Medicaid reimbursements for the residents under 65.

Some NIMH officials believe that the statutory prohibition against using Federal Medicaid funds for persons under 65 in SNFs and ICFs which meet the definition of an institution for mental disease hinders deinstitutionalization.

They believe that limiting the number of mentally ill persons that can reside in SNFs and ICFs hinders the facilities' development of appropriate programs for such persons.

An HEW study in one State in February 1975 found that the State had licensed a special category of SNFs solely for the mentally ill. The HEW team visited three such facilities and found that many of the patients were under 65. At 1 facility, for example, the team found that there were 76 patients between the ages of 18 and 91, with an average age of 30. Almost all of the patients were Medicaid recipients.

More efforts needed by HEW to identify inappropriate placements

HEW was generally not making concerted efforts in the five regions we reviewed to identify the inappropriate placement of mentally disabled in SNFs or ICFs. MSA and OLTC officials told us that mental health had not been a priority under Medicaid because of lack of staff, other priorities, and insufficient training in the mental health area. The Director, OLTC, said she believed that more monitoring and enforcement efforts were needed by HEW in the mental health area but the regional office staffs generally did not have sufficient training to do this. She said that training funds had been requested from MSA but that they were not available.

We also met with MSA staff and the MSA Commissioner to discuss the placement of mentally ill persons under 65 in SNFs and ICFs that had more than 50 percent mentally ill patients or residents. An MSA staff member told us that this situation apparently existed in several States. The MSA Commissioner stated that this problem had not been examined because staff was not available.

In November 1975 MSA instructed the HEW regional offices to make a preliminary assessment of the problem. The instruction stated that it had come to MSA's attention, through recent regional office findings and a GAO review, that Federal Medicaid funds may have been improperly claimed for persons under 65 in institutions (SNFs and ICFs) for mental diseases. The instruction stated that, to the extent that this had been or was being done, there was a serious potential for sizable audit exceptions. It further stated that, in some instances, facilities may be "primarily" concerned with mentally ill persons because they concentrate on managing patients with behavior or functional disorders and are used largely as an alternative care facility for mental hospitals, even if less than 50 percent of the patients or residents are mentally ill.

IMPROVEMENTS NEEDED IN RELEASE PLANNING, REFERRAL, AND FOLLOWUP

Many persons have been released from State mental hospitals and institutions for the retarded without (1) adequate plans, (2) provisions for needed followup services, (3) assurances that prescribed services were obtained, and (4) clear identification of responsibility for care or followup in the community. HEW regulations require release plans for each patient or resident of mental hospitals and institutions for the retarded participating in Medicaid and Medicare. The Joint Commission on Accreditation of Hospitals standards for mental hospitals and institutions for the retarded also require release plans. Release plans must generally include provision for appropriate services, protective supervision, and followup in the community.

HEW needs to (1) strengthen, clarify, and make more consistent its release-planning requirements and (2) make more concerted efforts to monitor, evaluate, and enforce compliance with such requirements. Also, HEW should help the States develop and implement (1) systematic release planning, referral, and followup procedures for persons being released from institutions and (2) effective coordination among federally supported programs to insure smooth transitions from institutions to the community and adequate followup. Although Medicaid does not cover the cost of caring for all persons served by mental hospitals and institutions for the retarded, we believe that these actions would induce the States to improve release planning, referral, and followup procedures for all persons being placed in the community.

Specific needs of persons being released not identified

Release plans were usually prepared but they were not comprehensive. However, there were persons who were released from mental hospitals or institutions for the retarded without any release plan. Some examples follow.

Massachusetts

In Massachusetts, the Departments of Mental Health and Public Welfare entered into an agreement under which the former would prepare plans for persons to be released from public institutions. These plans were to identify each person's comprehensive needs in the community. Despite this agreement, the comprehensive needs of persons being released from the State mental hospital we visited were not identified in the release plans. Hospital officials told us that they did not identify patients' comprehensive needs because, in most cases, some of the needed services were not available. Therefore, they thought there was no point in including such information.

However, as a result, some patients were not being referred to the State vocational rehabilitation agency to determine if they were suitable candidates for such services. For example, the hospital staff could not explain why some of the persons in our sample had not been referred for vocational training. One caseworker said that his patient was a suitable candidate for such a referral.

At the State institution for the retarded, we found that release plans had not been prepared. Background data on the resident, such as a brief social history and level of retardation, was provided to the agency or facility to which the person was referred. The residents' specific service needs in the community were not identified.

Nebraska

In Nebraska written release plans usually were not prepared at the State institutions we visited. State Medicaid officials said they had not believed it was their responsibility to require written release plans. However, they said such plans would be required in the future.

In May 1975 an interagency committee studying problems associated with deinstitutionalization of the retarded in Nebraska recommended that:

--Staff at the institutions making community placements or at community-based programs develop a complete programmatic need profile for each person.

--The needs profile be transmitted to the appropriate local office of mental retardation and the appropriate staff in the welfare department.

--The institution staff, the welfare department, and the local office of mental retardation jointly determine that the programmed needs are available at the suggested home or community program and that all parties are willing and able to provide the necessary services.

Maryland

Staffs at the public institutions we visited in Maryland were identifying some, but not all, of the needs of persons being released. Staff and officials told us that they identified only those needs for which they knew community services were available.

At the mental hospital we visited, release plans for the patients we traced identified only primary health-related service needs, such as therapy and medication, and referral points, such as clinics or day care centers. For instance, social services had been recommended for only 1 of 58 patients we traced. However, we determined that 22 of the 58 persons had either applied for or were provided social services by the social services department in the county to which they were released. Social services had not been identified as a postinstitutional service need for any of the 22 patients.

Identifying the needs of persons returning to the community would better assure that needs for which services might be available are not overlooked and would help to identify what facilities and services need to be developed.

Referral procedures

Procedures for referring persons being released from public institutions varied considerably. Some referrals were made by telephone, some by written notices to the agency to which the person was being referred, and some during release planning conferences between staff from other agencies and the institution. The agency to which an institution referred a person was usually aware that he or she had been referred.

The most frequent breakdown in the referral process was in Maryland. The mental hospital we visited did not have a formal procedure for referring patients to county mental health clinics. Although a representative from a county clinic usually attended release planning conferences at the mental hospital, only 8 of the 47 patients we traced who were recommended for mental health clinic services went to the clinics. The clinics had records on only 5 of the remaining 39 patients. Therefore, according to clinic officials, 34 of the 47 patients had not received their recommended aftercare services.

Followup

Information on what happened to former mental hospital patients and residents in institutions for the retarded was generally not available. Followup of released persons was generally haphazard, fragmented, or nonexistent. Without adequate followup, States had no assurance that community placements were appropriate to the person's needs and that those needs were being met satisfactorily, particularly so that steps could be taken to avoid unnecessary readmission.

Some of the reasons given for the lack of followup were:

--The large number of agencies involved in providing services to released persons made followup difficult.

--The responsibility for determining the type of followup to be performed by the institution staff and the staffs of other agencies was not clearly defined.

--Followup staff was not available at institutions and other agencies.

Oregon

Followup of former institutionalized persons in Oregon has been limited. State institutions only followed up in cases where mentally retarded persons had been released on a trial-visit status. Much of the followup responsibility has been placed with community agencies, but their efforts have been limited. No single agency appeared to be exercising overall responsibility for assuring that the different agency efforts were meeting the person's needs.

Oregon Mental Health Division officials said they believed that local mental health clinics or other agencies, and not State mental hospitals, were responsible for followup. The director of social services at the State mental hospital we visited said that a number of the mentally ill patients they refer to county clinics never show up.

Clinic officials in two counties said that when hospital patients fail to keep appointments, they generally try to contact them once or twice by phone or mail to reschedule the appointment. More intensive efforts were sometimes made for patients who kept initial appointments. The director of one county mental health program told us that the county clinics had not taken an aggressive followup role because they could provide only limited services. The supervisor of one community clinic in the county noted that clinic staff rarely had the time to make followup visits.

We found that 13 of 49 persons referred to mental health clinics were not receiving services there. Of the 13, the clinics showed no referral record for 5; a referral record for 3 but no followup; an inability to locate 2; and 3 who refused services.

For the mentally retarded, the extent of followup for persons released from the State institution we visited depended on the type of release. The State institution was responsible for the followup of persons placed in the community on a trial-visit status. The institution's staff said they made periodic reviews and evaluations of each person's progress while they were in such a status. We were told that in two counties, the institution's normal followup procedure was supplemented by weekly meetings at group homes, activity centers, and workshops. Representatives from the institution and the public welfare and vocational rehabilitation agencies participated in these meetings.

Followup for retarded persons discharged directly from State institutions or after a trial visit in the community was not so systematic. The Mental Health Division, however, had placed service coordinators in the community to provide followup on mentally retarded persons discharged from State institutions and was increasing the number of such coordinators. Our visits to three counties, however, showed that they had been unable to provide followup services to many retarded persons who had been discharged in their counties.

One county service coordinator said that she did not have the time and was not kept informed about who had been discharged to her county. A service coordinator in another county said she had a list of 218 persons discharged from the institution and placed in her county, but she didn't know what happened to them because she only had time to followup problem cases that came to her attention.

Other agencies, such as public welfare, vocational rehabilitation, and employment, were also providing only limited followup. For example, Oregon's Employment Division staff said they were responsible for followup for 30 to 45 days after they placed a person into a job, but this was not long enough. They believed that longer followup by mental health personnel was needed and could greatly increase the chances for employment success but that such followup was infrequent.

Michigan

The extent of followup of mentally disabled persons released from State institutions varied considerably.

In Detroit, persons placed in homes operated under contract with the Department of Mental Health were visited periodically. However, many persons placed in homes supervised by the Department of Social Services were not. The difference was attributable to the size of the agency workers' caseloads.

Caseworkers responsible for persons placed in homes operated under contract with the Department of Mental Health had relatively small caseloads, usually 25 to 35 clients. However, the average caseload for each Department of Social Services caseworker was about 200 for adult foster homes and 1,400 for nursing homes.

Mentally retarded persons we traced who were released to the Macomb-Oakland Regional Center were receiving periodic followup. The Center developed a system to assure the continued development of its clients. Each social worker was responsible for 25 to 50 clients, depending on the type of home the client was in.

Need for clarifying and strengthening regulations

Adequate release plans and followup are important to make sure that (1) needs are identified and arranged for, (2) roles and responsibilities are clearly identified, and (3) community facilities and services continue to fill people's needs. In addition, release plans specifying the needs of persons in the community would help to determine which facilities and services need to be developed. A comparison of the needs identified in such plans with available facilities and services would also help determine the need for and desirability and feasibility of community placement. (See ch. 7.)

Medicaid regulations for release planning and followup vary by type of facility. Because mental hospitals serving persons 65 or older must meet Medicare standards to participate in Medicaid, release planning and followup requirements under Medicare also apply to mental hospitals participating in Medicaid. In addition, JCAH standards are applicable to mental hospitals under Medicare and Medicaid. We reviewed program regulations, guidelines, instructions, and standards to determine the extent to which they identified the specific release-planning and followup requirements for mental hospitals, institutions for the retarded, and SNFs under Medicaid and Medicare. (See app. II.) We also reviewed individual service plan requirements of several other HEW programs. (See app. III.)

Some of our observations follow.

--Regulations and standards for mental hospitals and institutions for the retarded do not specify (1) that release plans identify the needs persons will have in the community, (2) what constitutes acceptable followup arrangements, or (3) who will be responsible for implementation and followup.

--Regulations for SNFs contain more specific requirements for release planning than the regulations for mental hospitals and institutions for the retarded.

--Medicaid guidelines for mental hospitals and institutions for the retarded contain additional information on discharge planning and followup, but are not as specific as those for SNFs.

--Instructions to surveyors and reviewers of mental hospitals and institutions for the retarded do not sufficiently specify what aspects of release plans and followup should be reviewed. Surveyors and reviewers of SNFs, however, have more specific instructions. A training manual for surveyors of institutions for the retarded specify detailed requirements for release planning and followup, but as indicated on page 100, apparently cannot be enforced because the regulations are not specific enough.

--Requirements for individual program plans and followup for some other programs specify steps which, if adopted for Medicare and Medicaid, would appear to help resolve some of the problems we identified. For example, individual plans under the Developmental Disabilities and Education for the Handicapped programs must specify who is responsible for implementation.

Because of the differences in discharge-planning and followup requirements and the need for clarifying program regulations for mental hospitals and institutions for the retarded as to what constitutes acceptable release plans and followup arrangements, we contacted several HEW officials and program staff and reviewed release-planning standards imposed on States by Federal courts.

HEW officials we contacted in OLTC, MSA, the Health Resources Administration, the Bureau of Quality Assurance, NIMH, and DDO stated that discharge plans should identify all of the specific needs of persons being released from mental hospitals and institutions for the retarded. Some of their statements are shown below.

Agency	
MSA-Division of Policy and Standards	State surveyors and HEW personnel monitoring the compliance of mental hospitals and institutions for the retarded would have to use their judgment in determining whether discharge plans meet regulatory requirements, since the regulations do not specify their content. It was intended that postinstitutionalization plans identify all the person's needs in the community, regardless of the availability of services.
Bureau of Quality Assurance-Division of Provider Standards and Certification	The key to successful release is proper planning. Discharge plans should identify all services a person will need to remain in the community and should be based on the same type of interdisciplinary evaluation required on admission to a mental hospital or institution for the retarded. HEW's regulations should more specifically identify the elements of an acceptable discharge plan.
NIMH-Division of Mental Health Service Programs	Research and experience point to the necessity for a comprehensive individualized assessment of the service needs of all patients before discharge in order to develop a plan for appropriate supportive and/or rehabilitative services to maintain community adjustment. The assessment should consider health, mental health, social and vocational functioning, and living arrangements and should identify services needed to enable clients to reach and maintain an optimal level of community functioning.

> The key to successful placement lies in the followup care in the community following discharge. Competent monitoring by informed and dedicated staff is about the only way that community placement succeeds. Simply referring clients from one agency to another without being sure that the necessary help is actually provided is not enough.

A Bureau of Quality Assurance training manual for surveyors evaluating institutions for the mentally retarded for participation under Medicaid states:

> "When the resident is to leave the facility, his record must describe the plans that have been made for providing all necessary services, including protective supervision and other follow-up services, in his new environment. The purpose of the post-institutional plan is to provide for an orderly transition from one living arrangement to another which continues to meet the needs of the individual and for which he has been properly prepared. While the facility may not have the responsibility to furnish the follow-up services, it does have the responsibility to arrange the continuity of services. It is not acceptable to discharge a resident with no place to live or no contacts in the community. If the resident is transferred to another facility, the discharge summary must state the needs of the resident at the time of discharge, and the capacity of the receiving facility to meet those needs must be documented."

However, a Bureau official said the surveyor's job is to determine that discharge plans are prepared, not necessarily to evaluate their adequacy. Thus, if a discharge plan identified one needed service, the surveyor would probably accept the plan. Without more specific requirements on the content of discharge plans and responsibilities for aftercare and followup, it would be hard to hold State surveyors accountable for enforcing continuity for care requirements. He believed that HEW's regulations should specify the content of discharge plans.

Standards imposed by the courts also included requirements for release planning. For example, in several cases, the court required a comprehensive assessment of each person's needs, including appropriate residential placement, a specific plan to meet those needs, and identification of the parties responsible for implementing the plans.

More monitoring, evaluation, and enforcement of discharge planning and followup requirements needed

Within HEW regional offices, several organizations are responsible for monitoring, evaluating, and enforcing discharge planning and followup requirements for mental hospitals and institutions for the mentally retarded. The organizations include MSA, the Offices of Long Term Care Standards Enforcement, BHI, and Special Initiatives Units in SRS.

However, HEW regional offices have generally not systematically evaluated the adequacy and appropriateness of discharge planning and followup for persons being released from mental hospitals and institutions for the retarded. Nor had they determined whether the interagency agreements required under Medicaid had been effectively implemented.

The reasons given for this lack of emphasis included staff shortages, lack of a mandate from HEW headquarters offices, and a low priority on mental health. For example:

--The Commissioner, MSA, said that mental health has had low priority in the Medicaid program in relation to other aspects of the program and that staffing shortages precluded MSA from devoting much effort to the mental health area. Furthermore, he stated that MSA has relied on BHI to monitor, evaluate, and enforce mental hospital compliance with standards. (See p. 119.)

--The acting director, Division of Utilization Control, MSA, told us that he had not issued instructions or guidance to HEW regional offices to make sure that HEW validation surveys of utilization controls determine whether the plan of care included a discharge plan or that discharge plans met regulatory requirements. He said that the 1974 HEW validation surveys addressed only whether there was a plan of care and whether it was updated as required. [1]

--The acting associate director, OLTC, said that no specific instructions were issued to regional Offices of Long Term Care Standards Enforcement on evaluating discharge plans at institutions for the retarded to make sure they were appropriate to the individual's needs. OLTC officials said that more emphasis was

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[1] The 1974 validation surveys were the most recent that had been done at the time of our review.

needed on discharge planning and followup requirements in HEW validation reviews and that they would consider what additional efforts HEW could take.

Relation of Medicaid requirements to those of other programs

Other HEW programs also have requirements for individual service plans, followup, identification of responsibilities, and interagency cooperation that affect deinstitutionalization and relate to Medicaid release planning and continuity of care requirements. (See app. III.) These other programs are important to deinstitutionalization because mentally disabled persons being placed in the community may be receiving assistance from one or more of these programs in addition to or rather than Medicaid. Compliance with the requirements of these other programs is important if the objectives of various Medicaid requirements are to be achieved.

For example, persons between 21 and 65 being released from mental hospitals would not have been eligible for Medicaid as inpatients but have or may have received assistance in returning to the community under the social services, SSI, or vocational rehabilitation programs. Therefore, the requirements of the Medicaid program as well as these other programs for individual service plans, followup services, and interagency cooperation and coordination must be viewed together.

Responsibility for overall planning, protective supervision, and followup services for persons being released from mental hospitals and institutions for the retarded was frequently not clearly identified, understood, or accepted. The importance of the interrelationship of Medicaid to the other programs is illustrated by the following example:

--In Oregon several State agencies had interagency agreements affecting mentally disabled persons being discharged from public mental hospitals and institutions for the retarded. No one agency had exercised overall responsibility for insuring that the person's needs were identified or addressed and for coordinating or overseeing the care of such persons. The following State agencies, all of which received Federal funds, had responsibilities relating to deinstitutionalization: Public Welfare, Vocational Rehabilitation, Children's Services, Mental Health, Health, Education, and Employment.

IMPLICATIONS OF ICF STANDARDS

HEW regulations published in January 1974 contained two sets of standards for institutions for the mentally retarded participating in the ICF program. One set of standards was considered interim and had to be met by March 1975. The second set was more stringent and must be met by March 1977. To participate in Medicaid, institutions not in compliance with the more stringent standards as of March 1974 were required to develop and implement plans for meeting them.

Many facilities do not meet standards

According to OLTC, as of June 1976 only about 68 of 197 State institutions for the retarded whose status was reviewed were expected to fully comply with the regulations to be met by March 1977; 54 facilities, however, were expected to comply with 80 percent of the requirements. In the 5 States we reviewed, 12 of 17 facilities, or about 71 percent, were not expected to fully comply with the requirements.

Furthermore, as of January 1976 JCAH had made onsite surveys at 63 public residential facilities for the mentally retarded. It had made decisions for 61 of these facilities and had accredited only 9, or 15 percent. JCAH standards for residential facilities for the retarded are similar to HEW's standards. Many of the problems related to the facilities' physical deficiencies and the lack of individualized programing for the residents.

Because many public institutions for the retarded are old and understaffed, it has been estimated that it would be very costly to bring them into compliance with Medicaid standards. For example, a 1975 survey conducted by Texas showed that 25 States estimated that it would cost a total of about $500 million to bring their institutions for the retarded into compliance. Fifteen States indicated that their estimates were supported by cost studies; the remaining States did not indicate how their estimates were determined. Although neither we nor HEW has validated these cost estimates, HEW officials believe they are overstated because of possible overestimates of the necessary improvements.

The need for improving facilities and expanding services at public institutions when the need for facilities and services in communities is also great has national policy implications which should be explored. Many superintendents of the Nation's public institutions for the retarded believe that more than half of both their residents and those on waiting lists could be treated in the community if appropriate facilities and services existed. At least five Federal laws enacted since 1974 and several recent Federal court orders or settlements mandate or provide for the care of the mentally disabled in the least restrictive environment appropriate to their needs. The Federal Government is paying a substantial portion of the costs for the care of the retarded in public institutions. During fiscal year 1975, for example, HEW estimated that it spent $210 million for the care of persons in institutions for the retarded under Medicaid and estimates that it spent $245 million in 1976.

The expenditure of substantial funds to bring these facilities into compliance with HEW standards may adversely affect the States' ability to provide community-based services. A case in point is Nebraska. In 1975 a court settlement was made in Nebraska under which the State was to establish and implement a goal of reducing its retarded institutional population from about 1,070 to 250 within 3 years. Thus, Nebraska must simultaneously (1) improve its institution for the retarded to meet HEW's standards by March 1977 or lose Medicaid eligibility, (2) develop additional community resources to enable it to reduce its institutional population by more than 76 percent, and (3) identify and provide services to retarded persons previously placed in the community who are not receiving needed services.

Because of the need for improvements in both institutional and community care, the Federal Government will have to determine the most cost-effective and beneficial use of its resources. To do this, the following types of factors must be considered:

--What is the least restrictive environment and what services in that environment are appropriate to the needs of persons currently in institutions for the retarded (and in nursing homes)?

--What criteria are to be used to determine the least restrictive environment appropriate to a person's needs?

--What improvements will be needed in institutions for the retarded to properly care for all of the current residents, only those residents who would need to be there if appropriate facilities and services existed in communities, and those expected to need institutional care in the future?

--What additional community facilities and services will be needed to enable retarded persons to be placed and appropriately served there?

--How much and what Federal resources should be used to help the States improve their institutions and community facilities and services and what changes are needed in Federal programs to encourage the appropriate placement of persons?

--What steps can be taken to avoid the possible premature release of persons from institutions for the retarded so that they will comply with HEW staffing or other standards by March 1977?

CHAPTER 7

BETTER USE OF UTILIZATION CONTROLS COULD ASSIST IN DEINSTITUTIONALIZATION

Public institutions are caring for mentally disabled persons who don't need to be there; other persons have been placed in skilled nursing or intermediate care facilities without provision for needed services. The Social Security Act (42 U.S.C. 1396) requires States to have utilization control programs to preclude, identify, and correct such conditions and requires HEW to conduct onsite surveys to validate the programs' effectiveness. 1/ Although HEW's 1974 validation surveys identified many deficiencies in State utilization control programs, the number, scope, and nature of such surveys were not adequate to evaluate these programs' accomplishments with regard to the mentally disabled. HEW and the States can more effectively use such control programs to help implement and evaluate deinstitutionalization.

More effective utilization controls alone, however, will not necessarily result in more appropriate placements or higher quality services for the mentally disabled. Federal State, and local agencies will have to intensify efforts to develop community-based alternatives if the intended benefits of utilization controls are to be achieved.

WHAT ARE UTILIZATION CONTROLS?

Federal legislation requires that States control the utilization of services by Medicaid recipients in mental hospitals, skilled nursing facilities, and intermediate care facilities, including institutions for the mentally retarded. Federal Medicaid reimbursements for persons in facilities more than the specified number of days may be decreased by one-third in States with ineffective control programs. 2/

1/Utilization controls must be established for all Medicaid recipients in these types of facilities, not only the mentally disabled.

2/The reduction would apply for persons in SNFs and ICFs more than 60 days or in mental hospitals more than 90 days during a fiscal year.

State utilization control programs are required to include:

- --A physician's certification of each person's need for admission and recertification for continued stay at least every 60 days (90 days for mental hospital patients).
- --A plan of care for each patient or resident, established and periodically reviewed by a physician.
- --A continuous review program whereby each person's admission to and continued stay in an institution are reviewed and evaluated by professionals not directly responsible for the person's care.
- --Independent medical or professional reviews for persons in mental hospitals, skilled nursing facilities, and intermediate care facilities.

Utilization reviews are required in mental hospitals, SNFs, and ICFs, including institutions for the retarded. Independent medical reviews have been required in mental hospitals and SNFs since July 1969. Independent professional reviews have been required in ICFs since January 1972. Effective July 1, 1973, the Social Security Act was amended to strengthen the utilization control requirements and to require a reduction in Medicaid reimbursements when States did not have effective utilization control programs. The amendments required HEW to validate the effectiveness of these programs.

Although there are differences in the review processes, they were established essentially to determine the (1) necessity for each person's admission to the facility, (2) adequacy of the services available to meet the needs of the patients or residents, (3) adequacy, appropriateness, and quality of services being rendered to each person, (4) necessity and desirability of continued placement in the facility, and (5) feasibility of meeting needs through alternative services.

WHY ARE UTILIZATION CONTROLS IMPORTANT TO DEINSTITUTIONALIZATION?

Utilization controls are important to deinstitutionalization of the mentally disabled because:

--They require a comprehensive plan of care--including a discharge plan--for each person. These plans must be reviewed by independent evaluators.

--They require reviews, including independent evaluations, of (1) the need for placement in a mental hospital, SNF, and ICF, including institutions for the retarded (2) the adequacy of services to meet each patient's or resident's needs, and (3) the feasibility of meeting needs through alternative facilities or services.

--State Medicaid agencies are required to take appropriate action on the reports and recommendations of independent review teams.

--If effective, they can provide information useful to planners and other officials responsible for developing alternatives to institutional care or for providing services to the mentally disabled.

UTILIZATION CONTROLS ARE NOT ACHIEVING INTENDED RESULTS

The extent to which utilization controls were effective--improving the quality of care and appropriate placements--varied by State. Utilization controls had not been fully effective in any of the five States we reviewed. Where they have been implemented, however, they appear to have been partially successful.

Following are some of the reasons why utilization controls were not achieving their intended results:

--Utilization reviews were not made, were made improperly, or did not result in correction of deficiencies identified.

--Independent medical and professional reviews frequently were not done or were done improperly. Limited effort was being directed toward evaluating the adequacy of services for the mentally disabled in SNFs and ICFs.

--State Medicaid agencies were not always taking appropriate action in response to reports and recommendations of the independent review teams or had not established effective ways to handle differences of opinion between institutional staffs and independent teams.

--When the independent review teams identified inappropriate placements, more appropriate facilities and services frequently were not available.

--HEW's validation surveys were not devoting sufficient emphasis to the needs of the mentally disabled, were directed toward determining whether State utilization control programs had been implemented and not what they were accomplishing, and did not determine the existence or adequacy of discharge plans as part of the individual plan of care.

Utilization reviews

In Massachusetts, 8 of 15 ICFs we visited had not conducted utilization reviews. An Oregon Medicaid official indicated that utilization reviews were not expected to result in many changes in placement because of the lack of alternatives. Nebraska Medicaid officials said that utilization reviews performed by service providers do not usually determine whether persons are receiving appropriate services and rarely recommend changes in level of care. In Maryland, the most recent independent review at one State institution for the retarded found that utilization reviews had not been done for 944 of 986 Medicaid recipients. A 1974 nationwide survey of 288 SNFs sponsored by the Office of Long Term Care showed that the utilization review committees' recommendations went unheeded by 1 of every 5 facilities surveyed.

Independent reviews

No independent medical reviews had been completed in Michigan's mental hospitals until March 1975, although they had been required by HEW regulations since May 1971 and by the Social Security Act since July 1969. In its report on one State institution for the retarded, a review team member stated that the team's recommendations for level of care were not well received by the facility and were not all accepted. The report did not indicate the disposition of the recommendations or resolution of the differences in opinion.

Independent medical reviews in Maryland's mental hospitals concluded that 59 percent of the patients reviewed no longer needed psychiatric hospitalization. The most recent independent review in Maryland's largest institution for the retarded showed that of 986 Medicaid recipients, 500 were not receiving needed social services and 645 did not have an individual plan of care. [1] Also, the review team recommended alternative placement for 184 residents (19 percent of those reviewed), some to other State facilities and some to foster homes or nursing care facilities. However, neither the State Medicaid agency nor the agency responsible for conducting the reviews had explored the use of community alternatives for inappropriately placed persons. The agency performing the reviews was responsible for taking corrective action only when levels of care were determined to be less than acceptable, and the State Medicaid agency had taken no action because community alternatives were known to be unavailable.

The most recent independent professional review at an ICF in Maryland, where many of the residents were former patients in mental hospitals or residents in institutions for the retarded, recommended a change in level of care for 30 of 134 residents reviewed. The review team also found that the residents were not receiving needed social and psychiatric services.

Independent reviews in mental hospitals in Massachusetts found inappropriate placements, a need for improvements in the quality of care, and the absence of social service plans and contained recommendations for alternate placements for inappropriately placed persons. However, appropriate action in response to the review team's recommendations was not always taken, according to State public health and welfare officials because:

- --The State welfare agency was reluctant to cut off Medicaid payments to State institutions to enforce compliance.
- --The hospital superintendent who was responsible for the patient did not always agree with the review team's recommendations and effective procedures for resolving differences of opinion did not exist.
- --Appropriate community alternatives were not available.

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[1] The number of Medicaid recipients was reduced to 119 in May 1975.

The 1974 HEW onsite validation survey of the utilization control program in Massachusetts did not include mental hospitals.

As of July 1975, independent professional reviews had been done in only 3 of the approximately 600 ICFs in Massachusetts because of insufficient staff. However, additional staff has been hired. We were told that teams performing independent reviews at ICFs will not include a mental health or retardation professional despite the large number of mentally disabled in these facilities.

In Oregon, the most recent independent professional review of ICFs, including institutions for the retarded, only covered a 25-percent sample of residents and did not evaluate each resident as required by HEW. The review team's report did not identify those residents who could be placed in the community if appropriate facilities and services were available. A recent study sponsored by Oregon's Developmental Disabilities Council and done at the State's largest institution for the retarded, showed that 63 percent of the residents could be placed in the community if appropriate facilities and services existed. HEW regulations require that (1) States document cases in which persons not needing that level of care are placed into ICFs because no other alternatives existed and (2) active exploration of alternatives be initiated. Independent review teams for SNFs and ICFs in Oregon did not include a mental health professional.

The most recent independent review performed at Nebraska's State institution for the mentally retarded covered 791 Medicaid recipients. The review team recommended nursing home or other community placement for 123 residents and improvements in care or programing for 120. Of the 123 recommended for placement, 42 were subsequently released and 16 were referred for community placement. The remaining 65 persons were still in the institution at the time of our review for such reasons as lack of community alternatives, need for pre-release training, further evaluation by the institution's staff on the desirability of community placement, or disagreement by institution staff on the desirability of community placements.

The independent reviews performed at Nebraska's ICFs and SNFs were apparently not making certain that the mentally disabled were properly placed or receiving needed mental health services. A State interagency committee recognized these problems and recommended that the independent review process be used to identify and correct such situations for the retarded.

The committee also recommended that records of all retarded persons, or persons suspected of being retarded, residing in SNFs or ICFs be evaluated annually to determine whether (1) a recent programmatic review of the resident had been performed by a mental retardation professional and (2) the person's needs were being met. The committee further recommended that, where appropriate, a representative of the local Office of Mental Retardation be involved in the latter determination.

NEEDED HEW IMPROVEMENTS

HEW should (1) conduct onsite validation surveys at more mental hospitals and institutions for the retarded, (2) evaluate whether utilization controls are accomplishing intended results, (3) evaluate whether discharge plans are adequate, and (4) use mental health and mental retardation professionals, possibly in cooperation with the National Institute of Mental Health and the Developmental Disabilities Office, to validate State independent reviews of the adequacy of services and appropriateness of placement of mentally disabled persons in institutions, SNFs, and ICFs. In addition HEW should amend its regulations to require that States either (1) include mental health and mental retardation professionals on independent review teams to evaluate the adequacy of services and appropriateness of placement of mentally disabled persons in SNFs and ICFs or (2) require that independent review teams make sure that such an evaluation was done by a mental health or mental retardation professional, as appropriate, on a periodic basis.

Because the lack of community alternatives has been a major reason why the utilization control programs have not been fully effective, HEW should amend its regulations to require that relevant data obtained by independent review teams be provided to those agencies responsible for planning, developing, and providing community-based alternatives. Federal agencies administering programs that can help develop community alternatives must also take appropriate action to help provide suitable alternatives.

Limited scope of HEW validation surveys

The 1972 amendments to the Social Security Act require HEW to conduct onsite surveys to validate that States have effective utilization control programs. HEW's 1974 validation surveys were limited to determining whether the States had implemented the controls, not whether the controls were effective. Although HEW identified many deficiencies in State utilization control programs, it did not evaluate the extent of the controls' effectiveness.

For example, HEW determined whether an independent review was made for the persons sampled, but did not evaluate the review's adequacy. Therefore, HEW did not determine whether the independent review team appropriately assessed (1) the mentally disabled person's need for continued stay in the facility, (2) the desirability and feasibility of alternative placement, (3) the adequacy of services to meet the person's needs, and (4) whether discharge plans were adequate. HEW regional officials responsible for conducting validation surveys said they did not determine whether discharge plans were properly prepared.

Although many mentally disabled persons had been released from institutions to SNFs and ICFs, HEW did not devote sufficient emphasis to the mentally disabled in its validation surveys. One reason appears to be the lack of mental health or retardation professionals on the validation teams.

The information in chapter 2 indicates that independent professional reviews at State institutions for the retarded should be identifying sizable numbers of residents who are inappropriately placed or for whom alternate placement is desirable or feasible. The independent review results we evaluated, however, generally did not identify large numbers of such persons. One reason for this appears to be that independent reviewers sometimes only identified inappropriate placements or the desirability or feasibility of alternate placements when alternatives existed. Another reason may be that reviewers use different criteria to evaluate the appropriateness of placement.

Limited coverage of mental institutions

HEW's 1974 validation of States' utilization control programs included 45 public and 2 private mental hospitals.

However, mental hospitals were included in validation surveys in only 19 of the 42 States, including the District of Columbia, that covered inpatient mental hospital care in their Medicaid programs. The validation survey reports prepared by HEW's regional offices and provided to HEW headquarters identified only four States in which public institutions for the retarded were included. 1/

The regional office reports showed that HEW validation surveys identified deficiencies in the utilization and independent medical review programs for mental hospitals in 11 of the 19 States. Deficiencies included failure to (1) perform utilization and independent medical reviews, (2) perform utilization reviews for patients who were inpatients for extended time periods, and (3) include a psychiatrist or a physician skilled in diagnosing and treating mental disorders in independent medical reviews in mental hospitals. HEW found deficiencies in utilization or independent professional reviews in each State in which an institution for the retarded was identified.

Gap in utilization control regulations

HEW's utilization control regulations do not require that independent review teams for general SNFs or ICFs include a mental health or retardation professional to evaluate the adequacy of services, appropriateness of placement, or desirability and feasibility of alternative placement for the mentally disabled. State independent review teams for SNFs and ICFs did not always include a mental health or retardation professional despite the large number of mentally disabled in such facilities.

An interagency committee recognized this problem in Nebraska with respect to the retarded. The committee recommended that a mental retardation professional participate in the review of the adequacy of services for the retarded in SNFs and ICFs.

1/Public institutions for the retarded may have been included in surveys in other States but were not identified as such in the regional office reports available at HEW headquarters.

Opportunities for better use of independent review results

If independent reviews were effective, program planners and others responsible for developing or providing services to the mentally disabled in communities could better use the review results. For example, HEW regulations require that States providing Medicaid benefits to persons 65 or older in mental hospitals show that they are making satisfactory progress toward developing and implementing comprehensive mental health programs, including provision for the use of CMHCs, nursing homes, and other alternatives to care in public institutions. As previously stated, HEW has not been enforcing this requirement, but it could require States to link the results of independent medical reviews to their progress reports on developing and using community alternatives.

The results of independent reviews could also be used in administering such acts as the Community Mental Health Centers Amendments of 1975 and Special Health Revenue Sharing Act of 1975, the Developmentally Disabled Assistance and Bill of Rights Act, and the Social Services Amendments of 1974. All of these provide for the elimination of inappropriate institutional placement.

HEW regulations require that reports containing the observations, conclusions, and recommendations of independent review teams be provided to the State Medicaid agency, the facility reviewed, State agencies responsible for licensure and certification or approval of the facilities for participation under Medicaid, and to other State agencies which require such information to perform their official functions. The regulations do not specify which other agencies, such as the State developmental disabilities agency or CMHCs, are to receive such data.

Therefore, all agencies whose participation is necessary for the utilization control process to accomplish its intended results are not required to be formally a part of the process. For example, in Nebraska the office responsible for operating the State's institution for the retarded is different from the office responsible for developing community programs. According to a State Medicaid official, reports of independent review teams were not provided to the latter office.

HEW should amend its regulations to require that relevant data obtained by independent review teams be provided to those agencies responsible for planning, developing, and providing alternative facilities and services when such agencies are different than those responsible for the facilities in which persons were inappropriately placed or were not receiving needed services.

COMMENTS BY ACTING DIRECTOR, DIVISION OF UTILIZATION CONTROL

In September 1975 the acting director of the Division of Utilization Control, Medical Services Administration, told us that:

--No one had contacted him concerning the relevance of the utilization control program with regard to deinstitutionalization of the mentally disabled. Therefore, he had not viewed his program in relation to deinstitutionalization and had not developed or issued guidance or instructions to the regions on this subject.

--More emphasis was needed on mental hospitals and institutions for the retarded in HEW's validation surveys and he will consider taking steps to make sure that they are given greater coverage in the future.

--Validation surveys should cover the effectiveness of utilization controls and put more emphasis on the mentally disabled. However, the regional staffs who conducted the surveys have other responsibilities and are not mental health or retardation professionals. Therefore, this would be difficult to achieve. NIMH and DDO staff assistance would be desirable, but the implications of such assistance would have to be explored.

--Requiring that State independent review teams for nursing homes include a mental health or retardation professional, as appropriate, to evaluate the adequacy of services, appropriateness of placement, and desirability and feasibility of alternate placement for the mentally disabled would also be desirable. However, this also could have a variety of implications which need t be explored, such as where these professionals would come from.

--Agencies responsible for planning, developing, and providing community-based services for the mentally disabled should receive relevant data on the results of independent reviews. He stated that instances in which agencies responsible for community programs were different from those responsible for operating State institutions had not been considered when the utilization control regulations were developed.

CHAPTER 8

IMPACT OF MEDICARE ON DEINSTITUTIONALIZATION

Because Medicare does not cover developmental services, such as habilitation training for the mentally retarded, it has more relevance to the deinstitutionalization of the mentally ill than the retarded. Limitations on coverage of outpatient care under Medicare for the mentally ill may be resulting in unnecessary institutionalization or inpatient hospital care. Furthermore, Bureau of Health Insurance monitoring of State agency surveys of mental hospitals for compliance with Medicare standards has been limited.

PROGRAM ADMINISTRATION

Medicare is the Federal health insurance program for the aged, for persons who have been entitled to Social Security Disability Insurance for at least 24 consecutive months, and for certain others.

BHI, a part of the Social Security Administration, is the principal Federal agency responsible for administering the Medicare program, although other Federal agencies are responsible for certain aspects. Other agencies include the Office of Long Term Care, the Bureau of Quality Assurance, and the regional Offices of Long Term Care Standards Enforcement.

State agencies' responsibilities under Medicare include conducting onsite surveys at mental hospitals and other provider facilities to determine whether they meet standards. BHI is responsible for monitoring State agency activities under the program, including onsite validation surveys at provider facilities to evaluate State agencies' procedures.

COVERAGE OF MENTALLY ILL

Medicare coverage of inpatient mental hospital care is limited to 190 days during a person's lifetime. Coverage of inpatient care in psychiatric wards of general hospitals is not subject to this limitation.

Medicare coverage of outpatient mental health care is limited to half the cost or $250 annually, whichever is less. This limitation appears contrary to the deinstitutionalization objective and may be resulting in unnecessary hospitalization, according to the National Institute of Mental Health. The dollar limit has not been increased since the Medicare program was enacted in 1965 despite increases in the cost of medical care.

Data obtained from the Bureau of Labor Statistics, Department of Labor, shows that the average cost of a visit to a psychiatrist's office for 1 hour of individual psychotherapy increased 70 percent between 1965 and 1975. According to data in "Medical Economics" obtained during a 1975 survey of psychiatrists, the median office-visit charge for 1 hour of individual psychotherapy was $40. Therefore, the $250 available annually under Medicare for outpatient mental health services would purchase fewer hours of therapy in 1975 than in 1965.

LIMITED MONITORING OF MENTAL HOSPITALS

Although the Medicare program does not purchase a relatively significant amount of inpatient mental hospital care, it is important in view of its relation to the Medicaid program. Mental hospitals must meet Medicare requirements to receive Medicaid reimbursement for inpatient mental hospital care for persons 65 or older.

Under Medicare, mental hospitals must be accredited by the Joint Commission on Accreditation of Hospitals or meet equivalent standards, inpatients must receive active treatment, and the hospitals must have utilization review programs. To make sure that persons receive active treatment, HEW Medicare regulations impose two special conditions on mental hospitals relating to staffing 1/ and medical records.

The regulations require that medical records for persons receiving inpatient psychiatric services in mental hospitals include a discharge summary. The summary is to

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1/HEW regulations require mental hospitals to have staff adequate in number and qualifications to carry out an intensive and comprehensive treatment program, including professional psychiatric, medical, surgical, nursing, social work, psychological, and activities therapies.

include a recapitulation of the patient's hospitalization, recommendations from appropriate services concerning followup or aftercare, and a brief description of the patient's condition on discharge. HEW had not provided guidelines or criteria on what the aftercare plans were to contain. The preprinted report form prepared by the Social Security Administration for surveys of psychiatric hospitals merely provides for verification that discharge summaries include aftercare plans. JCAH accreditation standards for psychiatric facilities require medical records to contain a discharge summary including recommendations and arrangements for future treatment and a notation covering prescribed medications and followup programs.

Mental hospitals accredited by JCAH are deemed to meet hospital standards, but are not deemed to meet the special staffing or medical record requirements. State agencies are responsible for surveying mental hospitals to determine whether they meet these special requirements, including those relating to discharge planning.

Because Medical Services Administration officials informed us that they rely on BHI monitoring of mental hospitals under Medicare to satisfy corresponding Medicaid requirements, monitoring and enforcement of mental hospital requirements under Medicare is especially important. However, BHI monitoring has been limited.

Comprehensive program reviews

BHI regional representatives are required to conduct comprehensive reviews of the effectiveness of State agencies' activities, including the agencies' surveys and certifications of facilities for Medicare participation. These reviews generally must be made every 18 months and must include onsite assessments of State agency surveys at the facilities.

We were informed by a representative of the Division of State Operations, BHI, SSA headquarters, that few mental hospitals had been included in BHI's evaluations of State agency surveys. A BHI representative in Region I said that BHI had not evaluated State agencies' surveys and certifications of mental hospitals because it did not have any expertise in the mental health area.

NIMH assistance program

BHI recognized as early as 1969 that greater assurance of mental hospital compliance with Medicare standards was needed. At BHI's request, NIMH established a program in June 1970 for assuring that mental hospitals participating in Medicare meet the special requirements for medical records and staffing. NIMH and BHI agreed that NIMH would hire and train consultants and provide staff to survey mental hospitals for this purpose. The agreement also called for NIMH to occasionally look into other requirements, such as those for utilization review. BHI reimburses NIMH for its costs in carrying out the agreement. Each NIMH review team includes a psychiatrist and a psychiatric nurse. A social worker is included if problems are anticipated in that area. Reviews are done either by NIMH personnel, consultants, or a combination of NIMH personnel and consultants.

Limited coverage under the program

The number of NIMH surveys has increased since fiscal year 1971 as follows:

Fiscal year	Hospitals	States
1971	21	12
1972	38	a/16
1973	37	b/15
1974	62	a/16
1975	85	a/21

a/Includes the District of Columbia.

b/ Includes the District of Columbia and Puerto Rico.

NIMH expects to survey 100 mental hospitals in fiscal year 1976. NIMH, however, usually surveys mental hospitals only at the States' request. As of October 1975, NIMH had not surveyed any public mental hospitals in 15 States. According to NIMH data, it had surveyed less than 100 of the 210 public mental hospitals certified under Medicare as of April 1975. Of those States NIMH had surveyed, it had not been to mental hospitals in seven States since fiscal year 1972 and had not been to an additional six since fiscal year 1973. Often there were no followup reviews to determine whether deficiencies found by NIMH had been corrected. Therefore, NIMH and BHI frequently did not have first-hand information on the extent to which noncompliance items were corrected. NIMH and BHI have recognized this problem and are exploring ways to resolve it.

According to a BHI representative, BHI has been trying to encourage more States to request reviews by NIMH or its consultants, but has met with State resistance. BHI headquarters has also been trying to encourage its regional offices to include more mental hospitals in comprehensive program reviews when States refuse to request an NIMH review. According to the BHI representative, BHI has been able to get some regional offices to include mental hospitals in comprehensive program reviews, but more coverage is needed. The representative also said that more emphasis had not been placed on mental hospitals by BHI because of its lack of staff with mental health expertise and because mental hospitals accounted for only a small portion of the Medicare program.

More emphasis on discharge planning needed

NIMH personnel told us that, although its reviewers determine whether discharge summaries and aftercare plans are prepared, usually they do not evaluate the adequacy of the summaries and plans in relation to the persons' needs but only determine whether a referral was documented. Two NIMH review team members told us that most of the discharge summaries and aftercare plans they had reviewed did not contain much detail on the aftercare services needed.

NIMH plans to study discharge planning in its surveys of mental hospitals during fiscal year 1976. BHI has also requested NIMH assistance in developing more specific regulatory requirements for patient treatment plans, including discharge plans.

More emphasis on followup of released patients needed

The survey report form used for psychiatric hospitals under the NIMH-BHI agreement does not provide for an assessment of followup for released persons. A BHI senior analyst told us that BHI has been concerned with the care of persons in the facility and not with what happens to them after their release. He said that BHI has made no special effort to monitor followup treatment of persons released from mental hospitals under Medicare.

SSA comments

SSA informed us that its enforcement of psychiatric health and safety requirements has resulted in the termination of several large State psychiatric hospitals from the Medicare program and the improved delivery of psychiatric care through increased staffing and structural improvements at State mental hospitals. SSA also said that it has proposed to fund NIMH sufficiently to perform all State mental hospital surveys, but NIMH was unable to comply because of insufficient consultant personnel. SSA said that the use of NIMH personnel to perform mental hospital surveys will be expanded each year.

SSA also said that in October 1976 it initiated an experiment in one State in which the $250 limit on mental health outpatient care was increased to $400.

CHAPTER 9

SUPPLEMENTAL SECURITY INCOME PROGRAM HAS BOTH HELPED AND HINDERED DEINSTITUTIONALIZATION

The Supplemental Security Income program has provided income support funds to help many mentally disabled persons to return to the community from institutions. However, some program aspects have hindered or could hinder deinstitutionalization. SSI recipients have been released from institutions and placed in substandard facilities or were not provided services. In addition, some aspects of the program may have inadvertantly resulted in continued institutional care or unnecessary placement in intermediate care facilities as a result of eligibility requirements; restrictions and limitations under SSI; or, from the States' perspective, the relationship of the financial incentives under SSI to Medicaid.

HOW THE PROGRAM OPERATES

The SSI program, administered by the Social Security Administration's Office of Program Operations, went into effect in January 1974. The program is to make sure that aged, blind, and disabled persons have at least a minimum income to help them be as independent as possible. Although the SSI program is not specifically for deinstitutionalization of the mentally disabled, this objective fits into the program's overall objectives. The income available to mentally disabled persons under the program helps make it possible for them to be released from institutions. Since the fall of 1974 SSA has allowed persons in institutions to apply for SSI before their release.

During fiscal year 1975, individuals could receive as much as $146 monthly from SSI. In July 1975 this figure was raised to $157.70, and in July 1976 it increased to $167.80. Many States supplement SSI payments to individuals.

Eligibility for SSI is based on age, blindness or disability, and income and resources. To provide work incentives, SSI regulations allow recipients to earn some income without having their SSI payments reduced. If income is above a certain level, SSI benefits are reduced depending on the amount of income. Department of Health, Education, and Welfare regulations allow disabled persons pursuing a self-support goal under an approved plan to exclude certain income and resources--needed to fulfill the plan--for up to 48 months so they can retain SSI eligibility.

Coverage of mentally disabled

SSA did not have data available showing the amount of SSI funds provided to the mentally disabled. HEW estimated that $312 million in SSI funds (excluding about $32 million for adjudicating claims) went to the mentally retarded in fiscal year 1975.

Data available on the Aid to the Permanently and Totally Disabled program--one of the programs that SSI replaced--indicated that (1) mental illness was the primary disabling condition for 19.1 percent of recipients of program funds, (2) mental retardation was the primary disabling condition for 16 percent of the recipients, and (3) mental illness ranked second and mental retardation third among the primary disabling conditions of recipients.

A June 1975 report by an HEW contractor showed that most of the 840 SSI recipients living in 140 domiciliary care facilities surveyed in 7 States were disabled and that almost all the disabled persons were mentally ill or mentally retarded. The study showed that many SSI recipients had been released from mental hospitals and institutions for the retarded.

A Nebraska official estimated that the mentally retarded in community programs in his State received $600,000 in SSI payments annually.

SSI RECIPIENTS PLACED INTO SUBSTANDARD FACILITIES OR WITHOUT PROVISION FOR SERVICES

Many mentally disabled persons who have been placed in substandard facilities or were not provided services were receiving SSI payments. 1/ Although this problem was more visible to us in Michigan than in the other States reviewed, data we obtained and data gathered by others indicate that this situation exists elsewhere.

1/This is not intended to imply that SSA caused this situation. Persons released from public institutions were not placed in the community by SSA.

A June 1975 report by an HEW contractor showed that 75 percent or more of the residents in domiciliary facilities in six of the seven States studied had not received restorative services. These findings may indicate one reason for increased readmissions at mental hospitals and institutions for the retarded. For example, the domiciliary care facilities the contractor visited in Massachusetts had an average annual turnover rate of 25 percent, and 76 percent of those leaving entered hospitals or long-term care facilities. Only 14 percent of the residents in the facilities reviewed in Massachusetts were reportedly receiving restorative services.

STRONGER CONTROLS NEEDED TO MAKE CERTAIN THAT BETTER PLACEMENTS ARE MADE

SSI legislation and regulations require that certain disabled SSI recipients who are alcoholics or drug addicts comply with provisions of treatment plans. In addition, disabled SSI recipients are required to accept offered vocational rehabilitiation services or treatment services unless they have a valid reason for not doing so. However, the legislation and regulations did not otherwise require SSI recipients to have treatment plans or be provided needed services. Nor did they impose any standards on facilities in which aged or disabled recipients are placed. 1/

As illustrated in Michigan, the lack of such requirements, coupled with the lack of appropriate facilities, has resulted in abuses. The operators of some homes have apparently taken advantage of the benefits available under SSI by crowding as many persons as possible into substandard facilities to maximize income. For example, beds in two homes we visited in Michigan were placed in what would ordinarily be the living and dining rooms of the homes. (See p. 17.)

SSI/MEDICAID INTERFACE

A problem had developed concerning the relationship between the Medicaid and SSI programs and its potential substantial adverse effect on deinstitutionalization. To prevent the payment of SSI funds to persons who need medical or remedial care but who are placed in substandard facilities to avoid meeting Medicaid standards, the Congress provided for reducing SSI payments under certain

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1/This was changed in 1976. (See p. 132.)

conditions. SSI benefits were to be reduced dollar for dollar for any supplementary or other payment that States made for any medical or other remedial care to inpatients in certain facilities if the care was or could have been provided under the Medicaid program. To assist in implementing this provision, the Social and Rehabilitation Service defined ICF care.

SRS regulations define ICF services as those provided to persons who, because of a physical or mental condition, need more than room and board but less than skilled nursing care. Therefore, the SSI payments for persons residing in facilities that provide services that could be covered under Medicaid could have been reduced one dollar for each dollar the State provided for such medical or remedial services.

During our review, SSA proposed to accept the SRS definition of ICF care and to therefore consider care or services beyond room and board to be care that could be provided under State Medicaid programs. A number of States, however, strongly objected that many mentally retarded persons needed some supervision and services beyond room and board, but not care as extensive as ICF care. The States believed that retarded persons needing some supervision and services were more appropriately placed in group or sheltered homes than ICFs or other institutional settings. They further believed that placing such persons in ICFs would result in unnecessary costs. The States also believed that placing such persons in medically oriented ICFs would be contrary to the normalization principle, which provides that persons should be provided care in as normal an environment as possible suitable to their needs.

As a result of the States' concerns, in April 1975 the President's Committee on Mental Retardation sponsored a meeting of State, SSA, Medical Services Administration, and Office of Long Term Care representatives and others to clarify the issues. The meeting demonstrated that the HEW organizations had not fully assessed the impact on deinstitutionalization of SRS's definition of ICF care and SSA's proposed action.

HEW later declared a moratorium on enforcing the SSI reduction and established a work group to resolve the dilemma. In June 1976, the work group decided to support the repeal of the section of the Social Security Act that provided for this reduction because of the difficulties of enforcing it. The work group believed some other way should be developed to accomplish the section's intent. The section was repealed in October 1976. (See p. 132.)

PROHIBITION AGAINST PAYMENTS TO PERSONS IN PUBLIC INSTITUTIONS

The Social Security Act prohibited paying SSI to persons in public institutions unless their care was reimbursed under Medicaid. 1/ In effect, this prohibited paying SSI to persons in group or sheltered homes, halfway houses, or hostels operated by State or local governments. This would include halfway houses for mentally ill persons that are required to be included among the mandatory services that CMHCs receiving funding under the Community Mental Health Centers Amendments of 1975 must provide. Forty-seven percent of the 603 CMHCs funded as of November 1975 were publicly sponsored.

SSA allows State and local governmental agencies to contract with nongovernmental organizations to operate the halfway houses or group or sheltered homes to enable the residents to be eligible for SSI. However, the prohibition seemed to conflict with the deinstitutionalization objective of treating the mentally disabled in the least restrictive environment suitable to their needs.

This prohibition could also have resulted in persons being placed or retained in places which provide levels of care higher than needed, but which were the only ones available because of the lack of funding for alternatives. For example, the Congress has authorized Federal reimbursement under Medicaid for retarded persons in public institutions that meet special standards under the ICF program. In addition, many mentally disabled persons have been placed in nursing facilities because Medicaid would cover the costs and other alternatives did not exist. (See pp. 10 to 16.) Therefore, by authorizing Medicaid reimbursement for the care of persons in large publicly run institutions and in nursing homes, but not in smaller, publicly operated community-based facilities such as group homes or hostels under SSI, the Federal Government appeared in some instances to be providing financial disincentives to care in the least restrictive environments.

1/ Persons in public medical institutions whose care is covered under Medicaid can receive up to $25 monthly in SSI payments. SSI regulations define an institution as an establishment that provides food and shelter and treatment or services to meet some need beyond food and shelter to four or more persons unrelated to the proprietor.

REDUCTIONS IN SSI PAYMENTS AS A RESULT OF UNEARNED INCOME

Another aspect of the SSI program that may have hampered deinstitutionalization was the treatment of support and maintenance payments made by public agencies for SSI recipients in the community as unearned income, thereby reducing the amount of SSI payments. These reductions may have resulted in mentally disabled persons being placed in skilled nursing facilities or ICFs because of State attempts to maximize Federal funding.

Federal legislation permits excluding from unearned income the value of certain support and maintenance of persons in nonmedical institutions furnished by private, nonprofit, nonmedical organizations; however, the value of such support and maintenance provided by a government source had to be considered as unearned income. Unearned income received by an SSI recipient that exceeds $20 each month reduces the SSI payment. 1/ Therefore, the value of support and maintenance provided by governmental agencies reduced SSI benefits. 2/ (See p. 130.)

The primary operator of group homes for the retarded in Maryland was told by SSA that State funds, treated as vendor payments, were considered as unearned income and would therefore disqualify residents for SSI. The operator said, if this problem were not resolved, it could impede the State's deinstitutionalization efforts because the State would have to pay the full per diem rate for residents to the group homes without the benefit of SSI assistance.

In Nebraska, county, State, and Federal program funds were paid directly to the community-based programs on behalf of the client. Local SSA officials believed these payments should not be considered unearned income but requested a decision from region VII officials.

According to SSA, these problems in Maryland and Nebraska have been or were being resolved.

1/Except for funds to be used to accomplish a self-support goal under an approved plan.

2/SSI payments were not reduced for governmental payments not earmarked for specific persons or earmarked for services rather than for shelter or food.

In November 1975, SSA proposed amending its regulations to limit the amount by which SSI payments would be reduced as a result of unearned income received for support and maintenance. According to these regulations, the maximum SSI reduction for a person having no other income and receiving support and maintenance from a governmental source would be $75.93. However, according to a National Association of Retarded Citizens representative, the association believes that the $75.93 reduction would still hinder deinstitutionalization.

FINANCIAL DISINCENTIVES

As discussed in chapter 6, because funds are available under Medicaid for SNF and ICF care and funds are lacking for alternative facilities and services, many mentally disabled persons have been placed in SNFs and ICFs. Some States supplement SSI payments because the payments are not sufficient to cover the costs of placing and providing services to persons in community settings. Moreover, as SSI payments are reduced and the State payments increase, there is more incentive to place persons in SNFs or ICFs, where the Federal Government will share at least 50 percent of the costs.

The financial incentives for SNF or ICF placement were greater in the 37 States that the Federal Government reimbursed for more than 50 percent of their SNF and ICF costs under Medicaid. For example, the Federal reimbursement rates under Medicaid were 58 percent in Nebraska, 59 percent in Oregon, 81 percent in Mississippi, 76 percent in Alabama, 70 percent in Utah, and 68 percent in Oklahoma. 1/ MSA reported that the average Federal reimbursement rate under Medicaid is about 55 percent nationwide.

The advantage to some States of placement under Medicaid versus SSI can be hypothetically illustrated as follows. For the 3 months ended June 30, 1975, one State reported an average monthly expenditure of about $374 for persons in ICFs. With a Federal reimbursement rate of 68 percent under Medicaid, the Federal Government would pay for up to $254, leaving the State to pay $120. Therefore, the cost to the Federal Government of such an ICF placement is considerably more than the maximum it would pay under

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1/Effective July 1, 1975, reimbursement rates were changed to 78 percent in Mississippi, 74 percent in Alabama, 67 percent in Oklahoma, and 56 percent in Nebraska.

SSI ($146 until July 1975, $157.70 until July 1976, and $167.80 thereafter). 1/ The State pays slightly less than the maximum SSI payment. Assuming that the person was placed in a group home not covered under Medicaid and the State provided or purchased services for the person, the State could end up having to pay more than the $120 a month if the SSI payments were reduced or not allowed (1) because of the value of support and maintenance payments counted as unearned income or (2) because the person was in a publicly owned or operated facility.

ICF placement would be further encouraged because, by making such a placement, the State would not have to arrange for various services to be provided by different organizations. The ICF would be responsible for this.

Therefore, regardless of what specific costs SSA counted as unearned income, as the amount of SSI was reduced, the State's incentive to maximize Federal funding through nursing home placement increased. Furthermore, excluding persons from SSI eligibility because they were in such facilities as group homes or hostels operated by governmental organizations would have a similar effect. In Nebraska, the counties had begun using their employees to operate community hostels for the retarded. Regional SSA officials requested an interpretation from SSA headquarters on whether these hostels are to be considered public institutions, thereby making the residents ineligible for SSI. SSA was evaluating this situation in Nebraska county by county.

Two other problems relating to the SSI program are discussed in our reports on the States included in our review. These problems are (1) delays in SSI payments which prevent persons from leaving institutions as soon as possible and (2) a breakdown in SSA's procedures for referring SSI recipients to State social services offices.

1/ The amount of Federal reimbursement for care in the community for persons placed there with SSI might be more because States may provide social services to them for which the Federal Government will reimburse the State for 75 percent of allowable costs.

NEW LEGISLATION

The Housing Authorization Act of 1976 (P.L. 94-375), enacted August 3, 1976, provides that effective October 1, 1976, the value of housing assistance provided to persons under certain Department of Housing and Urban Development programs may not be considered as income or a resource for determining eligibility for, or the amount of, SSI payments. This provision was enacted to prevent SSA from considering Federal housing assistance payments as unearned income and reducing SSI payments accordingly.

On October 20, 1976, the Unemployment Compensation Amendments of 1976 (P.L. 94-566) were enacted. This law contains several changes to the SSI program, many of which are related to deinstitutionalization. For example, the law

--excludes publicly operated community residences serving 16 or fewer residents from the definition of public institutions, thereby allowing SSI payments to eligible persons in such facilities;

--provides that State and local government subsidies to SSI recipients would not reduce SSI benefits;

--repeals the section of the Social Security Act that requires a reduction in SSI payments for persons residing in facilities that provide services which could be covered under Medicaid; and

--requires the States to establish, maintain, and insure enforcement of standards for any category of institutions, foster homes, or group living arrangements in which a significant number of SSI recipients reside or are likely to reside. Such standards must be appropriate to the needs of the SSI recipients and the character of the facilities involved and must include such matters as admission policies, safety, sanitation, and protection of civil rights. SSA must reduce SSI if States provide any payments for remedial or medical care provided by a group living facility that does not meet the standards established by the States.

CHAPTER 10

IMPACT OF

SOCIAL SERVICES PROGRAMS

ON DEINSTITUTIONALIZATION

The social services programs have helped mentally disabled persons return to and remain in communities. Many mentally disabled persons, however, have been released from institutions and placed into substandard facilities in communities or were not provided services needed to help them be as independent as possible. More effective use of the social services programs could help solve this problem.

HOW THE PROGRAMS OPERATED

Under titles IVA and VI of the Social Security Act, HEW through the Public Services Administration, reimbursed the States for 75 percent of their allowable costs in providing social services to families with dependent children and to the aged, blind, and disabled. HEW could provide up to $2.5 billion for these services annually. Although the social services programs were not established solely for deinstitutionalization of the mentally disabled, they were established to help needy persons attain or retain capability for self-support, self-care, and reduced dependency in the community and to remain in or return to communities. The mentally disabled were among those eligible for the social services.

Although title IVA emphasized services that would help persons obtain employment, services included those needed to help mentally disabled persons return to communities from institutions and to prevent such persons from going into institutions. Such services included day care, arranging foster care, and protective services.

Social services under title VI were for helping the aged, blind, and disabled who were former, current, or potential recipients of SSI attain or retain capability for self-support and self-care. A principal objective of the title VI program was to enable persons to remain in or return to their homes or communities. Services included services in halfway houses, arranging foster care, day care, activity centers, protective services, and arranging for persons needing services to obtain them.

In October 1975 a new Federal-State social services program went into effect, replacing the programs under titles IVA and VI. Some changes made under the new program and their potential impact on the mentally disabled are discussed on page 137.

Coverage of mentally disabled

PSA estimated that the States spent $250 million in Federal social services funds in fiscal year 1975 to serve the mentally retarded. A similar estimate for the mentally ill was not available. In fiscal year 1975 Nebraska used about $6.9 million, or 38.5 percent, of its Federal social services funds to operate its community programs for the mentally retarded. The $6.9 million in Federal funds accounted for about 48 percent of the State's budget for community programs for the retarded. 1/

During fiscal year 1975 the Michigan Department of Social Services reported spending $15.8 million on mental health services under titles IVA and VI. This figure represents only those mental health services obtained from other agencies; it does not include the total amount of social services funds expended on the mentally disabled. According to an interagency agreement, the department of social services was to purchase such services as release planning, assistance in making community placements, day care, and followup services from the department of mental health to help place persons in communities.

IMPORTANCE OF PROGRAMS TO DEINSTITUTIONALIZATION

Federally reimbursable social services to help mentally disabled persons return from institutions to communities could be provided at the institutions or in the community. The programs were important to deinstitutionalization because they (1) provided funds to help place and serve persons in the community and (2) required State to make sure that each client had an up-to-date service plan and that foster care placements were acceptable and were, and continued to be, appropriate to the persons's needs.

The programs were also important because they could serve persons not eligible for inpatient mental hospital services under Medicaid or Medicare. Discharge planning requirements under those programs do not apply to these persons, except to the extent that the facility must meet Joint Commission on Accreditation of Hospitals or equivalent standards. In addition, since SSI regulations did not generally require discharge

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1/HEW has questioned the allowability of some of the amount claimed by the State, but the issue had not been resolved at the time we completed our fieldwork.

or service plans and did not impose standards on facilities in which persons are placed, the social services programs may have been the only federally supported program with such requirements that was used to help return mentally ill persons to the community.

MORE EFFECTIVE USE OF PROGRAMS NEEDED

HEW regulations required that the needs of persons being served under the social services programs be adequately assessed, that plans to meet these needs be developed and implemented, and that persons placed in the community under the programs be placed in appropriate facilities with provision for needed services. The regulations also required that State mental health and welfare agencies in the 42 States providing inpatient mental hospital services to persons 65 or older under Medicaid develop alternatives to institutional care.

More specifically, HEW regulations required that:

--Each person receiving services under titles IVA and VI have a written service plan responsive to his or her needs which was reviewed at least annually to see that it continued to relate to the person's needs and that it was being followed.

--When foster care arrangements were made under titles IVA and VI, States make sure that (1) the placements were appropriate to the needs of the person, (2) the persons received proper care, (3) the placement continued to be appropriate and necessary through periodic reviews, at least annually, and (4) the foster homes had to be approved as meeting licensing standards or be licensed.

--The social services agency monitor local agencies and service contractors to make sure that social services funds were appropriately and effectively used.

--In States providing inpatient mental hospital services to persons 65 or older in mental hospitals, State mental health agencies cooperate with State welfare agencies to develop and implement, for persons of all ages, comprehensive mental health programs, including alternatives to institutional care.

--States receiving title VI funds provide social services to enable persons, including the mentally disabled, to remain in or to return to their homes or communities. These services had to include (1) helping to locate suitable independent living arrangements or making arrangements for placement in foster family or protected care settings and (2) helping to secure additional special arrangements or supportive services needed.

As indicated in chapter 2, these requirements were not always applied to effectively preclude the inappropriate placement of mentally disabled persons in communities.

Lack of HEW monitoring

Although staff at PSA headquarters had identified the need for monitoring and evaluating the impact of the social services programs on deinstitutionalization, PSA had not done the needed monitoring and evaluating. The PSA officials and staffs at the five HEW regional offices we reviewed attributed their inaction in this area to staffing limitations, other priorities, and the lack of instructions or a mandate to work in this area.

In 1971 a joint review by PSA, MSA, and HEW region I was proposed to evaluate the relationship between the social services and mental health programs for aged persons released from mental hospitals in one State. The review was to include an assessment of coordination between the social services and mental health agencies in planning releases, making arrangements for the individual's return to the community, evaluating the proposed living arrangements before release, and following up after release. The social services agency was to be evaluated to determine (1) whether the agency's manual clearly set forth the caseworkers' responsibilities for aged persons being released from mental hospitals and described how to secure services for such persons from other agencies and (2) whether caseworkers clearly understood and carried out their responsibilities and, if not, why not.

According to a PSA official, this study was abandoned after a preliminary test in the State showed that sufficient information was not available. He said that the evaluation was not attempted in other States because of the lack of interest by top PSA management.

ALLOTTED FUNDS NOT USED

In 1972 the Congress imposed a $2.5 billion annual ceiling on the social services programs. Restrictions were also placed on the amount of social services funds that could be expended on persons not receiving public assistance. Although certain groups, including the mentally retarded, were exempt from these restrictions, many States did not use all the

Federal social services funds available to them during fiscal years 1974 and 1975 because:

- --States did not have accurate information on the amount of funds being used to provide services to nonrecipients of public assistance, and they did not want to exceed their allotments; therefore, they spent social services funds conservatively.
- --States did not have or want to provide the needed matching funds.
- --Controversy, confusion, and disagreement existed between the States and HEW over what services were eligible for Federal reimbursement, particularly services purchased by the social services agencies from other agencies for persons in institutions.

Preliminary data showed that 41 States did not use $540.3 million of the funds allotted to them under titles IVA and VI for fiscal year 1975. The expenditure data for that year for the five States we reviewed is shown below:

State	Allotment	Expenditures	Unused funds
	(millions)		
Maryland	$ 48.7	$38.0	$10.7
Massachusetts	69.5	52.0	17.5
Michigan	109.0	90.8	18.2
Nebraska	18.3	17.9	.4
Oregon	26.2	26.2	-

Michigan did not use $18.2 million available to it under the social services program. Yet, mentally disabled persons had been placed into foster homes operated under the supervision of the State department of social services without provision for services. State officials attributed this situation to the restrictions imposed on the use of funds and confusion over the services for which HEW would reimburse the State under the program.

IMPLICATIONS OF TITLE XX

In January 1975, title XX (42 U.S.C. 1397) was added to the Social Security Act in response to the controversy over titles IVA and VI. Title XX combined the social services programs under titles IVA and VI and made major changes in the way the program operated. The new program went into effect in October 1975.

HEW's regulations allow the States flexibility in developing their programs. Within specified limits, the States can define the social services they will provide under the program. The services must be directed toward one or more of the five program goals set forth in the regulations. Two of these goals are related to deinstitutionalization of the mentally disabled and others.

--Preventing or reducing inappropriate institutional care by providing community-based care, home care, or other less intensive care.

--Securing referral or admission for institutional care when other care is not appropriate or providing services to individuals in institutions.

States must make at least three services available to SSI recipients [1] and provide at least one service for each of the five program goals. The regulations specify the circumstances under which States could provide social services to persons in institutions, including skilled nursing facilities and intermediate care facilities, under the program.

Title XX imposes more stringent eligibility requirements than did titles IVA and VI by basing the eligibility for services on income. Only recipients of SSI, State supplements to SSI, and cash benefits under the Aid to Families with Dependent Children program and persons with incomes below specified limits are eligible for services under title XX.

Title XX regulations require the State agency administering the social services program to describe how planning and services provision will be coordinated with other specified programs, including developmental disabilities, Medicaid, vocational rehabilitation, housing, employment, SSI, and mental health. They do not, however, require State social services agencies to describe their actions to coordinate activities aimed at reducing and eliminating inappropriate institutional placements with other federally supported programs having congressional mandates to achieve this goal.

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[1] According to PSA, this means that at least three services must be available, not that each SSI recipient must be provided three services.

Nor do the regulations require the States to report accomplishments in reducing or eliminating inappropriate institutional placements.

Apparent weakening of regulations under title XX

Because title XX became effective after our fieldwork, we did not assess the impact of the program changes on deinstitutionalization. However, HEW's title XX regulations may be weaker than title IVA and VI regulations in making sure that persons had service plans responsive to their needs and that foster placements were appropriate.

HEW regulations implementing title XX do not require individual service plans responsive to each persons needs. Title XX regulations published in June 1975 required client data files which had to identify the services provided, the goals to which the services are directed, and other data as the Secretary may have required. However, in May 1976, HEW revoked the requirement for client data files.

HEW title XX regulations require that States whose programs include services to persons in foster homes and institutions (includes all residential facilities providing group living) must designate a State agency responsible for establishing and maintaining standards for such facilities. Also, to receive Federal reimbursement for special services provided to persons by foster family homes, a qualified professional must document that (1) the person requires such services because of a health (mental or physical), emotional, or behavioral problem and (2) the caregivers have the special training needed to provide the services. The regulations, however, do not specify that States making foster care or other community placements are to periodically make sure that (1) placements are appropriate to the needs of the person, (2) persons placed received proper care, and (3) placements continue to be necessary and appropriate.

Possible impact of title XX program

It was too early to assess the impact of title XX social services on deinstitutionalization. On the one hand, by requiring States to make at least three services available to disabled SSI recipients, the program should help make sure that mentally disabled persons released from institutions who receive SSI after release receive at least some services.

On the other hand, States are no longer required to provide services according to service plans responsive to individual needs. Therefore, services provided by the States to mentally disabled persons may not be the services they need the most to help them remain in the community.

State social services agencies are apparently not responsible for making sure that foster or other community placements they make are or continue to be appropriate to individual needs. Specific service responsibilities of social service agencies for mentally disabled persons being released from institutions who are eligible for social services, but who are not SSI recipients, are not clear. Also, State social services agencies are not specifically required (1) to describe how they will coordinate with other agencies specifically for deinstitutionalization or (2) to report on how well they are meeting this objective.

CHAPTER 11

THE VOCATIONAL REHABILITATION PROGRAM NEEDS TO EMPHASIZE SERVICE TO THE MORE SEVERELY MENTALLY DISABLED

Although the States have made efforts with Federal assistance to rehabilitate the mentally disabled in institutions and communities, more emphasis needs to be placed on the more severely mentally disabled if the deinstitutionalization goal is to be achieved.

For the mentally retarded, vocational rehabilitation has been primarily directed toward the less severely retarded (or those who may not be retarded) and apparently toward those in the community instead of those in institutions. In previous years, rehabilitation for the mentally ill often focused on drug addicts, alcoholics, and those with behavioral disorders. These forms of mental illness were not categorically considered severe disabilities by the Rehabilitation Services Administration under the Rehabilitation Act of 1973, as amended (29 U.S.C. 701).

We believe that additional focus on the more severely mentally disabled in or released from public institutions is needed and would be facilitated by:

- --Greater emphasis on this mentally disabled population by RSA headquarters and HEW regional offices.
- --A clearer definition of severely disabled as it relates to the mentally retarded.
- --More coordinated efforts for this target group by RSA, the National Institute of Mental Health, the Developmental Disabilities Office, and the Department of Labor.

PROGRAM BACKGROUND

The vocational rehabilitation program includes (1) basic formula grants to States for providing rehabilitation services to persons with physical or mental disabilities which constitute handicaps to employment and (2) formula grants to States to initiate and expand services to groups of handicapped persons, including those in institutions who have been underserved. In addition, HEW provides funds to the States for rehabilitating SSI and Social Security Disability Insurance recipients. RSA provides grants for research and demonstration projects, training, and special projects and for constructing rehabilitation facilities. [1]

State-administered vocational rehabilitation programs can provide to the handicapped a variety of services, including

--evaluation of rehabilitation potential;

--counseling, guidance, referral, and placement services;

--vocational training services;

--physical and mental restoration services;

--subsistence costs while in training;

--transportation; and

--followup, follow-along, and other postemployment services to help persons maintain employment and secure needed services from other agencies.

Eligibility criteria for vocational rehabilitation services are (1) a physical or mental disability which constitutes or results in a substantial handicap to employment and (2) a reasonable expectation that vocational rehabilitation services may make the person more employable. HEW regulations provide that decisions on a person's ineligibility for vocational rehabilitation services must be made in full consultation with the person (or his or her parent or guardian) or after affording a clear opportunity for such consultation. Eligibility can be denied only upon certification that the absence of vocational rehabilitation potential has been demonstrated beyond any reasonable doubt. Denials and related certifications must be reviewed at least annually.

The Federal Government reimburses States for 80 percent of their allowable costs under the basic formula grant program, 90 percent under the Innovation and Expansion Grant Program, and for 100 percent for services to SSI and Social Security Disability Insurance beneficiaries.

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[1] This chapter discusses RSA's activities only as they relate to the vocational rehabilitation program. Until August 1975, the Developmental Disabilities Office was in RSA; the developmental disabilities program is discussed separately in ch. 4.

The Rehabilitation Act of 1973 requires that States provide services first to those persons with the most severe handicaps. Severe handicaps are defined in the act as disabilities which require multiple services over an extended period and result from impairments that include mental illness and mental retardation. State vocational rehabilitation plans must describe methods to be used to expand and improve services to persons with the most severe mental and physical handicaps.

Funds available under the Innovation and Expansion Grant Program are to be used for planning, preparing, or initiating special programs for expanding vocational rehabilitation services to the most severely handicapped, particularly services to poor handicapped persons with unusual and difficult rehabilitation problems. This includes persons for whom responsibility for education, treatment, and rehabilitation is shared with other agencies.

EMPHASIS BY STATES ON PERSONS WITH PSYCHOTIC AND PSYCHONEUROTIC DISORDERS

Data on the amount of funds spent by State rehabilitation agencies to serve persons with psychotic and psychoneurotic disorders was not readily available. However, data on the rehabilitation of persons classified as mentally ill under the vocational rehabilitation program shows that the percentage of rehabilitated persons with other character, personality, or behavior disorders (not classified as severe disabilities) more than doubled between fiscal years 1968 and 1975 while the percentage of rehabilitated persons with psychotic and psychoneurotic disorders (classifiable as severe disabilities) increased only slightly. The following table illustrates this.

Classification	Percent of all clients reported as rehabilitated 1968	1973	1975 (note a)
Psychotic disorders	6.4	5.2	5.1
Psychoneurotic disorders	4.4	5.3	6.6
Alcoholism	2.6	5.0	4.8
Drug addiction	0.2	1.2	1.4
Other character, personality, and behavior disorders	6.0	14.1	12.8
Total mental illness	19.6	30.8	30.7

a/Based on preliminary estimate of rehabilitations.

According to RSA, vocational rehabilitation program emphasis between fiscal year 1968 and the enactment of the Rehabilitation Act of 1973 was on helping disadvantaged persons who were not necessarily severely disabled to become self-sufficient. Emphasis was placed on groups, such as welfare recipients, public offenders, Selective Service rejectees, and other similar groups that often had relatively minor physical and mental impairments. It was during this period that the term behavioral disorder was authorized as a qualifying disability in the vocational rehabilitation program to facilitate the entry of disadvantaged persons into the service system.

It was not until the enactment of the Rehabilitation Act of 1973 that vocational rehabilitation program emphasis was statutorily mandated for the severely disabled. Also, as a result of this act, behavioral disorders were removed as a disability category for service eligibility. Since the passage of the act, there has been a positive trend toward serving the more severely mentally disabled.

According to RSA, small but consistent percentage increases have been reported in the rehabilitation of persons classifiable as severely mentally disabled as a percentage of the total number of mentally disabled persons rehabilitated. For example, in fiscal year 1973, psychotic and psychoneurotic rehabilitations accounted for 34.1 percent of all rehabilitations of persons classified as mentally ill; this increased to 36 percent in fiscal year 1974 and about 38.1 percent in fiscal year 1975.

In March 1974 RSA established a Psychiatric Rehabilitation Task Force to fill the need for increased action to rehabilitate the more severely disabled mentally ill. However, the goals of the task force were not fully achieved.

The task force, composed of regional and State vocational and rehabilitation personnel, was to help RSA plan and develop programs to expand services to the severely disabled mentally ill. RSA also established an internal psychiatric rehabilitation work group to develop a plan for expanding vocational rehabilitation coverage of the more severely disabled mentally ill. As a result of task force initiatives, RSA:

--Surveyed State vocational rehabilitation administrators to identify models of psychiatric rehabilitation programs.

--Awarded a grant for the development of training materials on psychiatric rehabilitation.

--Established working relationships with NIMH to jointly try to expand and improve services for the severely handicapped mentally ill.

In November 1975, however, an RSA official told us that the internal work group had not developed a plan because of difficulties in getting the work group members together for meetings. According to RSA's Assistant Commissioner for Program Development, because developing this plan was not an objective in HEW's operational planning system, the work group members could not devote enough time to developing it.

The Assistant Commissioner added that RSA's efforts with NIMH have been directed toward developing closer ties between the vocational rehabilitation program and community mental health centers. However, he believed that the two agencies had not sufficiently focused on the relationships between the vocational rehabilitation program and mental hospitals and that this issue should be addressed.

In a January 1975 memorandum, RSA told State rehabilitation agencies and HEW regional offices that virtually no gains had been made for nearly a decade in rehabilitating persons with psychosis or psychoneurosis. RSA said the increases often cited for rehabilitating the mentally ill were primarily attributable to increased rehabilitation of persons with behavioral disorders which no longer are qualifying disabilities in determining eligibility. Although RSA encouraged its regional offices and State agencies to improve services to the mentally ill, it did not specify actions for them to take.

MORE EMPHASIS NEEDED ON RETARDED PERSONS WITH THE MOST SEVERE HANDICAPS

State vocational rehabilitation agencies seemed to be serving many persons who were not retarded but were apparently classified as mildly retarded because of maladaptive behavior or other problems. Certain State practices and disability classification procedures appeared to result in the lack of emphasis on or denial of vocational rehabilitation opportunities to the more severely retarded.

RSA defined mental retardation in accordance with the definition established by the American Association on Mental Deficiency, a major professional organization in the mental retardation field. The association and RSA define mental retardation in terms of subaverage intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.

RSA's manual for classifying persons according to disability states that the adaptive behavior component is more meaningful than the intelligence component of the definition in determining a person's vocational rehabilitation needs and ultimate employment potential. It states, however, that intelligence can be very important to the counselor.

The manual defines subaverage intelligence as that below 85, in accordance with the retardation scale adopted by the association in 1961. However, in 1973 the association revised its definition of mental retardation by reducing the subaverage intelligence quotient limit to below 70 and dropped the previous classification of "borderline retarded" with intelligence quotient levels between 70 and 85. RSA did not change its manual to reflect this change.

For the retarded, RSA's manual defines severely handicapped as those whose retardation is moderate or severe. The manual adds that those sometimes termed profoundly retarded are generally in institutions where they must receive continuing care and supervision, are incapable of gainful employment, and thus are not suitable candidates for vocational rehabilitation.

According to the Director of RSA's Division of Special Populations, RSA did not know to what extent States were currently classifying persons with intelligence quotients above 70 as retarded. He said that RSA has been discussing the change in the definition of retardation with the association to assess its impact.

In October 1974, RSA wrote to the association expressing concern over the impact the revised definition of retardation would have on the vocational rehabilitation program and requesting assistance in resolving RSA's dilemma. RSA stated that if it accepted the association's definition, a large number of people with intelligence quotients between 70 and 85 would not qualify for vocational rehabilitation services even though many such persons need them. RSA said that for that year slightly more than 50 percent of the persons with a primary disability of mental retardation who are rehabilitated by State agencies would fall in the 70 to 85 intelligence quotient range. As of July 1976, RSA had not received a reply from the association.

Persons with intelligence quotients below 55 frequently have multiple disabilities, such as physical impairments or blindness, and may therefore have limited or no potential for achieving employment goals; however, research has shown that persons with low intelligence quotients have been able to learn vocational skills.

Maryland

In fiscal year 1974, Maryland's vocational rehabilitation program served 3,928 persons it classified as retarded. A breakdown by level of retardation is shown below:

Classification			
Maryland	Association	Served	Rehabilitated
Mild	Not retarded	2,600	813
Moderate	Mild	1,144	235
Severe	Moderate	184	53
		3,928	1,101

As indicated by this table, the Maryland rehabilitation agency was concentrating on persons who were classified as mildly retarded under the State's scale but who would not have been considered retarded under the association's scale. Relatively little effort was devoted to the more severely retarded.

A comparison of the Maryland and association scales for classifying persons as retarded follows:

	Intelligence range	
Classification	Maryland	Association
Mild	70-85	55-69
Moderate	55-69	40-54
Severe	40-54	25-39
Profound	39 and below	24 and below

According to a Maryland official, Federal guidelines allow the States to define retardation for determining vocational rehabilitation program eligibility and that most States use the same scale as Maryland.

In its program and financial plan for fiscal years 1976 to 1981, the Maryland Division of Vocational Rehabilitation recognized the need to expand services to the more severely retarded in conjunction with the mandate in the Rehabilitation Act of 1973 and stated this as a program objective. The Division identified the following problems it believed needed to be resolved to accomplish this objective.

--The extension of services to the more severely retarded will require longer and more comprehensive services and may necessitate additional training for counselors serving this disability group.

--More coordination between the institution-based vocational rehabilitation programs and community agencies is needed to assure the continuity of services.

--State institution-based evaluation and training programs need to modify their programs to better serve more severely retarded persons.

--Existing workshops need to expand services to include more programs for the severely disabled.

--More community-based residential facilities for the severely retarded are needed to contribute to and enhance rehabilitation efforts.

Oregon

In Oregon some confusion existed about whether services should be diverted from the "borderline retarded" in the community to the more severely retarded in the institutions. Oregon's vocational rehabilitation psychological consultant told us that many of the persons classified as retarded and served by Oregon's vocational rehabilitation program were not retarded according to the association's 1973 criteria. The psychological consultant estimated that many of the retarded served by the program fit in the borderline category and were already in communities. He said that most of the institutionalized retarded served were moderately or severely retarded.

The psychological consultant said the association's change puts the agency in a position of having to either discontinue service to people with intelligence levels over 70 or not use the association's classification system. He said that discontinuing service to people with intelligence levels over 70 would cause problems because persons in the community with levels between 70 and 85 have greater potential for being rehabilitated more quickly and cheaply, and have better chances for placement than the more severely disabled in institutions. He concluded that, if the vocational rehabilitation agency diverted more of its resources to the more severely retarded, it would hamper its ability to help the less severely retarded in the community who also need its services.

The consultant stated that the association's change was made unilaterally, without contact with the State agencies. State agencies have been notified by HEW not to make any drastic changes. As a result, Oregon's vocational rehabilitation agency is continuing to consider anyone with an intelligence level under 85 as being mentally retarded.

Massachusetts

At the institution for the retarded we visited, residents with intelligence quotients of 50 or below were not referred to the State vocational rehabilitation agency because a local counselor considered them untrainable. Massachusetts Rehabilitation Commission officials stated that this situation may be caused by a subjective interpretation of one of its policies, which states, in part: "* * * below I.Q. 50, a client, while eligible, may not be susceptible to rehabilitation services."

A State mental retardation official believed that the commission was not fulfilling its responsibility in serving retarded because it focused on persons with higher potential. A commission official replied that, if emphasis is placed on the severely disabled, as required by the Rehabilitation Act of 1973, a disproportionate amount of resources will have to be devoted to a smaller number of clients. This will result in fewer people being served and possibly fewer rehabilitations. According to a former director of mental retardation programs at the commission, the policy of not serving clients with intelligence quotients below 50 was no longer valid and a client's functional level is considered when screening him or her for vocational rehabilitation potential. However, another commission official stated that the agency's Professional Manual of Policies and Procedures still cites 50 as the intelligence quotient below which a person may not be susceptible to rehabilitation services and indicated that counselors may be interpreting this as a lower limit.

Michigan

The Michigan vocational rehabilitation agency has helped retarded persons return to communities, but it had focused its efforts on the less severely retarded already in the community and had not emphasized screening or providing services to the more severely disabled institutionalized retarded. The Michigan agency recognized this problem and, in 1974, reported that after 1968 many retarded persons had been released from institutions (using aid to the disabled and SSI funds) but had not received adequate vocational education or rehabilitation services because of the lack of staff, money, and facilities.

The agency acknowledged not accepting referrals of many retarded persons because it believed they were too severely disabled. The agency reported that one way to increase the number of severely disabled served would be to encourage referrals of institutionalized clients as well as those from nursing homes.

Other States

A 1976 report prepared for the President's Committee on Mental Retardation by the National Association of Coordinators of State Programs for the Mentally Retarded contained the following data from a 1974-75 survey of its members on the impact of the Rehabilitation Act of 1973:

--Of 48 respondents to a question on whether the coordinators perceived changes in goals and priorities of rehabilitation agencies as they relate to the severely retarded after passage of the act, 15 perceived a noticeable change, 27 perceived little or no change, and 6 reported that strong cooperative relationships existed between State mental retardation and vocational rehabilitation agencies before the act and that the cooperation is continuing.

--22 of 40 coordinators who definitively responded to another question said they believed that the mentally retarded were not being given a "fair shake" in gaining access to vocational rehabilitation services.

NEED FOR MORE EMPHASIS BY RSA

Although RSA has told the States to focus on persons on public support, such as the institutionalized mentally disabled, it did not specify what they could or should do for this group. RSA did not

- --make deinstitutionalization an operational objective;
- --participate with DDC in proposed joint efforts directed at deinstitutionalization of the retarded;
- --designate the mentally disabled as priority service target groups during any of the 4 years (1972 through 1975) that we reviewed;
- --designate deinstitutionalization as a priority effort under the Innovation and Expansion Grant Program, although HEW was authorized to designate priorities under the program; or
- --monitor or evaluate the extent States provided special attention to deinstitutionalization.

RSA officials initially informed us that deinstitutionalization of the mentally disabled had not been a priority issue in the agency, that they believed including mental disability in the definition of severe handicap was sufficient emphasis, and that additional directives on the subject were not needed.

In April 1975, however, the R[illegible] Commissioner stated that the November 1971 Presidential statement on deinstitutionalization had not been addressed seriously enough and that more intensified efforts should be devoted to it by RSA and other agencies. According to RSA's Assistant Commissioner for Program Development, some Innovation and Expansion Grant Program funds have been used for deinstitutionalization but more emphasis is needed in this area. For example, he said that he would attempt to specify deinstitutionalization of the mentally disabled as a priority area in RSA's Innovation and Expansion Grant Program guidance in the future.

Effort by regional offices

None of the RSA officials we contacted in the five regional offices reviewed had acted specifically toward deinstitutionalization or had evaluated State vocational rehabilitation programs' impact on it. For example, RSA officials responsible for administering the vocational rehabilitation program at HEW's Chicago regional office said that:

--Deinstitutionalization was not a goal, priority, or objective in their program and they had no specific responsibility in this area. No instructions had been received on this subject.

--They had not worked with other agencies in this area, although they had contacted Labor officials on the affirmative action program for employing the handicapped.

--They had not monitored or evaluated the impact of State vocational rehabilitation agencies on deinstitutionalization, although they knew that State agencies provided services to the mentally disabled in institutions.

According to an RSA official in the Kansas City regional office, his office did not consider the impact of State vocational rehabilitation programs on deinstitutionalization in reviewing State grant applications. He said that the vocational rehabilitation program did not have any clear deinstitutionalization objectives but that the program's impact in this area should probably be considered.

DEFINITION OF SEVERE HANDICAP

In March 1976 an HEW contractor completed a report on its analysis of RSA's definition of severe handicap. The contractor's study included a review of 400 vocational rehabilitation case files in 4 States and used a questionnaire to identify problems State vocational rehabilitation agency staffs were having using RSA criteria for defining severe handicap. The definitions of severe mental illness and mental retardation were included in the study.

The contractor identified several problems with RSA's criteria for defining severe mental handicaps and recommended that RSA change the criteria. Some of the contractor's recommendations were that:

--Criteria be established for determining other personality, character, or behavior disorders that would be severe handicaps.

--Criteria be changed for determining whether persons with psychosis and psychoneurosis have severe handicaps to employment.

--RSA review its definition of mental retardation and clarify the role of intelligence quotients in determining the levels of retardation and severity of handicap.

In April 1976 RSA established a task force to refine and improve the definition of severe handicap for use in the vocational rehabilitation program. The RSA Commissioner expected to be able to revise program regulations, guidelines, and training materials by the end of September 1976.

We recognize that establishing criteria for defining severe mental handicaps is difficult and that differences of opinion may often exist regarding whether certain mentally disabled persons have severe handicaps. Differences of opinion also exist regarding how and when various agencies should serve mentally disabled persons with the most severe handicaps who need multiple services over extended periods. Regardless of the resolution of the definition problems, however, many mentally disabled persons with severe handicaps who remain in institutions could be returned to the community if provided needed services, many of which could be provided or funded by the vocational rehabilitation program in cases where vocational potential exists. Therefore, as discussed in chapter 3, if deinstitutionalization is to be achieved, the role of the vocational rehabilitation program needs to be clearly delineated, and RSA and the States must make certain that this role is carried out.

CHAPTER 12

MORE HELP

NEEDED FROM HUD

Inadequate housing is a critical obstacle to returning the mentally disabled to the community. In a November 1971 statement, President Nixon directed the Department of Housing and Urban Development to help develop special housing for the retarded in the community. The President also designated the Secretary of HUD as a member of the President's Committee on Mental Retardation in March 1974. In 1974 President Ford stated that, primarily through its housing agencies, the Federal Government would help retarded adults obtain suitable homes.

Only one of the eight local housing authorities we contacted had addressed the needs of the mentally disabled in its housing assistance plan. Two studies by others also showed that local housing authorities had generally not considered the needs of the mentally retarded. (See p. 58.) In commenting on the relevance of its programs to the President's deinstitutionalization goal, HUD stated in a 1972 report that HUD-assisted housing and community development programs

> "* * * without question represent resources for the development of living arrangements for retardees which might be desirable alternatives to institutions. * * * Given State involvement under contract to assure professional services and program responsibility, housing programs could more readily be used for some categories of the mentally retarded now in institutions."

Although HUD has stated that its program could be used to further deinstitutionalization, it has neither developed a plan or strategy for implementing the Presidential directive nor encouraged or informed local housing authorities and managers or sponsors of HUD-assisted projects about considering the needs of the mentally disabled. Many regional and area officials we contacted were not aware of the directive or the eligibility of the mentally retarded for HUD-assisted housing. HUD did not have data on (1) the needs of the mentally disabled for housing or community development services or (2) the conditions under which the mentally disabled were served by its programs.

Examples of successful uses of HUD programs for the mentally disabled are discussed beginning on page 161. We believe more could be done if HUD would (1) develop a strategy and plan for implementing the Presidential objective, (2) inform its headquarters, regional, and area officials of how the mentally disabled could be served by the HUD programs, (3) work more closely with HEW, State, and local mental health and retardation officials, and (4) inform and encourage local housing authorities and managers and sponsors of HUD-assisted projects to consider and help meet the needs of the mentally disabled.

HUD headquarters officials and staff attributed their inaction mainly to the lack of a more substantive mandate from the Congress, the President, or the Office of Management and Budget setting forth specific steps to be taken. HUD regional and area office officials and staff attributed their inaction to (1) the lack of specific mandates and directives from HUD headquarters and (2) their lack of awareness of the Presidential statements on mental retardation and a 1971 decision by the HUD General Counsel that retarded persons could be considered as handicapped in determining eligibility for housing assistance under HUD programs (See p. 156.)

HUD PROGRAMS

HUD administers various housing programs to enable persons with low and moderate incomes to live in decent, adequate housing and a community development program under which needed community facilities and services can be provided. The programs include providing (1) direct loans for congregate housing for the elderly and handicapped, (2) mortgage insurance for skilled nursing and intermediate care facilities, (3) below market interest rate loans for constructing or rehabilitating rental units to enable persons with low and moderate income to pay lower rents, (4) rental assistance payments, (5) community development block grants, and (6) loans and annual subsidies to local housing authorities for public housing. Community housing eligible for HUD assistance includes group homes and apartments.

Community Development Program and housing assistance plans

The primary goal of HUD's Community Development Program is to develop viable urban communities, with decent housing and a suitable living environment and expanding economic opportunities, principally for persons of low and moderate income. Activities that can be funded under the program include the acquisition of land; the acquisition, construction, or installation of neighborhood facilities; and the provision of public services not otherwise available. These services must be directed toward improving the communities' public services, including those concerned with employment, economic development, crime prevention, child care, health, drug abuse, education, welfare, and recreation.

Applications for participation in the program must contain a plan which identifies community development needs, demonstrates a comprehensive strategy for meeting these needs, and sets forth objectives developed in accordance with areawide developmental planning. Applications must also contain a housing assistance plan. This plan is to include estimates of the housing assistance needs of lower income persons (including the elderly and handicapped) either already residing or expected to reside in the community. HUD regulations require community development plans to consider any special needs found to exist in any identifiable segment of the total group of lower income persons. Housing assistance plans are required to consider and also summarize any such special needs.

ELIGIBILITY OF MENTALLY DISABLED FOR HUD PROGRAMS

Many mentally disabled persons have low or moderate incomes and would be eligible for HUD-assisted housing. With some exceptions, however, eligibility for several HUD-assisted housing programs is limited to low- or moderate-income families. Two exceptions relate to the elderly and handicapped, who can qualify even if they are single.

Before the Housing and Community Development Act of 1974, HUD's definition of tenant eligibility on the basis of a handicap was based on the definition in the Housing Act of 1959. According to the act and HUD's regulations, persons were considered handicapped if they were determined to have a physical impairment which (1) was expected to be of long-continued and indefinite duration, (2) substantially impeded their ability to live independently, and (3) was such that their ability to live independently could be improved by more suitable housing. Based on this definition, HUD concluded that physical impairments did not include mental retardation.

As a result of inquiries by the Michigan State Housing Development Authority, however, HUD's General Counsel decided in August 1971 that mentally retarded persons could be considered handicapped if the mental retardation stemmed from a physical impairment, such as brain damage or a chemical or neurological physical impediment to normal growth.

The extent to which HUD notified its regional and area office officials of this decision is unclear; however, a forme

Deputy Assistant to the Secretary, Programs for the Elderly and Handicapped, told us that copies of the decision were not distributed to HUD's regional and area offices. Some of the regional specialists for the elderly and handicapped we contacted were aware of the decision, but many were not.

In March 1972 HUD issued instructions to its regional and area offices for implementing its subsidized housing program for the elderly and handicapped. In its instructions HUD defined handicapped on the basis of physical impairments and did not refer to the General Counsel decision of August 1971.

The Housing and Community Development Act of 1974 changed the statutory definition of handicapped for HUD's programs by omitting the word "physical" before impairment and by specifically including the developmentally disabled under the handicap definition. The definition of handicap as changed by the act would apparently enable the mentally ill to qualify as handicapped if they meet the revised definition and the other requirements of the act.

EFFORTS BY HUD HEADQUARTERS

In March 1972 HUD established the Office of Assistant to the Secretary, Programs for the Elderly and Handicapped, as the focal point for housing and related facilities and services for the elderly and handicapped. This office was responsible for reviewing the adequacy of HUD's policies and procedures, coordinating HUD activities, and helping plan and determine reporting needs as they relate to the elderly and handicapped.

In November 1972 this office requested RSA assistance in assessing HUD-sponsored projects for the handicapped and establishing a temporary program of centralized review of applications for projects involving housing for the handicapped. These actions were to eventually result in the publication of guidelines for HUD field specialists in processing and approving housing projects for the handicapped. RSA and HUD later established a task force in response to this request. The task force held a series of meetings during the first 4 months of 1973 and developed more than 50 tentative recommendations of ways for HUD to help provide community housing and services for the physically and mentally disabled.

Those recommendations dealt with organization, legislation, policy, design, and market analysis and research. However, because of funding and staffing cutbacks at HUD, a moratorium on HUD-subsidized housing programs, and the departure of several high-level HUD officials concerned with programs for the elderly and handicapped, the HUD-RSA task force was disbanded before it could present its recommendations.

The Office of the Assistant to the Secretary, Programs for the Elderly and Handicapped, had taken little action to implement the President's 1971 directive or to help in deinstitutionalization. The office had not:

--Issued guidance to other headquarters or regional and area offices concerning the President's directive or the deinstitutionalization objective. (It did, however, sponsor a training session in 1972 for some regional staff.)

--Monitored or evaluated the extent to which the mentally disabled were being served by HUD-assisted programs, the quality of services being provided, or the activities of the regional specialists for the elderly and handicapped.

--Required HUD offices to routinely report to it on activities relating to the mentally disabled.

Officials from this office said they had not acted to carry out the President's directive because they had not received instructions from the President, OMB, or the Secretary of HUD.

Other offices

We contacted officials and staff in several divisions and offices at HUD headquarters, including Housing Management, Housing Production and Mortgage Credit, Community Planning and Development, and Economic and Market Analysis. We also met with members of a HUD task force on the handicapped.

According to officials and staff we contacted, HUD had not taken substantive, specific action to assist in deinstitutionalization. For example, a multi-family housing programs specialist in the Office of the Assistant Secretary for Housing Production and Mortgage Credit said she had not pushed for aggressive action to implement the President's directive because no information was available on the HUD-assisted projects that have been used to house the retarded or on the success of such projects. Therefore, she did not know what to recommend. An official in the Office of the Assistant Secretary for Housing Management said he had discussed with HEW the housing needs of the retarded, recognized the need for a variety of types of housing for them, and helped to identify some steps HUD could take. He said he could not act because HUD did not have a mandate to do so in spite of the 1971 Presidential directive.

In January 1976 HUD amended the regulations for its community development grant program to exclude group homes, halfway houses, sheltered workshops, and central social service facilities from those facilities and activities that could ordinarily be funded under the program. In August 1976, however, the Housing Authorization Act of 1976 added centers for the handicapped to the types of facilities that can be funded under the Community Development Program.

HUD had not issued guidelines to field offices for reviewing housing assistnace plans to insure that the housing needs of the eligible mentally disabled residing in or expected to reside in the community were included in assessments made by local housing authorities.

EFFORTS BY HUD FIELD OFFICES

In 1972 HUD instructed each of its regional offices to designate specialists to insure effective assistance in providing specialized housing for the elderly and handicapped. The responsibilities of these specialists included (1) remaining aware of HUD housing policies and activities as they relate to the elderly and handicapped, (2) assisting groups interested in developing housing for the elderly and handicapped, (3) meeting with groups to facilitate the use of programs on the varied needs of these target populations, and (4) training other HUD personnel in matters relating to housing for the elderly and handicapped.

We contacted regional officials or specialists for the elderly and handicapped and officials in three HUD area offices in the five regions reviewed. We contacted eight persons in three additional HUD regional offices who had been designated as specialists for the elderly and handicapped. We also contacted the community services advisor in one HUD area office in another region that had taken specific action to help in deinstitutionalization.

None of the officials or specialists for the elderly and handicapped in the eight regional offices and the three area offices had taken specific action (1) to implement the President's 1971 directive, (2) to inform applicants or local housing authorities about helping in deinstitutionalization or to encourage them to do so, or (3) to evaluate the extent to which HUD's programs were serving the mentally disabled. Very few persons we contacted were even aware of the 1971 HUD General Counsel decision on mental retardation or the 1971 and 1974 Presidential statements on HUD involvement in helping to provide community housing for the mentally retarded. The officials or specialists generally said they had not acted in this area because they had received no mandate or instruction to do so.

For example, the acting administrator of HUD region I said:

--Regulations and instructions contained a definition of handicapped to include only a physical impairment.

--Region I area offices received no identifiable project applications for deinstitutionalization of the mentally disabled.

--Regulations and instructions delineating HUD's role in this area did not exist except for the nursing home program.

According to another HUD region I official, efforts had not been made to make sure that local housing authorities included the needs of the mentally disabled in their housing assistance plans required under the community development program.

Region III HUD officials said that the housing needs of the mentally disabled were not required to be included in housing assistance plans and that HUD guidelines did not identify the mentally disabled as a segment of the total group of lower income persons whose special needs must be considered by an applicant. The HUD officials believed that the mentally disabled, who frequently need supportive services, were not as suitable for conventional HUD-assisted housing as the physically handicapped, who could usually live independently once architectural barriers were removed. They suggested that the most effective way to insure housing for the mentally disabled would be to include local housing authorities in the release planning process and have them set aside carefully selected units for deinstitutionalization.

According to the Assistant Regional Administrator for Community Development in HUD region V, local housing authorities were required to assess the housing needs of low income persons residing in or expected to reside in the community. He added, however, that (1) local housing authorities were not required to address or break out the needs of the mentally disabled, (2) when HUD reviews the plans prepared by the local housing authorities, it does not evaluate whether the needs of the mentally disabled have been considered, and (3) unless the mentally disabled have a strong voice or advocacy group locally, their needs will not be properly met under the HUD programs.

The Deputy Director of HUD's Portland, Oregon, area office in region X said that:

- --Certain personnel in the office were given additional responsibilities for activities for the elderly and physically handicapped only.
- --HUD had no statutory, regulatory, or program basis on which to take the initiative to determine the needs of the mentally disabled.
- --All statutory and regulatory definitions of handicapped before 1974 were either silent about or excluded the mentally handicapped.

WHAT CAN BE DONE

Following are examples of how HUD-assisted programs can be used to assist in deinstitutionalization.

Dallas area office

The Dallas area office was the only area office HUD headquarters officials could identify that had taken specific, sustained action to help provide community housing for the mentally disabled. The Dallas office had taken several actions to help local housing and mental health and retardation authorities in Texas and New Mexico use HUD-assisted programs to help deinstitutionalize the mentally disabled. The Dallas efforts resulted from the initiative of one office employee, who requested information from headquarters on HUD programs that could be used to house the mentally disabled. In response to his request, he was informed about the August 1971 HUD General Counsel decision concerning the inclusion of the retarded in the definition of handicapped and the President's November 1971 statement containing the directive to HUD to help provide special housing arrangements for the retarded.

After receiving the information, he developed guidelines to be used in placing the handicapped and the elderly in HUD-assisted projects. 1/ With the support of area office officials, he worked with State and local mental health and retardation officials and housing authorities in Texas and New Mexico to use existing space, rehabilitated buildings, and newly constructed centers under HUD-assisted programs to provide community housing and training for the mentally disabled. As of October 1975 the Dallas area office had helped provide 41 homes and apartments in Texas and New Mexico cities to house and provide community-based care to 170 mentally disabled persons. The Dallas office had also helped provide six clinics and centers in three cities in Texas and one in New Mexico which served over 600 mentally disabled persons monthly.

The accomplishments of the Dallas office in helping in deinstitutionalization were reported in a March 1975 HUD publication. Subsequently, the Dallas office received requests for information from local housing authorities interested in providing housing to the retarded. One request was from the Salem, Oregon, housing authority included in our review that was experiencing considerable difficulty in getting a program started to provide community housing for the mentally retarded. (See p. 59.)

HUD-assisted housing for discharged mental patients in Ohio

At HUD-assisted housing projects in two Ohio cities, some housing units were earmarked for persons discharged from State mental hospitals. In Columbus 55 of 226 units were reserved for discharged mental patients, and in Toledo 30 of 100 units were so reserved. The Toledo project opened in 1967 and the Columbus project opened in 1968.

The two projects were started as a result of efforts by the Ohio State Department of Mental Health and Mental Retardation to develop community facilities to serve exclusively as alternatives for elderly patients in mental hospitals who no longer needed institutional care. However, to comply with Federal housing legislation and policies, the residential units had to be made available to other segments of the population who were eligible for federally assisted housing. The State department entered into agreements with local housing

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1/ In February 1976 headquarters approved these guidelines as provisional pending departmental consideration as official policy.

authorities in Toledo and Columbus under which it agreed to provide supportive services to residents during the project's 40-year financing period.

As of June 1975 these two projects had, over the years, housed 185 persons in 85 units reserved for discharged mental patients. At that time 95 persons, ranging in age from 38 to 81, were living in the 85 units. Persons under 62 years of age were requred to meet disability criteria in the Social Security Act.

Efforts in Michigan and Massachusetts

The Michigan State Housing Development Authority initiated plans in 1972 to construct group homes for the retarded using a combination of State grants or loans and HUD interest or rent subsidies. As of August 1975, 24 group homes had been built or started. The State housing authority entered into cooperative agreements with the State departments of mental health and social services under which these two agencies would provide services or funds for services for the retarded persons placed in the group homes.

Massachusetts State legislation requires that at least 5 percent of certain public housing constructed after August 1971 be set aside for the handicapped. Although most of such housing was for the physically handicapped, the State department of community affairs helped fund seven community residences which housed 84 mentally disabled persons. To assist local housing authorities, the department of community affairs, in conjunction with the State developmental disabilities council, provided each housing authority with estimates of the number of retarded expected to be placed from institutions into their areas. The department also prepared guidelines on housing for the handicapped and on steps local housing authorities could take to educate the communities.

In addition, recognizing the lack of efforts by local housing authorities to help provide community housing for the retarded, the developmental disabilities council awarded a grant to the department of community affairs for hiring staff to work with local housing authorities in providing housing for the retarded.

HUD-Administration of Aging agreement

An example of specific action that HUD could take for the mentally disabled is an April 1975 interagency agreement between HEW's Administration on Aging and HUD. According to this agreement, HUD field offices were to take several actions aimed at helping the Administration on Aging implement its nutrition program by working with State and local housing authorities and managers of other HUD-assisted housing to make certain that they coordinate with State agencies on aging.

CHAPTER 13

OPPORTUNITIES FOR MORE INVOLVEMENT BY LABOR

Suitable employment is another critical need of many persons attempting to move from mental hospitals and institutions for the retarded and maintain residency in the community. Mentally disabled persons have been served by Department of Labor programs and have been helped to return to communities from institutions through job training and placement. Such training and placement have not been available to many mentally disabled persons remaining in or released from such institutions.

Labor administers several programs to help disadvantaged persons, including the mentally disabled, prepare for and obtain suitable employment. Labor has not, however, made a departmentwide, systematic effort to use its programs to help in deinstitutionalization. Also, Labor could help HEW and State and local mental health and retardation agencies accomplish deinstitutionalization by

--making more periodic evaluations of sheltered workshop compliance with regulations and success in preparing clients for and placing them in competitive employment;

--strengthening the role of the U.S. Employment Service in assisting in deinstitutionalization;

--more aggressively using leverage available under section 503 of the Rehabilitation Act of 1973, as amended, to help obtain suitable employment for the mentally disabled so that they can be returned to the community; and

--determining what additional steps can be taken to make the Comprehensive Employment and Training Act program more responsive to the needs of the mentally disabled released or to be released from public institutions.

BACKGROUND

Recognizing the importance of job training and employment for the handicapped, the President in 1947 established the President's Committee on Employment of the Handicapped to advise and assist on such matters and to serve as an advocate for the handicapped. In 1966 the Secretary of Labor was designated a member of the President's Committee on Mental

Retardation, and in 1974 President Ford urged employers to use the U.S. Employment Service as much as possible to help find jobs for the mentally retarded.

In 1954 the Congress, in Public Law 565, required the Employment Service to provide employment counseling and placement services to handicapped persons. It also required each State employment agency to designate at least one person in each employment office to see that the needs of the handicapped are met. In addition, legislation has been enacted (1) authorizing employers to pay subminimum wages to the handicapped so that they would not be denied employment opportunities, (2) requiring Federal contractors to take affirmative action to hire the handicapped, and (3) establishing the Comprehensive Employment and Training Act program to provide funds for job training and related services.

MENTALLY DISABLED IN SHELTERED WORKSHOPS

The Rehabilitation Act of 1973 required HEW to study the role of sheltered workshops in rehabilitating and employing the handicapped. HEW submitted its report to the Congress in 1975. The report, prepared by an HEW contractor, included the following information.

--There were more than 3,000 sheltered workshops in the United States, of which Labor permitted more than 2,700 to pay subminimum wages.

--Sheltered workshops served about 410,000 clients annually; the daily average was about 140,000. About 72 percent of those served were mentally disabled--53 percent mentally retarded and 19 percent mentally ill. About 22 percent of the mentally ill and about 13 percent of the mentally retarded workshop clients were from institutional settings.

--Although workshops were relatively successful in reducing the number and severity of problems of the handicapped, they had only limited success in preparing clients for and placing them in competitive employment and in providing long-term remunerative employment.

--Workshops placed only an estimated 10 percent of the clients they served annually into competitive employment. The most common type of employment for former workshop clients sampled was low-level, low-paying service jobs. Only 10 percent of the 182,000 persons leaving workshops annually were estimated to be placed into competitive employment. The study indicated that many persons from the workshops could end up unemployed.

--Of the 140,000 clients served daily, about 100,000 were engaged in extended employment by the workshop and earned low wages. Workshops serving the mentally disabled paid their clients about $1,0[illegible] annually. Many continued to depend on public support, such as SSI.

The contractor made a number of recommendations, including (1) lessening the extent to which SSI was reduced as a result of earnings, (2) making greater use of legislative requirements to employ the handicapped, and (3) intensifying placement efforts to obtain suitable jobs.

The Wage and Hour Division, Employment Standards Administration, is responsible for administering Labor's program for authorizing employers to pay subminimum wages to handicapped workers. Division officials said that they had not undertaken any efforts specifically directed toward the mentally disabled in sheltered workshops and that they annually made only a few onsite evaluations of workshops' compliance with regulations. According to them, this was because they did not have a specific mandate or enough staff.

MORE ASSISTANCE NEEDED FROM U.S. EMPLOYMENT SERVICE

State and local employment agencies received about 13.3 million applications during fiscal year 1974. Of these about 819,000 (6 percent) were from handicapped persons, including about 71,300 classified as mentally ill or retarded. Therefore, less than 1 percent of all applicants and about 9 percent of handicapped applicants were classified as mentally disabled. The employment agencies placed about 22,500 persons classified as mentally disabled during the year. Information on the number of these that were from institutions was not available.

Labor's Employment Service provides financial assistance to States for establishing and maintaining over 2,400 public employment offices. These offices are responsible for providing job assessment, outreach, training, counseling, testing, placement, and followup services to various groups, including the handicapped. However, (1) there has been no systematic effort to use the Employment Service program to assist in deinstitutionalization, (2) increased cooperation and coordination between State mental health agencies and State employment offices were needed, and (3) Labor's formula for reimbursing the States for their costs under the program did not appear to provide sufficient incentives to work with the more severely handicapped.

For example, officials from the Massachusetts Division of Employment Security said that:

--An agreement between the department of mental health and the division pertaining to cooperative efforts was not being fully implemented. For example, at the two institutions we visited no one from the division was participating in the case conference committees as called for by the agreement.

--Some mentally disabled persons referred to the division from other State agencies were not ready for competitive employment.

--Although a person in each division office had been designated as a "specialist" for services to the handicapped, the designation was only a formality in many offices primarily because of staff shortages.

--Labor's formula for determining the division's funding level, which emphasizes the number of job placements, has resulted in an effort to handle the nonhandicapped, who are easier to place.

According to an official from the Michigan Employment Security Commission, persons released from mental institutions and referred to his agency have not always been prepared for employment. He said that, when the mentally disabled came to his agency for job placement, they frequently needed education and training before they could be considered employable. He reportedly had difficulty placing the mentally ill because employers were afraid to hire them. He suggested more intensive placement efforts, an education program for employers, and a separate agency or staff of trained persons to work with the mentally disabled.

More incentives needed for placing the handicapped

Labor uses a balanced placement formula to allocate available funds to the States. The formula, designed to measure State agencies' performance, emphasizes the number of job placements. Although the formula was intended to motivate the States to serve special groups, including the handicapped, a Labor official said the formula did not provide enough motivation to serve the handicapped, who are harder to place.

According to an Employment Service official, she had neither received nor issued any instructions on the use of the employment program to assist in deinstitutionalization. She was aware of situations in which staff from local employment offices participated in release planning activities at mental hospitals and institutions for the retarded, but said this was not happening on a large-scale, systematic basis. She said that, were there a mandate to direct Employment Service efforts at deinstitutionalization, Labor could require or urge State and local employment offices to become more involved in such activities as release planning conferences and to help find suitable jobs for persons being returned to the community.

SLOW IMPLEMENTATION OF AFFIRMATIVE ACTION PROGRAM FOR THE HANDICAPPED

Section 503 of the Rehabilitation Act of 1973, as amended, and Labor regulations require each Federal contractor with a contract exceeding $2,500 to take affirmative action to employ and advance qualified handicapped persons in carrying out the contract. Executive Order 11758, dated January 15, 1974, gave Labor overall authority and responsibility for implementing section 503, including developing regulations. The order also required that the Federal Procurement Regulations, the Armed Services Procurement Regulations, and, to the extent necessary, any supplemental or comparable regulations by any Federal agency be amended to require compliance with section 503 and related Labor regulations.

On August 14, 1975, we issued a report to Congressman Dodd on the implementation of section 503 (MWD-76-20). We reported that Labor's implementation had been limited to issuing regulations and handling complaints by handicapped persons alleging employment discrimination. Labor had done little monitoring of contractors' compliance with its regulations and had not enforced some of the requirements.

Labor's progress had been hindered by such difficulties as staffing shortages, lack of coordination with State vocational rehabilitation agencies, and problems with its initial regulations. Also, as of July 1, 1975, the Armed Services Procurement Regulations had not been amended as required by Executive Order 11758 to require Department of Defense contracts to include provisions for compliance with section 503 and the regulations.

Labor has amended its regulations and established the Office of Federal Contract Compliance Programs to consolidate and improve three separate affirmative action programs: those for veterans, minorities and women, and the handicapped.

Labor officials told us in April 1975 that they had not made any specific efforts to use the affirmative action program to help deinstitutionalize the mentally disabled. Such efforts may be needed, however, in view of the findings of the HEW sheltered workshop study (see p. 166) and statements by some officials about trouble placing mentally ill persons because some employers were reluctant to hire them. (See pp. 168 and 198.)

LIMITED INVOLVEMENT UNDER THE COMPREHENSIVE EMPLOYMENT AND TRAINING ACT

The Comprehensive Employment and Training Act provides for job training and employment opportunities for the economically disadvantaged, unemployed, and underemployed. Under the act State and local governments sponsor comprehensive employment and training programs and receive grants from Labor.

Services that can be provided include recruitment, orientation, counseling, testing, placement, classroom instruction, institutional and on-the-job training, allowances for persons in training, supportive services, and transitional public service employment. Title III of the act provides for additional services to persons in particular need of such services, including youths, offenders, persons of limited English-speaking ability, older workers, and others that the Secretary determines have particular disadvantages in the labor market.

Although these programs have served the mentally disabled, no systematic effort has been made to use the programs to help achieve deinstitutionalization. According to a representative from Labor's Office of Policy, Evaluation, and Research, Labor had not worked specifically toward deinstitutionalization through the Comprehensive Employment and Training Act. Also, Labor had not designated the mentally disabled in or out of institutions as a special target group with particular disadvantages in the Labor market and eligibility for additional services under title III.

Labor has, however, worked with the National Association for Retarded Citizens to help fund on-the-job training programs for the retarded. The association combines funds from

Labor's Office of National Programs under title III of the act with other Labor funds it obtains from prime sponsors in 48 States and the District of Columbia to operate the program. During 1975 Labor provided about $770,000 to the program in addition to other Labor funds provided by the States.

Under the program, the association reimburses employers for part of the wages they pay to persons with intelligence quotients of 80 or below during initial on-the-job training. The entry wage must be at least $2.00 per hour and employment must average 35 hours weekly during training. Certain employers, such as Federal agencies, sheltered workshops, and institutions for the mentally retarded, cannot participate in the program.

Since 1967 about 12,000 retarded persons have been placed in competitive employment under the association's program. It was estimated that more than 5,500 retarded persons would receive training under the program during 1975. However, the program does not appear to be helping many institutionalized retarded persons return to the community. According to the association, only 183 retarded persons were moved from State institutions to community employment positions under the program in 1974.

Labor has also funded a project to train and place at least 94 mentally or emotionally handicapped persons in specific civil service positions with various Wisconsin State agencies. As of January 1976, 62 persons had been trained and employed under the project and another 15 were in training. Labor provided about $400,000 for this project, which started in April 1974 and is scheduled to be completed in June 1977.

CHAPTER 14

CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

Mentally disabled persons have been released from public institutions without (1) adequate community-based facilities and services being available or arranged for and (2) an effective management system to make sure that only those needing inpatient or residential care were placed in public institutions and that persons released were appropriately placed and received needed services. As a result, many mentally disabled persons enter, reenter, or remain in public institutions unnecessarily. Many others have been placed in substandard facilities or were not provided needed services. Many persons released from mental hospitals and institutions for the retarded have been placed in nursing homes, not necessarily because they were the most appropriate setting but because they were the only available alternative.

States have primary responsibility for caring for the mentally disabled. However, the Federal Government's role has grown to the point where it pays much of the cost both in institutions and in communities. The availability of funds under various programs and the restrictions and requirements imposed on the States using these funds heavily influenced the States' decisions on where to place the mentally disabled.

Mentally disabled persons frequently have a variety of needs, including housing, income support, mental health and medical care, education, vocational training, employment, and social services. When a person is in a public mental hospital or institution for the retarded, the institution is generally responsible for identifying needs and providing or arranging for services to meet these needs. However, when a person is placed in the community, several agencies share responsibility for providing services and funds, depending upon such factors as a person's age or income, the nature of disability or handicap, or the setting in which the person is placed.

Because State mental health and retardation agencies had to provide funds to operate and improve institutions for those who needed such care, they could not provide all the funds needed to place and support mentally disabled persons in communities. Most of their mental health budgets were generally used to support the care of persons in public institutions. They therefore had to rely on other agencies to provide funds and services for mentally disabled persons in communities.

In addition, other agencies are usually responsible for monitoring the quality of care being provided to the mentally disabled in communities, such as those in nursing homes.

Deinstitutionalization involves all levels and branches of government and many governmental agencies. Many problems associated with deinstitutionalization were attributable to:

--The absence of an effective management system for clearly defining objectives, roles, responsibilities, actions to be taken, and monitoring and evaluation to be done by various agencies and for effectively handling individual transitions from institutions to communities.

--The lack of a systematic way to finance deinstitutionalization which assures that persons are placed in the least restrictive environment most appropriate to their needs with provision for needed services most cost-effectively.

--The lack of criteria or standards for defining adequate or acceptable community placement and the least restrictive environment appropriate to the needs of persons with various types and degrees of mental disability.

Service delivery, legal, and financial responsibility for the mentally disabled in communities is divided among several agencies and all levels of government. However, with a few exceptions, the roles and responsibilities of agencies had not been clearly defined, understood, or accepted. Agreements among State agencies were frequently made, but they were either not comprehensive or not implemented. Several Federal and State agency officials and staffs we contacted were either uncertain of their roles and responsibilities or said they had none. For the most part, agencies administering programs that could help accomplish deinstitutionalization had not assessed the programs' impact on this goal or what more they could do to help implement it. Also, these agencies had frequently not acted systematically or sufficiently to help accomplish the goal.

Improvements are needed in procedures for moving persons from institutions to communities to make sure they are properly placed, continue to receive appropriate services, and are not unnecessarily returned to institutions. Release plans frequently either were not prepared or were incomplete; in some instances referral procedures were not adequate; and followup was frequently haphazard or nonexistent.

In most cases effective mechanisms for dealing with the division and fragmentation of responsibility and for effectively handling individual transitions from institutions to the community had not been developed or implemented. When such mechanisms did exist for pinpointing responsibility and effectively handling such transitions, conditions appeared to be better than when such mechanisms did not exist.

Federal, State, and local governments have not developed systematic ways to finance deinstitutionalization and the long-term care of mentally disabled persons not residing in public institutions or nursing homes. State mental health and retardation agencies, primarily responsible for the mentally disabled, generally devote most of their budgets to institutional care. The National Institute of Mental Health and the Developmental Disabilities Office provide only a small portion of the funds needed and used for care in communities. State and local agencies therefore rely on other State and Federal agencies to help provide funds for community-based care. Although other agencies have given support, they have not given enough to provide the needed community-based facilities and services.

The lack of funds specifically for deinstitutionalization has forced States to use whatever funds they could and to maximize Federal reimbursements. States have relied heavily on those Federal funds most readily available, particularly Medicaid and SSI. The availability of Medicaid funds for nursing home placements (coupled with difficulties in using such funds for other types of community care), restrictions under SSI, and other problems have resulted in many disabled persons being shifted from public institutions to nursing homes, which were frequently not the most appropriate setting. Various restrictions and prohibitions in the SSI program sometimes precluded the States from putting together a package of publicly funded services from several programs for persons in the community, thereby further encouraging placement in public institutions or nursing homes under Medicaid.

There has been no clear, comprehensive, consistent Federal strategy for helping State and local governments to return mentally disabled persons to, or keep them in, communities. Such questions as what constitutes acceptable community-based care and who should be treated in various settings have not been answered. In some cases, Federal courts have dictated procedures for answering such questions.

In addition roles, responsibilities, resource commitments, and specific actions to be taken by Federal agencies have not been determined. As a result, Federal agencies, including HEW, have not addressed deinstitutionalization comprehensively or systematically or given needed attention to it. Federal agency officials and staff administering programs that can or do greatly affect deinstitutionalization have not viewed their programs as affecting it and have not made such an effect an objective.

Federal requirements that can or do affect deinstitutionalization in such areas as program plans, interagency cooperation and coordination agreements, program implementation, and monitoring and evaluation are dispersed among several programs and agencies and have usually not been effectively applied to insure that mentally disabled persons receive needed services in the most appropriate setting most cost-effectively. Sustained, combined efforts directed at deinstitutionalization among Federal agencies, even within HEW, had not been undertaken.

Mechanisms for coordinating Federal efforts either have not addressed deinstitutionalization or have not been effective. Neither the Office of Management and Budget nor Federal regional councils have addressed deinstitutionalization or used the interdepartmental management by objectives system to manage deinstitutionalization. The President's Committee on Mental Retardation has tried unsuccessfully to mobilize or coordinate Federal agency efforts. An effective mechanism did not exist within HEW for coordinating efforts for the mentally ill.

The two principal Federal programs specifically directed at deinstitutionalization of the mentally disabled--community mental health centers and developmental disabilities--have helped, but have not fully accomplished their objectives. Other Federal programs have more greatly affected deinstitutionalization, but not always favorably. Developmental disabilities program objectives for stimulating, influencing, coordinating, and monitoring other agencies' activities have not been fully achieved. Coordination among agencies has improved but remains a serious problem. Likewise, many gaps in community services and facilities remain because of (1) the need for State mental retardation agencies to support both institutional and community programs, (2) the need for more community facilities and services than can be supported by the funds available under the program, and (3) the insufficient assistance by other Federal, State, and local agencies.

State developmental disabilities councils and agencies have recognized some of these problems, but their authority to resolve the problems was not commensurate with their responsibilities. Their roles for stimulating, influencing, coordinating, monitoring, and evaluating other agencies need to be strengthened and more clearly defined, and their efforts in these areas need to be intensified, particularly at the local level. HEW and other Federal agencies must also support State developmental disabilities programs by identifying specific actions other federally supported agencies can and should take to help accomplish program objectives.

The Developmentally Disabled Assistance and Bill of Rights Act of 1975 contains several provisions which, if effectively implemented, should resolve many problems we identified. However, without greater commitment and cooperation of other federally supported programs at the State and local level, substantial difficulty will apparently be experienced in achieving the act's objectives.

Although CMHCs and mental health clinics have increased the availability of community-based mental health services, they have not been totally successful in reducing unnecessary admissions or use of mental hospitals or in providing services to persons released from such hospitals. Community-based mental health services comprehensive enough to prevent unnecessary admissions to public mental hospitals and to provide a full range of mental health services to persons released from these hospitals did not exist in many communities. Medication was the only service provided to many released patients.

A coordinated system of care for the mentally ill through the CMHC program remains a goal rather than a reality. The CMHC program has developed separate from the public mental hospital system, making integration of the two care systems even more difficult. Because programs administered by other than mental health agencies can greatly affect deinstitutionalization, mental health agencies, CMHCs, and clinics must work more closely with the agencies administering these other programs.

Funding for community-based mental health services has not grown in proportion to the need. Mental hospitals still generally account for the major portion of State mental health budgets, and limitations, restrictions, and other problems have limited the opportunity for using such sources as SSI, Medicaid, and Medicare to help fund community-based care for the mentally ill. Declining Federal financial support for CMHCs has resulted in some communities being unwilling or unable to participate in the program. Some of these problems, and others, may lessen the States' ability to achieve the objectives of the Special Health Revenue Sharing Act of 1975 and the Community Mental Health Centers Amendments of 1975.

The Medicaid program appears to have been one of the most important factors influencing deinstitutionalization. But its impact has not been all favorable. Restrictions and incentives under the Medicaid program, coupled with restrictions and problems in other Federal programs and the lack of sufficient Federal action to provide alternatives to nursing home care, have resulted in shifts of:

--Many mentally disabled persons from facilities having specific standards for their care and treatment to skilled nursing and intermediate care facilities which generally do not have to comply with such standards.

--The costs of caring for the mentally disabled from mental health to welfare budgets and from State to Federal budgets.

--Responsibility for caring for the mentally disabled from the mental health system to the welfare system, which was frequently not prepared or equipped to handle the special needs of the mentally disabled.

Other than SNFs and ICFs, the development and use of alternatives, such as day treatment, clinic services, or home health, to inpatient mental hospital care and residential care in public institutions for the retarded under Medicaid has been limited. Federal requirements that directly or indirectly pertain to the development or use of such alternatives differ by type of Medicaid coverage--inpatient mental hospital care for persons 65 or older or under 21 and residential care in public institutions for the retarded. HEW needs to more aggressively monitor and enforce existing requirements. Incentives for developing and using alternatives to inpatient, residential, and nursing home care and measures for reducing and eliminating restrictions against or impediments to developing and using such alternatives need to be explored.

HEW was not enforcing its regulations that required States receiving Medicaid reimbursement for the care of persons 65 or older in mental hospitals to make at least annual showings that they were satisfactorily progressing toward developing and implementing comprehensive mental health programs for persons of all ages. States receiving Federal Medicaid reimbursements for the care of retarded persons in public institutions are not required to develop and implement plans for using community-based alternatives. HEW regulations require that States document instances in which persons are placed in ICFs only because of the absence of alternatives and that active exploration for alternatives be initiated. More emphasis needs to be placed on effectively implementing this requirement.

SNFs and ICFs have many mentally disabled patients and residents, but there are no special standards for them except when more than half the residents in an ICF are retarded. In some States, SNFs and ICFs have been filled with so many mentally disabled persons that other persons needing care in such facilities cannot obtain it. As a result, excessive costs have been incurred under Medicaid for unnecessary stays in general hospitals. Also, in some instances States apparently may be improperly claiming Federal reimbursement for mentally ill persons under 65 in those SNFs and ICFs in which more than half the patients or residents are mentally ill.

HEW also needs to improve its program for identifying and correcting situations in which mentally disabled persons are inappropriately placed or are not receiving needed services in public institutions, SNFs, and ICFs. Utilization controls have not achieved their intended results.

Required reviews were frequently either not done or not done properly. Deficiencies identified by such reviews were not always corrected because effective mechanisms did not exist for resolving differences of opinion, State Medicaid agencies did not always make sure that appropriate action was taken in response to the reports and recommendations of review teams, or suitable alternatives did not exist. If utilization controls are to be effective, more efforts need to be devoted to developing such alternatives to care in mental hospitals, institutions for the retarded, SNFs, and ICFs. There also appears to be a need for mental health and retardation professionals to participate in the utilization control process for mentally disabled persons in SNFs and ICFs.

For the most part, States have not implemented systematic procedures for release planning and followup to make sure that persons receive needed services in the community and that their placement continues to be appropriate. HEW needs to clarify and strengthen its requirements for release planning and followup, provide more assistance to the States in developing systematic approaches to release planning and followup through Medicaid and other programs, and monitor and enforce compliance with applicable requirements.

Many mentally disabled persons need supervision and support services in addition to room and board but do not need the medically oriented care provided or required to be provided by ICFs. Because of the complexities of Medicaid requirements and their orientation toward medical rather than rehabilitative or developmental needs, the development of ICFs with less than 16 beds for the retarded has been limited. Also, restrictions in the SSI program, if enforced, would limit or prohibit the use of such funds for persons needing some supervision and support services, thereby limiting the States' ability to use alternatives to ICFs. Because of these problems, there is a need to determine how Federal funds could best be used to help the States provide the type of care needed by mentally disabled persons not always needing the medical care typically associated with ICFs.

Furthermore, efforts [illegible]blic institutions for the retarded to comply with IC[illegible]irements could result in the inappropriate placement of retarded persons in communities or the expenditure of funds to improve institutions to a greater extent than needed inasmuch as many of the residents and those on the waiting lists are believed not to need care in such facilities. HEW therefore needs to closely monitor and evaluate the impact of its ICF regulations in this regard.

The Medicare program may be encouraging unnecessary hospitalization by restricting outpatient mental health care it covers to 50 percent of the cost, or $250 annually, whichever is less. This dollar limitation has not changed since the Medicare program was enacted in 1965 despite increases in the costs of medical care. In addition, HEW monitoring of State agency surveys of mental hospital compliance with discharge planning and followup requirements under Medicare has been limited. Furthermore, HEW frequently did not obtain first-hand information on the extent to which mental hospitals corrected deficiencies it identified because it did not make routine and systematic surveys at such hospitals.

SSI funds have helped mentally disabled persons return to and remain in communities. However, the lack of standards in the SSI program has allowed persons to be placed into substandard facilities or without provision for support services. In addition, certain aspects of the SSI program may have hampered deinstitutionalization by inadvertantly resulting in the inappropriate placement of mentally disabled persons.

Reductions in SSI payments resulting from support and maintenance provided by public agencies may have influenced the placement of persons in ICFs under the Medicaid program. The prohibition of SSI payments to persons in community-based public facilities and the financial incentives to the States under Medicaid compared to SSI (1) may have resulted in the placement in ICFs of persons who did not need that level of care and (2) may have inhibited the provision of halfway house services by publicly operated CMHCs. Enforcement of

SSI requirements pertaining to the reduction of SSI benefits for persons placed in facilities providing services that could be provided in ICFs under Medicaid also could have hindered the development of alternatives to institutional and nursing home care. Financial incentives to the States under Medicaid relative to SSI could also result in persons being placed in ICFs to enable the State to minimize its own expenditures.

The social services programs have provided funds for helping mentally disabled persons return to and remain in communities. Although many mentally disabled persons have been released from public institutions without provision for needed services, many States had not used all the Federal funds available to them under the social services programs. Reasons for this included the controversy and confusion surrounding the program and the inability or unwillingness of States to provide the necessary matching funds.

In addition, HEW had not monitored or enforced requirements for social service plans responsive to individual needs and for appropriate foster placements. A new social services program went into effect in 1975. However, HEW's regulations for the new program do not require that service plans be responsive to each person's needs or that foster placements are and continue to be appropriate. Furthermore, although deinstitutionalization is a program goal, HEW's regulations do not require States to link their program plans to similar goals of mental health agencies, CMHCs, or other agencies.

HEW and State vocational rehabilitation agencies need to give more emphasis to serving the more severely mentally disabled. HEW needs to (1) define an appropriate role for the vocational rehabilitation program for assisting in deinstitutionalization, (2) provide more assistance and guidance to States and monitor and evaluate their efforts relating to this goal, (3) clarify the definition of severe disability for the retarded and make sure that the States use consistent classification procedures, and (4) make sure that decisions to deny vocational rehabilitation services are made in accordance with its regulations.

Rehabilitating the more severely mentally disabled will clearly be more difficult and costly than rehabilitating the less severely disabled. However, if these persons are to be successfully deinstitutionalized, their needs must be better recognized. Because of the pressures on the State agencies to show successful rehabilitations, funds may need to be earmarked for these persons so that they will not have to compete with the less severely disabled in the community.

The lack of suitable housing is preventing many mentally disabled persons in public institutions from being returned to the community and causing others to be inappropriately placed in nursing homes. The Federal Government, primarily through Medicaid, is paying at least half the costs for caring for many of these persons.

Recognizing the need for suitable community housing for the retarded, the President directed HUD to help develop special housing arrangements to facilitate independent living for retarded persons in the community. HUD had not taken substantive action to inform or instruct its headquarters and field staffs or local housing authorities about what they were to do to carry out the President's directive. Almost without exception the officials and specialists for the elderly and handicapped we contacted in HUD's regional and area offices were not aware of the Presidential directive, did not know that the retarded could be regarded as handicapped for HUD programs, and had not acted to inform or instruct local housing authorities or others about what they could do to help in deinstitutionalization or to consider the needs of the mentally disabled in their housing assistance plans.

Local housing authorities we contacted had generally not identified the needs of the mentally disabled in their housing assistance plans. Many did not understand how their programs could assist in deinstitutionalization.

Labor programs have helped mentally disabled persons return to communities from institutions by providing job training and placement and by authorizing the payment of subminimum wages so that the mentally disabled who were not fully productive could be employed. The Secretary of Labor, however, had not informed or instructed the Department's staff about their roles and responsibilities for helping in deinstitutionalization, and program administrators had not considered their programs' impact on this objective. Many mentally disabled persons served by sheltered workshops were not placed into competitive, productive employment, and others need job training and placement assistance to help them lead normal or close to normal lives in the community.

Actions Labor can take to more effectively help mentally disabled persons return to and remain in communities include (1) making more periodic evaluations of the progress made by sheltered workshops in preparing mentally disabled persons for and helping them obtain suitable employment and (2) strengthening the role of the Employment Service, Comprehensive Employment and Training Act programs, and the affirmative action program for the handicapped to help train and place mentally disabled persons.

RECOMMENDATIONS TO THE CONGRESS

Solutions to many deinstitutionalization problems involve many Federal agencies under different congressional committees. Therefore, we recommend that each House of the Congress consider designating a committee with overall responsibility to oversee all Federal efforts toward deinsitutionalization of the mentally disabled. This committee should:

--Make sure that Federal programs be directed so that the congressional policy that the mentally disabled have a right to be treated in the least restrictive setting appropriate to their needs is achieved. For example, the Congress could make deinstitutionalization a specific objective of HUD's housing and community development programs

--Establish legislative links among federally supported programs so that they are mutually supportive in accomplishing deinstitutionalization and that they are used to make sure that mentally disabled persons are placed in the least restrictive setting appropriate to their needs with needed support services provided most cost-effectively. For example, Medicaid requires States to implement utilization control programs to, among other things, identify persons inappropriately placed in mental hospitals, SNFs, and ICFs, including institutions for the retarded. Federal legislation also requires States to develop plans for eliminating inappropriate institutional placements under developmental disabilities and mental health programs. However States are not required to specifically identify how they will implement their title XX programs to (1) help eliminate or reduce inappropriate placements identified by utilization controls, (2) support State mental health and developmental disabilities programs aimed at deinstitutionalization, or (3) help make sure that eligible persons released from institutions are not placed in substandard facilities or without provision for needed services.

Because the lack of coordination and case management at the local level was identified as a major problem, the Congress should consider requiring State developmental disabilities programs to concentrate on the solution of this problem.

Also, the Congress should consider amending section 1833(c) of the Social Security Act to increase the amount of outpatient mental health coverage available under Medicare. This could be done by increasing the $250 limit, the percent of Federal reimbursement, or both or by authorizing a combined limit on inpatient and outpatient mental health care to encourage outpatient care.

In several laws the Congress has expressed its preference for community-based care for the mentally ill. Declining Federal financial support for CMHCs has impeded the development of them and of mental health programs in communities. There remains a critical shortage of community mental health services, and successful methods for financing these services have not yet been developed. The most direct Federal funding for such services comes from the CMHC and Special Health Revenue Sharing programs. Although Special Health Revenue Sharing funds are administered by the States, CMHC grants are generally made directly by the Federal Government to local applicants. As a result, two separate mental health "systems" continue to be promoted--mental hospitals and CMHCs. Coordination between CMHCs and mental hospitals and between mental health agencies and others remains a serious problem.

Therefore, the Congress should consider consolidating the funds earmarked for mental health under the Special Health Revenue Sharing and CMHC programs into a formula grant to State mental health agencies. This combined grant could (1) more effectively accomplish the objectives of the two programs, (2) give State mental health agencies greater capability and flexibility so they can provide a coordinated, comprehensive mental health system with emphasis on community-based care, and (3) provide a more stable funding source for community mental health services until other funding methods are fully developed.

Because of (1) the problems cited by the Department of Labor that could hinder greater efforts for the mentally disabled in its programs, (2) the problems cited by an HEW contractor regarding finding suitable jobs for the mentally disabled leaving sheltered workshops, and (3) the problems experienced by State vocational rehabilitation agencies in serving the more severely mentally disabled, the Congress should consider whether additional legislative initiatives are needed to help Federal, State, and local agencies expand their efforts for the severely mentally disabled. One problem appears to be insufficient consideration for the extra efforts and difficulties involved in trying to help groups with particular disadvantages, such as the mentally disabled. Options to consider include earmarking funds for this purpose or establishing a weighted case closure or funding formula to encourage services to this group.

RECOMMENDATIONS TO THE DIRECTOR OF OMB

We recommend that the Director of OMB:

1. Direct Federal agencies to develop and implement an interdepartmental objective for accomplishing deinstitutionalization and recommend that the President adopt deinstitutionalization as a Presidential objective in the interdepartmental management by objectives system.

2. Clearly identify the roles and responsibilities of and specific actions to be taken by Federal agencies.

3. Direct Federal regional councils to mobilize, coordinate, and evaluate Federal agency deinstitutionalization efforts at the regional level.

RECOMMENDATIONS TO THE SECRETARY OF HEW

We recommend that the Secretary of HEW:

4. Define roles and responsibilities of and specific actions to be taken by HEW agencies to accomplish deinstitutionalization objectives.

5. Designate an agency or official responsible for overseeing and coordinating the Department's efforts relating to deinstitutionalization.

6. Determine how best to make sure that State agencies administering HEW-supported programs develop and implement effective case management systems for persons being released from public institutions so that (a) individual's needs are fully assessed, (b) arrangements are made for appropriate placement and needed services, (c) sufficient followup is provided to ascertain that placements continue to be appropriate, services needed are received, and changes needed in placement or services are effected, (d) responsibilities and accountability are clearly identified, and (e) programs are evaluated for their cost effectiveness.

7. Determine what changes need to be made in the Medicaid program or other Federal programs to give States incentives to (a) place mentally disabled and other persons needing housing, income maintenance, some supervision, and support services, but not always medical care, in the most appropriate setting and (b) avoid unnecessary placements in SNFs and ICFs.

8. Determine what roles CMHCs, developmental disabilities, social services, and other Federal programs should have in helping to resolve the problems associated with the placement of large numbers of mentally disabled persons in SNFs and ICFs and to achieve systematic approaches to release planning and followup.

9. Require HEW agencies to help States develop alternative facilities or provide services to those persons identified by independent medical or professional review teams to be inappropriately placed or not receiving appropriate services.

10. Guide HUD, Labor, ACTION, and other Federal agencies on specific actions they can take to assist in deinstitutionalization and recommend to the President that such actions be taken.

11. Develop a coordinated departmental research, evaluation, and technical assistance effort to help the States provide cost-effective community-based care to the mentally disabled who are more appropriately served there than as inpatients or residents in institutions.

12. Determine, in consultation with the States, a clear and consistent Federal role in the mental health and retardation area and make appropriate recommendations to the Congress for a long-term approach to alleviating the problems identified in this report.

13. Establish guidance or criteria, in cooperation with the States, on (1) the least restrictive environment appropriate for persons with various types and degrees of mental illness and retardation and (2) under what conditions (for example, the types, quantities, and quality of facilities and services available) persons should be treated in institutions or communities.

14. Request permission from the House Committee on Interstate and Foreign Commerce and the Senate Committee on Labor and Public Welfare to accept this report and the five related reports to the directors of the HEW regional offices as partial fulfillment of the requirements for studies in section 204 of Public Law 94-103.

15. Require HEW-supported State and local agencies to coordinate with State developmental disabilities councils and agencies in achieving deinstitutionalization objectives.

Developmental disabilities

16. More clearly identify in HEW's regulations the responsibilities of State developmental disabilities councils and agencies for stimulating, influencing, coordinating, monitoring, and evaluating other agencies' activities, including local housing and community development, employment, and manpower training. This could include requiring State developmental disabilities councils or agencies to help (a) local governments prepare and implement their housing assistance and community development plans as they relate to the needs of the developmentally disabled and (b) State and local employment agencies in developing better ways to assist in deinstitutionalization by providing training to their staffs and encouraging them to participate in release activities.

17. Monitor and evaluate State progress and problems in carrying out their responsibilities.

18. Require State developmental disabilities councils and agencies to devote more effort to local coordination, particularly in regard to making certain that agency responsibility for providing facilities, services, and followup for persons in the community is defined.

19. Designate the problems identified in this report as areas of national significance and direct that some of the Department's discretionary funds be used to develop and test solutions.

20. Require State developmental disabilities councils to make sure that the roles and responsibilities of and specific action to be taken by State and local agencies for deinstitutionalization are identified.

21. Obtain the assistance of State Governors in making the developmental disabilities program more effective in coordinating and stimulating State and local agency efforts toward deinstitutionalization.

Special Health Revenue Sharing and CMHCs

22. Direct that State mental health plans required under the Special Health Revenue Sharing Act of 1975 clearly identify the roles and responsibilities of mental hospitals, CMHCs, clinics, and other agencies for mentally ill persons in communities and that States describe procedures for making sure that these are understood and accepted, through such mechanisms as agreements among the concerned organizations. The agreements could cover such responsibilities as developing, providing, or funding community alternatives to institutional care; preparing and implementing individual service plans; following up on persons after release from mental hospitals; and overall monitoring, evaluation, and case management to make sure that the system established functions effectively.

Medicaid

23. Monitor and enforce compliance with Medicaid regulations requiring that:

    a. States prepare annual reports on progress toward developing and implementing comprehensive mental health programs for persons of all ages. This should be coordinated with requirements under the Special Health Revenue Sharing Act of 1975.

    b. States (1) document instances in which persons are placed in ICFs because of the unavailability of community alternatives and (2) actively seek alternatives.

    c. Release plans which include arrangement for appropriate services, protective supervision, and followup be prepared and implemented.

    d. SNFs and ICFs be capable of providing appropriate restorative and development services to their mentally disabled patients and residents.

    e. Mentally ill persons under 65 are not entitled to Medicaid benefits in SNFs and ICFs considered to be institutions for mental diseases.

    f. Interagency agreements required under Medicaid are developed and implemented and adequately address roles and responsibilities for deinstitutionalization.

24. Clarify and strengthen release planning and followup requirements so that persons' comprehensive needs are assessed and that responsibilities for implementing release plans and followup are clearly identified. Make release planning requirements as consistent as possible for mental hospitals, SNFs, and ICFs, including institutions for the retarded. This should be done in coordination with the Bureau of Health Insurance and other appropriate agencies.

25. Help States develop and implement systematic approaches to release planning and followup.

26. Guide the States on the types of services to be provided to mentally disabled persons in SNFs and ICFs.

27. Clarify the ICF regulations on facilities with fewer than 16 beds and determine whether the requirements are too medically oriented to meet the needs of the retarded.

28. Evaluate the impact that the 1977 ICF standards will have on deinstitutionalization and determine whether national policies or actions will be needed to preclude the release of retarded persons to inappropriate community settings as a result of efforts by public institutions to meet staffing and other requirements.

29. Require States to effectively implement utilization controls and make sure that they accomplish intended results through HEW's validation surveys.

30. See that more mental hospitals and institutions for the retarded are included in validation surveys of State utilization control programs.

31. Require that mental health or retardation professionals be included on such validation surveys to evaluate the appropriateness of placement; feasibility of alternate placement; and appropriateness of services for mentally disabled persons in public institutions, SNFs, and ICFs.

32. Require that (a) State independent review teams include mental health or retardation professionals, as appropriate, to make similar evaluations for the mentally disabled or (b) State review teams determine that such evaluations had been made for mentally disabled persons by qualified mental retardation or mental health professionals or provide additional training in mental health and retardation to those conducting independent reviews for the States.

33. Require State Medicaid agencies to see that other State and local agencies responsible for planning, developing, and providing community-based alternatives or services become a formal part of the utilization control process by receiving pertinent reports and recommendations of independent review teams.

34. Make certain that States have effective mechanisms for implementing recommendations of independent review teams and for resolving differences of opinion between the teams and staffs at the facilities being reviewed.

Medicare

35. Expand monitoring and enforcement of requirements for release planning and followup at mental hospitals under Medicare to provide more systematic coverage of such facilities. This should be done in conjunction with similar efforts for compliance with Medicaid requirements.

Social services

36. Evaluate State implementation of HEW regulations under title XX to determine whether (a) individual needs are being fully assessed, (b) services provided are responsive to individual needs to keep persons in the community, and (c) more specific requirements for individual service plans are needed.

37. Consider the desirability and feasibility of requiring States participating under title XX to (a) make certain that eligible persons placed in foster care or other residential settings by State or local agencies are in settings which are appropriate to their needs and which meet applicable minimum standards, that they receive appropriate services, and that they continue to be appropriately placed and receive appropriate services responsive to their needs and (b) provide certain services to eligible persons to enable them to return to or remain in communities, particularly to help prevent admission or readmission to public institutions.

38. Evaluate the extent to which State title XX agencies describe and implement coordinated planning and services provision with other agencies, such as developmental disabilities, health, mental health, Medicaid, social security, education, and housing, as they relate to deinstitutionalization. Determine whether legislative or regulatory changes or other actions are needed to help insure adequate linkages among related programs.

Vocational rehabilitation

39. Provide more assistance and guidance to State vocational rehabilitation agencies and monitor and evaluate their programs so that they devote appropriate efforts to help the more severely mentally disabled, particularly those in and released from institutions. This should be done in coordination with NIMH, DDO, and the Department of Labor.

40. Clarify the definition of severe disability as it relates to the retarded and make certain that States are using consistent procedures and criteria for classifying persons as retarded.

41. Make certain that decisions to deny vocational services to the mentally disabled on the basis of their incapability of achieving a vocational goal are made only when the absence of vocational potential has been demonstrated beyond any reasonable doubt and in consultation with a mental health or retardation professional.

RECOMMENDATIONS TO THE SECRETARY OF HUD

We recommend that the Secretary of HUD, in cooperation with HEW:

42. Direct that a Department-wide action plan be developed, possibly through its MBO system, identifying roles and responsibilities of component agencies, as well as specific steps to be taken, to assist in deinstitutionalization.

43. Expand efforts to inform and train regional and area office personnel on the applicability of HUD programs to deinstitutionalization and what their specific responsibilities are, including actions to be taken.

44. Issue guidelines to HUD regional and area offices and to local governments and housing and community development agencies so that mentally disabled persons are housed in appropriate facilities and that arrangements for support services have been made with mental health, social services, or other agencies and organizations.

45. Direct that regional and area office personnel work more closely with HEW, State, and local mental health and mental retardation officials so that housing provided to the mentally disabled is appropriate.

46. Inform local governments and housing and community development agencies, as well as directors and managers of HUD-assisted projects, on the applicability of HUD-assisted programs to the mentally disabled and on specific steps that can be taken, such as earmarking a specific number of housing units for the mentally disabled.

47. Monitor and evaluate the extent to which and how the mentally disabled have been served by HUD-assisted programs and the extent to which local agencies have considered the needs of the mentally disabled in their community development and housing assistance plans.

RECOMMENDATIONS TO THE SECRETARY OF LABOR

We recommend that the Secretary of Labor, in cooperation with HEW:

48. Direct that a Department-wide strategy and plan be developed and implemented to help accomplish deinstitutionalization objectives.

49. Expand efforts to monitor and evaluate the compliance of sheltered workshops with requirements.

50. Strengthen the role of State and local employment agencies by (a) encouraging or instructing them to assist mental health and retardation agencies by participating in release planning and followup and helping to find suitable jobs for the mentally disabled, (b) providing more incentives to them to assist the more severely mentally disabled, and (c) making sure that the specialist for the handicapped in each employment office is adequately trained to help the mentally disabled.

51. More aggressively monitor and enforce the requirements under section 503 of the Rehabilitation Act of 1973, as amended, so that employers take affirmative action to hire the handicapped, including the mentally disabled.

52. Determine what additional steps can be taken to make the Comprehensive Employment and Training Act program more responsive to the needs of the mentally disabled released from public institutions.

CHAPTER 15

AGENCY COMMENTS AND OUR EVALUATION

We received comments on a draft of this report from the Office of Management and Budget; the Departments of Health, Education, and Welfare; Housing and Urban Development; Labor; and Justice; and the National Association of State Mental Health Program Directors.

These Federal agencies and the association generally agreed with the thrust of our report. HUD and the Department of Labor generally concurred in our recommendations and outlined a number of actions they have taken, were taking, or planned to take to help in deinstitutionalization.

Because of the complexities of the issues and the number of agencies involved, HEW provided only brief formal comments on our draft report and did not comment on our recommendations. However, the HEW Assistant Secretary for Planning and Evaluation was given responsibility for coordinating the Department's response to our recommendations and for developing an implementation plan. HEW said this plan and HEW's comments on our recommendations will be provided within 60 days following the issuance of this report.

The comments we received and our evaluation are summarized below.

OFFICE OF MANAGEMENT AND BUDGET

OMB endorsed the goal of appropriate care and treatment of the mentally disabled with a full range of community care as an alternative to institutional care. It cited its proposal to consolidate 16 categorical Federal health programs as an attempt to help overcome the fragmentation problem.

OMB stated that the administration will continue to support appropriate services to the mentally disabled by

--requesting appropriate levels of Federal resources to support State and community efforts to develop appropriate service alternatives for the mentally disabled;

--supporting the State and local decisionmaking responsibilities in this area; and

--proposing consolidation into block grants of narrow categorical health and related service programs which, as currently designed, make program integration and coordination at the State and local level extremely difficult.

OMB said, however, that the actions we proposed it take, as stated on page 184, were unwarranted and would constitute an unjustifiable intrusion into traditional and appropriate State and local responsibilities. We recognize that improved coordination at the local level should result from removing impediments at the Federal level, such as the multiplicity of programs. However, this will be a long-term effort, and even with some program consolidation, there are and will be several Federal departments and agencies administering programs that can, do, or could affect deinstitutionalization.

Because OMB and Federal regional councils are responsible for coordinating Federal agencies' activities, we believe the actions that we are recommending they take are necessary and appropriate. Further, we do not believe these actions would interfere with State and local responsibilities. The actions we are recommending are aimed at making certain that roles, responsibilities, and actions to be taken by Federal agencies within their legislative authority are clearly identified and that their activities are coordinated and evaluated. The recommendations are aimed at (1) removing obstacles to the development of appropriate community alternatives for the mentally disabled, (2) providing positive actions by Federal agencies to assist State and local governments in doing this, and (3) enhancing interagency collaboration.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

HEW generally agreed with the thrust of our report and recommendations. Because of the many HEW agencies involved in deinstitutionalization and the complexities of the issues, HEW provided only brief formal comments on our draft report. However, HEW staff provided informal comments on our draft report, and we made technical changes where appropriate.

In addition, HEW staff believed that certain aspects of deinstitutionalization needed further analysis and consideration. Some of their comments follow.

Assistant Secretary for Planning and Evaluation

Deinstitutionalization is a joint responsibility of Federal, State, and local governments. Although there are many actions that the Federal Government could and should take to address deinstitutionalization, it is largely a State responsibility and the impetus must come from the States. Some of the major reforms States must be willing to make are

--reforming budget processes to enable funds to flow to a variety of care settings rather than only to institutions,

--coordinating different services at State and local levels,

--extending existing or developing new intergovernmental relations with communities and shifting partial or total responsibility for care to communities,

--developing community services,

--working with communities to help them become more receptive to having mentally disabled persons reside in their neighborhoods, and

--working with unions and State employees whose employment in institutions may be affected.

The Federal Government should assist States in these actions through fiscal incentives and capacity building efforts.

More emphasis needs to be placed on determining the costs of serving persons in alternative long-term care settings. Findings of various studies comparing the costs of institutional and community care are not conclusive and indicate that the state of the art of determining the costs of alternative care settings needs to be further developed.

Assistant Secretary for Health

Better planning efforts at Federal, State, and local levels are needed so that a balanced system of care is developed which provides relevant and high-quality services in institutions and communities. Also, fiscal incentives are needed to encourage local communities to accept responsibility for serving the more chronically disabled, and more interaction is needed between State and local governments.

The problem of finding, training, and supervising, and monitoring the personnel needed in a community care system needs to be addressed. The National Institute of Mental

Health has recently identified training and retraining for deinstitutionalization and community support as a major priority for its services manpower program. Also, the Division of Long-Term Care in the Health Resources Administration believes that there is a need to increase efforts to adequately prepare staff in community long-term care facilities to serve persons released from State institutions and that such efforts are related to its mission.

There are no clear and generally agreed upon criteria for determining what services and settings are most appropriate and least restrictive for persons with different types and degrees of mental illness or disability under varying circumstances. There is a need for (1) additional research to determine the relative costs, benefits, and cost distribution among agencies for community-based care and rehabilitation programs and (2) continuing discussion about this issue among consumers, service providers, professionals, citizens, lawyers, and others.

Assistant Secretary for Human Development

Since the enactment of the Rehabilitation Act of 1973, State vocational rehabilitation agencies have been realigning their resources to concentrate on serving more persons with severe mental disabilities and have increased the proportion of rehabilitated persons who are classified as severely mentally disabled. However, program improvements in the coverage of mentally disabled persons, including those in institutions, do need to be made.

The Education for All Handicapped Children Act of 1975 provides for substantial Federal support for the education of handicapped children both in public schools and in institutions. The implementation of this act can greatly affect deinstitutionalization.

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

HUD stated that, in general, our report accurately reflected many problems historically associated with attempts to use its housing programs for mentally disabled persons.

In regard to our recommendations, HUD stated that it has taken, was taking, or would take several actions to improve the Department's responsiveness to the Federal deinstitutionalization effort. HUD said that it:

--Issued instructions to its field offices in early 1975 directing its regional administrators to give adequate and full support to increasing HUD's responsiveness to the special needs of the elderly and handicapped.

--Selected 10 applicant groups in April 1976 for direct loans whose projects should provide about 450 living units for the developmentally disabled. These projects will be monitored by HUD in cooperation with HEW and will serve as a basis for establishing standards for this type of project and should permit greater use of HUD programs for such facilities.

--Has established a departmental action force to plan for the implementation of section 504 of the Rehabilitation Act of 1973 (see p. 215) pending the issuance of guidelines by HEW.

--Was considering adopting regulations that would prohibit automatically denying admission of mentally retarded or mentally ill persons, as defined in HUD legislation, to low income housing.

--Was directing its field offices to screen more carefully all community development applications for strict compliance with requirements to assess the housing needs of the handicapped. However, HUD said it is difficult to find that local housing assistance plans are not consistent with housing and community needs and objectives as the plans relate to the handicapped because complete data on such needs and objectives usually is not available.

--Will revise its low income housing production procedures so that they address the housing needs of the mentally disabled as well as the needs of the elderly and physically handicapped.

--Will sponsor a demonstration and evaluation of small group homes which will result in guidelines for HUD staff and for sponsors on how to develop such facilities for the handicapped using HUD resources.

--Plans to sponsor a conference of housing managers for the handicapped to enable them to discuss their management problems, exchange ideas, and learn of new concepts to enhance the development and delivery of housing for the handicapped.

In addition, the Assistant Secretary for Consumer Affairs and Regulatory Functions said that she was incorporating a number of action steps into the fiscal year 1977 operating plan under the Department's Goals Management (management by objectives) System aimed at preventing unnecessary institutionalization of mentally and physically handicapped persons. Specific actions will include

--a review of the applicability of existing HUD minimum property standards to the development of small group homes and similar supportive-type living arrangements,

--a mangement meeting with HUD field personnel to enhance their capability to help sponsors use HUD resources to meet the special housing needs of the handicapped,

--coordinating the publication and distribution of an updated management guide for congregate housing facilities, and

--assuring the delivery of adequate social and other services in coordination with other Federal agencies.

The Assistant Secretary will also coordinate consumer input into the formulation of HUD policy on criteria for selecting applicants for loans under its section 202 program for the elderly and handicapped. The goal will be to make certain that small, nonprofit, community-based organizations are afforded the same opportunity to receive funding as are larger, more experienced applicants.

With respect to recommendation # 44, HUD stated it could not issue guidelines to make certain that adequate facilities and supportive services are provided to the mentally disabled through the community development block grant program because such action would be contrary to legislative intent. However, our recommendation was not intended to mean that HUD funds necessarily be used, but rather that organizations responsible for administering HUD-assisted programs make certain that mentally disabled persons are not placed in their facilities without assurances from mental health, social services, or other agencies or organizations that the facilities are appropriate and that needed supportive services will be provided.

We believe that the actions recently taken by HUD as well as those it is taking and plans to take are responsive to the needs of the mentally disabled and to our recommendations. We believe, however, that HUD should work with HEW to develop and implement effective procedures for making certain that the housing and community development needs of the mentally disabled are identified and made available to local governments and HUD field offices. One potential source of some of this information might be the reports of independent medical and professional review teams required under Medicaid. (See ch. [illegible])

DEPARTMENT OF LABOR

The Department of Labor, which provided oral comments on our draft report, generally agreed with our findings and recommendations. Labor officials said that Labor programs have helped train and find jobs for many mentally disabled persons. They stated, however, that providing more help to the mentally disabled presented particularly difficult problems, especially in its Employment Service and Comprehensive Employment and Training programs, because of (1) the distance between public institutions and employment offices and Comprehensive Employment and Training program sponsors, (2) incentives in both programs aimed at making as many job placements as possible, which might discourage efforts to help the more hard to place mentally disabled, and (3) limited resources in both programs for addressing the problems of target groups, such as the mentally disabled, with particular problems in the employment market. The reluctance of many employers to hire the mentally disabled was also cited as a problem.

In addition, Labor stated that the decision to further expand training and employment services to this especially disadvantaged group using resources available under the Comprehensive Employment and Training Act rests primarily with the State and local prime sponsors. They determine how allocated resources will be used in their jurisdictions.

Labor officials also said that as a result of a 1973 decision by the U.S. District Court for the District of Columbia, it had been enforcing standards for the payment of minimum and subminimum wages to patients who also work in State institutions, including those for the mentally ill and retarded. They believed that the enforcement of these standards helped the deinstitutionalization effort by (1) making certain that mentally disabled persons who could be returned to the community were not kept in institutions to perform work for low wages and (2) helping to identify those who were ready for community placement by identifying persons who should be receiving the minimum wage. They believe that the capability of a mentally disabled person to earn or be entitled to the minimum wage is an indicator of his or her potential for community placement.

Labor has curtailed its efforts to enforce its standards on the payment of minimum and subminimum wages to patient workers in State institutions as a result of a June 1976 decision by the U.S. Supreme Court. The Court ruled that portions of the Federal law authorizing Labor's activities in this area were not constitutional.

Labor officials provided the following comments in response to our recommendations.

--They believed that a Department-wide strategy and plan for deinstitutionalization are desirable and will develop such a plan, in cooperation with HEW. The plan will represent activities that can realistically be carried out within (1) the missions of the various constituent agencies of Labor and (2) the limits of available resources.

--They will expand efforts to monitor sheltered workshop compliance with applicable requirements. Labor had also recognized this need and has initiated action to expand such efforts in fiscal year 1977. The limited number of inspections of sheltered workshops resulted, in part, from the lack of trained staff and incentives to inspectors. Workshops are more difficult to evaluate than other types of facilities, and Labor's compliance officers generally don't have special training in this area. Also, the "rewards" system for Labor's compliance officers has been primarily based on obtaining back wages. Since relatively large sums would usually not be involved in the workshop area, Labor field staffs have had little incentive to emphasize workshop evaluations. Labor is sponsoring a pilot training project on workshop evaluations in one of its regions. If the project is successful, it will be extended to all Labor regional offices.

--Labor will explore, with HEW, what can be done to further meet the employment assistance needs of the mentally disabled released and to be released from institutions. Labor will continue to make certain that someone in each local employment service office is trained to help the mentally disabled.

Labor said that for financial reasons, many employment service agencies have not been able to provide complete services to the mentally disabled because services to this group frequently involve intensive counseling and job placement, which are time consuming and expensive. Therefore, it is not possible to guarantee a totally effective and nationwide program for this group within present budgetary constraints.

--Labor has provided for more aggressive monitoring of contractor compliance with the requirements of section 503 of the Rehabilitation Act of 1973, as amended. Labor issued revised regulations in April 1976 which (1) require contractors to make mental and physical requirements job related to prevent systematic exclusion of classes of handicapped persons and (2) provide that Federal contracting agencies notify contractors of their obligations under section 503 and report to Labor any employment conditions they identify during their onsite visits to contractor facilities that may violate section 503 so that Labor can make an investigation.

--Labor will encourage better communications between Comprehensive Employment and Training Act title I prime sponsors and vocational representatives of public institutions for the mentally ill and retarded. Labor will suggest that each State Manpower Coordinating Council put this item on its agenda. Labor believed that title I of the Comprehensive Employment and Training Act program had greater potential for assisting in deinstitutionalization than title III of that program. They said, however, that some difficulties exist which might impede the development of specific projects for the mentally disabled. These include:

1. The distance between public institutions, often located in remote areas, and title I program sponsors, usually located in urban centers.

2. The lack of the highly vocal community representation for the mentally disabled that other community groups have to pressure local program sponsors.

3. The reluctance of many employers to hire employees with past histories of mental illness; this creates some reluctance by trainers to designate large groups for training who will later be difficult to place and would result in their showing

fewer job placements than if they trained easily placeable groups.

Labor also said that in June 1976 it released a solicitation for grant applications for innovative and replicable projects designed to serve population segments which have special employment and training needs. A total of $20 million was made available for these projects. The mentally handicapped were identified as one of the eligible population segments. As of September 1, 1976, the grantee selection process had been completed in seven regions. At least 46 projects have been selected for implementation; of these 8, or about 17 percent, were designed to serve the mentally disabled.

We believed that the actions Labor has taken and proposed are responsive to our recommendations and should help to alleviate some of the problems associated with training, counseling, and finding jobs for the mentally disabled.

DEPARTMENT OF JUSTICE

The Department of Justice stated that it was taking an active role in Federal courts throughout the country to establish as a constitutional principle the right to receive treatment in the setting that is least restrictive of personal liberty consistent with treatment needs. It pointed out that one of its major cases involving the mentally retarded was recently dismissed on the grounds that the Attorney General has no statutory authority to bring such suits.

The Department feels that it does not need a specific statute to sue to prohibit widespread and severe deprivation of constitutional rights and has appealed the dismissal. Justice believes, however, that a specific statute would help it gain State and local government acceptance of institutionalized persons' rights. In February 1976, a bill (H.R. 12008) was introduced to authorize the Attorney General to bring suit to protect the constitutional rights of persons involuntarily confined in institutions, but no action was taken on the bill.

NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

In general, the association concurred in our findings and supported our recommendations. It believes that the report represents the experiences of a vast majority, if not all, of the States.

The association said that additional consideration needs to be given to deinstitutionalization's impact on communities and on steps necessary to prepare communities for it. Also, the association believes that the importance of court decisions should be emphasized and that decisions have to be made on the priority of upgrading institutional care versus developing community care. The association said that Federal regulations or limitations by judicial actions require States to implement both simultaneously without providing adequate resources.

To promote better coordination, the association believes that (1) Federal programs should not bypass State, county, and city governments, (2) the flow of funds from the Federal Government needs to be simplified, (3) coordination must be effected at the service delivery level as well as among Federal agencies, and (4) the lack of coordination among Federal regulation drafters leads to poor service delivery, duplication, internal contradictions between different funding sources, and high administrative costs.

Concerning funding, the association stated that (1) Medicaid funds have not increased State resources for deinstitutionalization or improved the quality of care provided, (2) funding for medical care should be separated from funding for other support systems, such as income support or social services, and (3) funds for mental health need to be earmarked because mental health is usually ignored in the implementation of general health programs.

With respect to the community mental health centers program, the association believed that (1) the legislative changes made to the program in 1975 were counterproductive because they mandated increased services without providing adequate funding, (2) the catchment area concept is not useful in high-density areas and is workable only if there is a single mental health care system, (3) because it bypasses State governments, the program results in a dual system, and (4) a mechanism is needed to give the States more flexibility in establishing and operating community mental health programs either directly or by contract.

The association stated that our recommendation that the Congress consider consolidating funds earmarked for mental health has great appeal, but an alternative would be for the Federal Government to contract with the States for the provision of community mental health services. The association also believed that the denial of Federal Medicaid benefits for persons between 21 and 65 in institutions for mental diseases should be reconsidered.

We generally agree with the concerns expressed by the association and believe that HEW and other Federal agencies should consider them in (1) developing a Federal strategy and plan for deinstitutionalization, (2) determining Federal agency roles and responsibilities, and (3) providing assistance to State and local governments.

MAJOR EVENTS IN THE GROWTH OF FEDERAL INVOLVEMENT IN DEINSTITUTIONALIZATION OF THE MENTALLY DISABLED

Year	Event	Pertinent provisions
1946	National Mental Health Act	Recognizing serious deficiencies in mental health manpower, research, and the quality of care in institutions, the Congress established the National Institute of Mental Health and authorized grant funds for mental health research, manpower training, and community mental health services. The Senate Committee on Education and Labor reported: "Mental out-patient clinics, conveniently located and offering facilities for early diagnosis and treatment, give every promise of being the most effective means at our disposal for combating mental disease." Grants for manpower training and services were authorized, among other reasons, to staff outpatient clinics so persons could be released from institutions and continue to receive mental health care in communities.
1955	Mental Health Study Act of 1955	Recognizing the large number of persons receiving only custodial care in mental institutions, the increasing cost to society of mental illness, and indications that community outpatient clinics were providing better treatment at lower cost, the Congress authorized a nationwide study of the human and economic problems of mental illness. The Joint Commission on Mental Illness and Health conducted this study and made recommendations to the Congress.

Year	Event	Pertinent provisions
1960	Report of Joint Commission on Mental Illness and Health, entitled "Action for Mental Health," submitted to the Congress	The Commission recommended (1) establishing community-based programs for the mentally ill, including (a) services to detect and treat mental illness before serious illness develops, (b) crisis intervention, and (c) intensive treatment for those with acute mental illness, (2) improving care in and reductions in the size of mental hospitals as well as creating community-based aftercare, intermediate care, and rehabilitation services, and (3) a greater Federal role in helping the State and local governments share mental health care costs. According to the Commission's report: "The objective of modern treatment of persons with major mental illness is to enable the patient to maintain himself in the community in a normal manner. To do so, it is necessary (1) to save the patient from the debilitating effects of institutionalization as much as possible, (2) if the patient requires hospitalization, to return him to home and community life as soon as possible, and (3) thereafter to maintain him in the community as long as possible."
1962	Report of President's Panel on Mental Retardation, entitled "A Proposed Program for National Action to Combat Mental Retardation," submitted to the President following a 1-year study.	The Panel made recommendations, including that (1) the Department of Health, Education, and Welfare be authorized to make grants to States for comprehensive planning for the retarded, (2) HEW be authorized to award project grants to State institutions for the retarded to upgrade the quality of services provided to help enable the residents to return to the community, and (3) local communities, in cooperation with Federal and State agencies, provide comprehensive community-based facilities and services for the retarded. The Panel stated that its report was predicated on a strong conviction that retarded

Year	Event	Pertinent provisions
		persons be served with as little dislocation from their normal environment as is consistent with their needs.
1963	President sent the first separate special message to the Congress on mental illness and retardation.	Citing overcrowding, debilitating, and undesirable aspects of institutions, the President called for a national program to combat mental illness and retardation with a whole new emphasis and approach based on developing and using community-centered agencies. These agencies were to provide a coordinated range of timely diagnostic, health, educational, training, rehabilitation, employment, welfare, and legal protection services. The objective was to keep the mentally disabled in the community and restore and revitalize their lives through better health programs and strengthened educational and rehabilitation services. The President stated that the number of patients under custodial care in mental hospitals could be reduced by 50 percent or more within a decade or two. An estimate for the reduction in the number of retarded in institutions was not made.
1963	HEW appropriations act for fiscal year 1963	Provided funds to the States to develop comprehensive mental health plans, including community-based mental health programs. (Additional funds were appropriated in fiscal year 1964.)
1963	Maternal and Child Health and Mental Retardation Planning Amendments of 1963	Recognizing that responsibility for providing services to the retarded was divided widely among health, welfare, education, and other agencies, the Congress authorized funds for States to develop comprehensive plans for preventing, ameliorating, and treating mental retardation in response to the President's Panel on Mental Retardation recommendations.

Year	Event	Pertinent provisions
1963	Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963	Authorized funds for constructing community-based mental health centers and facilities for the mentally retarded. The objective was to provide "seed" money to help the States develop new and expanded resources rather than long-range operating subsidies. In reporting on the legislation, the House Committee on Interstate and Foreign Commerce stated that it was intended that community mental health centers would transfer the care of the mentally ill from custodial State institutions to community facilities comparable to those provided for the physically ill. The committee report further stated that a choice had to be made between developing community resources or improving State mental hospitals and that it had chosen the former because new methods of treatment were being developed, the mentally ill were capable of rehabilitation, and there was less inclination to reject and isolate the sufferers.
1965	Social Security Amendments of 1965	Enacted Medicare and Medicaid programs which included coverage for inpatient hospital care for the mentally ill and skilled nursing home care. Medicare provided inpatient coverage for the elderly mentally ill in general hospitals and limited benefits as inpatients in mental hospitals and as outpatients. Medicaid also provided for inpatient mental hospital benefits for the elderly and for care for all eligible mentally ill in general hospitals and as outpatients. The act authorized inpatient mental hospital benefits for the mentally ill. This was to encourage States to discharge the elderly who, with financial assistance and supportive services, were able to care for themselves in the community. It was intended that

Year	Event	Pertinent provisions
		the Federal assistance for the institutionalized mentally ill would enable the States to shift their funds to developing alternatives to care in mental hospitals and to improve the care provided in such facilities to help persons return to communities. The act imposed stringent requirements under both programs to make sure that persons receiving inpatient mental hospital benefits receive active treatment rather than custodial care. Requirements were also imposed under Medicaid to make sure that (1) the person's need for inpatient care was periodically evaluated, (2) mental health and welfare agencies cooperatively developed and used alternatives to inpatient mental hospital care for persons of all ages, and (3) Federal funds not be used to merely replace State funds. To provide inpatient mental hospital care to persons 65 or older under both programs, the facilities had to be accredited by the Joint Commission on Accreditation of Hospitals or meet equivalent standards. JCAH standards are based on the fundamental principle that the objective of inpatient care in mental hospitals is to restore persons to an optimal level of functioning and to return them to the community. The act authorized additional funds for the States for fiscal years 1966 and 1967 to coordinate State and local efforts for the retarded and to begin implementing comprehensive mental retardation plans for which funds were previously authorized.

Year	Event	Pertinent provisions
1965	Mental Retardation Facilities and Community Mental Health Centers Construction Act Amendments of 1965	Authorized staffing grants for community mental health centers, citing the inability of States and communities to immediately free enough funds to start providing adequate community mental health services. It was intended that Federal support be temporary until permanent funding sources were developed. In its report, the Senate Committee on Labor and Public Welfare stated: --CMHCs are to serve as the major alternative to existing massive public mental hospitals and as the continued treatment resource for persons returning to communities following periods of longer term hospitalization. --Being community based and coordinated with all other community resources, the CMHC offers the greatest hope for the care, treatment, and rehabilitation of the mentally ill. CMHC's purpose is to help restore the patient and family members to their fullest mental, physical, social, and vocational abilities.
1965	Federal Assistance to State Operated and Supported Schools for the Handicapped	The act authorized Federal grants to the States for educating handicapped persons in State operated and supported schools, including those in public institutions for the mentally disabled.

Year	Event	Pertinent provisions
1965	Vocational Rehabilitation Act Amendments of 1965	Authorized constructing community residences for retarded persons receiving vocational rehabilitation services in workshops and extending to 18 months the time retarded persons were eligible for rehabilitation services.
1966	Comprehensive Health Planning and Public Health Services Amendments of 1966	Required that at least 15 percent of State formula grant allotments for public health services be available only for mental health services. The funds were to be used for community mental health services rather than residential care in mental hospitals.
1966	Executive Order 11280	The President established the President's Committee on Mental Retardation to, among other tasks, recommend Federal action needed, coordinate Federal activities, and stimulate action for the mentally retarded.
1967	Partnership for Health Amendments of 1967	Required that, beginning in fiscal year 1969, at least 70 percent of the public health services funds for mental health be available for providing services in communities.
1967	Mental Retardation Amendments of 1967	Authorized staffing grants for community facilities for the retarded for a 51-month period.
1968	Vocational Rehabilitation Amendments of 1968	Authorized a project grant program for rehabilitating the mentally retarded and redefined followup services, recognizing that the mentally disabled needed longer followup than was usually allowed under prior legislation.

Year	Event	Pertinent provisions
1970	Developmental Disabilities Services and Facilities Construction Amendments of 1970	Replaced the community facilities construction and staffing grant program for the retarded with a program providing formula grants to the States for comprehensive, coordinated planning, comprehensive services, and constructing facilities for the developmentally disabled. In its report on the act, the House Committee on Interstate and Foreign Commerce (1) urged improving institutional facilities by eliminating the overcrowding, oversize, and inadequate or inappropriate staffing and environment that existed and (2) cited the need to develop appropriately staffed, community-based, nonmedical day care and residential facilities.
1970	Report of the President's Task Force on the Mentally Handicapped, entitled "Action Against Mental Disability" submitted to the President	The Task Force made several recommendations, including (1) the continued emphasis on community-based care rather than institutional care, (2) a sharper focus and more emphasis on the needs of the mentally disabled by other agencies, (3) more coordinated efforts among agencies, and (4) expanded coverage of the mentally disabled under Medicare and Medicaid. The Task Force also recommended establishing a Joint Council on Disabilities with subordinated Presidential committees for mental retardation, mental illness, and physical disability. The Council would have direct access to the President and the Congress to provide more visibility, review, and evaluation of agency efforts and effective advocacy to resolve problems. (The Council was not established.)
1970	Housing and Urban Development Act of 1970	Required the Department of Housing and Urban Development to encourage public housing agencies to design, develop, or acquire residential settings

Year	Event	Pertinent provisions
		(congregate housing) to accommodate the special needs of elderly and handicapped persons who need some services to sustain independent living, but not enough to need institutionalization.
1971	HUD General Counsel Decision	Responding to inquiries from the State of Michigan, the HUD General Counsel stated that mental retardation could be included as a handicapping condition under certain HUD programs if it stemmed from a physical impairment.
1971	Presidential Statement on Mental Retardation	President Nixon established a major national goal to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community. The President stated that counseling, job training, placement services, and suitable living arrangements must be made available in the community. All executive departments and agencies were directed to evaluate their programs to provide maximum support to PCMR. The Department of Justice was directed to initiate action to strengthen the assurance of full legal rights for the retarded. HUD was directed to assist in developing special housing arrangements to facilitate independent living for retarded persons in the community.
1971	Amendments to Social Security Act	Authorized care in intermediate care facilities under Medicaid. This program included residential care in public institutions for the retarded that provided health or rehabilitative services, met prescribed standards, and provided active treatment to residents. Medicaid coverage for persons under 65 in institutions for the mentally ill was excluded.

Year	Event	Pertinent provisions
1972	Social Security Amendments of 1972	Authorized inpatient mental hospital care for persons under 21 under Medicaid in facilities that met prescribed standards and provided active treatment. The Senate Committee on Finance's report stated that outpatient treatment in the patient's own community should be used whenever possible and that Federal funds were being authorized to support the cost of inpatient care, when necessary, to help restore mentally ill children to where they are capable of rejoining and contributing to society as active and constructive citizens. This legislation also provided for financial penalties on States not implementing effective programs for controlling the unnecessary use of mental hospitals, skilled nursing facilities, and ICFs, including institutions for the retarded. It also established the Supplemental Security Income program to federalize and standardize the assistance programs for the aged, blind, and disabled which were previously administered by the States. The program became effective in January 1974.
1972	Wyatt v. Stickney	The U.S. District Court, Montgomery, Alabama, rendered its decision on the first class-action suit successfully brought against a State's entire mental health system. The court ruled that the mentally ill and mentally retarded had a constitutional right to treatment in the least restrictive setting necessary. The court also imposed minimum constitutional standards for adequate habilitation of the mentally disabled in the State's mental institutions. One such standard also stated that no person shall be admitted to the institution unless a prior determination has been made that residence in the institution

Year	Event	Pertinent provisions
		is the least restrictive habilitation setting feasible for the person. The decision of the court was later affirmed by the U.S. Court of Appeals. The Department of Justice participated in this case as a friend of the court.
1973	Rehabilitation Act of 1973	Required State vocational rehabiliitation agencies to serve the more severely disabled first. Another purpose of the act was to initiate and expand services to groups of handicapped persons, including those who are institutionalized or who have unusual or difficult problems being rehabilitated and for whom responsibility for treatment, education, and rehabilitation is shared among agencies. The act also required HEW to establish priorities for services and authorized joint funding of projects by more than one Federal agency. In reporting on this legislation, the Senate Committee on Labor and Public Welfare stated that it was giving the Rehabilitation Services Administration greater control over, and therefore accountability for, establishing service priorities because it wanted RSA to exert more leadership in assisting the States to help the handicapped. The conference report stated that it was not their intention that State agencies discontinue or refuse services to handicapped persons because of the type of disability, but stressed that eligibility for services in the basic program is intended for persons with severe physical or mental disabilities and that persons with social disadvantages or handicaps are not by virtue thereof eligible.

Year	Event	Pertinent provisions
		Also, the report of the House Committee on Education and Labor stated that it authorized joint funding of single projects by more than one agency and permitted consolidating State developmental disabilities and vocational rehabilitation plans.
		The act required any contractor with a Federal contract in excess of $2,500 to take affirmative action to employ and advance in employment qualified handicapped persons.
		The act also provided that no otherwise qualified handicapped person shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.
1974	Rehabilitation Act Amendments of 1974	In authorizing a White House Conference on Handicapped Individuals, the Congress stated that: "* * * it is essential that recommendations be made to assure that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective; * * * all levels of Government must necessarily share responsibility for developing opportunities for individuals

Year	Event	Pertinent provisions
		with handicaps; and it is therefore the policy of the Congress that the Federal Government work jointly with the States and their citizens to develop recommendations and plans for action in solving the multifold problems facing individuals with handicaps."
1974	Housing and Community Development Act of 1974	Made substantial changes to Federal housing and community development programs and changed the statutory definition of handicapped for HUD programs to specifically include the developmentally disabled.
1974	Welsch v. Likens	The U.S. District Court, District of Minnesota, affirmed that mentally retarded persons civilly committed to the State's institutions have a constitutional right to treatment and care in the least restrictive practicable alternative to hospitalization and to a humane and safe living environment.
1974	United States v. Solomon	The Department of Justice initiated its first class action suit on behalf of the right of institutionalized mentally retarded persons to treatment.
1974	Executive Order 11776	The President reaffirmed the national goal of returning one-third of the retarded in public institutions to useful lives in their communities. He extended PCMR and required it to evaluate the national effort to combat mental retardation, identify potential of various Federal programs for achieving the Presidential goal, and providing advice and assistance to the President. Federal

Year	Event	Pertinent provisions
		departments and agencies were directed to designate liaison offices with PCMR and provide it with information on programs relating to the goals.
1974	Presidential Statement on Mental Retardation	The President stated that, with appropriate training, the retarded are capable of continuing development in normal community settings. He stated that primarily through its housing agencies, the Federal Government will help retarded adults obtain suitable housing, but the real help must come from the local level. He also urged employers to use the U.S. Employment Service to the fullest extent possible in hiring retarded persons.
1975	Social Services Amendments of 1974	Replaced two existing social services programs with a new one which included the following objectives: --Achieving or maintaining self-sufficiency, including reducing or preventing dependency. --Preventing or reducing inappropriate institutional care by providing community-based care, home-based care, or other forms of less intensive care. --Securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to persons in institutions.

Year	Event	Pertinent provisions
1975	Special Health Revenue Sharing Act of 1975	Amended the formula grant program for public health services to (1) require developing and implementing State mental health plans which are designed to eliminate inappropriate placement in institutions of persons with mental health problems, (2) insure the availability of appropriate community services for such persons, and (3) improve the quality of care for persons for whom institutional care is appropriate.
1975	Community Mental Health Centers Amendments of 1975	The Congress (1) stated that community mental health care is the most effective and humane form of care for a majority of mentally ill individuals and (2) strengthened program requirements to insure that CMHCs were more effectively working toward reducing inappropriate institutional placement.
1975	Developmentally Disabled Assistance and Bill of Rights Act	The act stated that persons with developmental disabilities have a right to appropriate treatment, services, and habilitation and these should be designed to maximize the developmental potential of the person and be provided in the setting that is least restrictive of the person's personal liberty. The act also stated that the Federal Government and the States both have an obligation to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that does not (1) provide treatment, services, and habilitation appropriate to the needs of such persons, (2) comply with adequate fire and safety standards as may be promulgated by HEW, and (3) meet other stipulated requirements. The act further requires States receiving formula grants thereunder to (1) prepare a plan for

Year	Event	Pertinent provisions
		eliminating inappropriate placements and improving the quality of care for persons for whom institutional care is appropriate, (2) support the establishment of community programs as alternatives to institutionalization, and (3) coordinate and work with other agencies to assure the provision of appropriate health, educational, or social services.
1975	Education for All Handicapped Children Act of 1975	This act authorizes grants to assure handicapped children a free appropriate public education to meet their special needs. The act requires HEW to evaluate the effectiveness of procedures undertaken by State and local educational agencies to assure this special education and related services in the least restrictive environment commensurate with their needs. HEW believes this act can have a great impact on deinstitutionalization of mentally disabled children.
1975	New York State Association for Retarded Children v. Carey	The U.S. District Court in Brooklyn, New York, issued an order ratifying the consent decree of the litigants. The court order and consent decree provided that the mentally retarded residents of the Willowbrook State School had a constitutional right to treatment in the least restrictive setting. The provision was based on the Eighth Amendment prohibiting cruel and unusual punishment and on the basis that harm can result not only from neglect, but from conditions which cause regression or which prevent development of an individual's capabilities. The court order imposed standards for the care of the retarded at Willowbrook and requirements on the State to, among other things, (1) require that residents be provided with the least restrictive and

Year	Event	Pertinent provisions
		most normal living conditions possible, (2) reduce the population of Willowbrook to 250 or fewer persons within a 6-year period (the population was about 5,200 when the suit was filed and about 3,000 when the case was completed), (3) develop and operate, or cause to be developed and operated, at least 200 new community placements to meet individual needs within 1 year, and (4) request from the legislature funds necessary to implement the order. The Department of Justice participated in this case as a friend of the court.
1975	O'Connor v. Donaldson	The U.S. Supreme Court ruled that a State cannot constitutionally confine without more [1] a non-dangerous person who is capable of surviving safely by himself or with the help of willing and responsible family members or friends. The Supreme Court did not rule on the right to treatment issue, which had been affirmed by the Court of Appeals. The Court of Appeals affirmed the lower court's decision that involuntarily, civilly committed mentally ill persons had a constitutional right to such treatment as will help them to be cured or to improve their mental condition.
1975	Dixon v. Weinberger	The U.S. District Court in Washington, D.C., ruled that involuntarily, civilly committed patients at Saint Elizabeths Hospital have a right to placement in the least restrictive setting necessary for their treatment or care. The court ruled that the Federal Government and the District of Columbia government

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[1] Presumably more than mere custodial care.

Year	Event	Pertinent provisions
		must provide alternative facilities for those civilly committed patients not needing hospitalization.
1975	Horacek V. Exon	The U.S. District Court in Nebraska approved a consent agreement under which Nebraska agreed to establish a goal to reduce the population of the State's institution for the retarded from about 1,070 to 250 within 3 years. The Department of Justice participated in this case as a plaintiff-intervenor.
1976	Housing Authorization Act of 1976	Excluded the value of housing assistance under certain Department of Housing and Urban Development programs from a person's income and resources for determining eligibility for or the amount of SSI. Also authorized the use of community development block grants for centers for the handicapped.
1976	Unemployment Compensation Amendments of 1976	Amended title XVI of the Social Security Act to --authorize SSI payments to eligible persons residing in publicly operated community residences housing 16 or fewer persons, --eliminate reductions in SSI payments as a result of State and local government subsidies based on need, --repeal the requirement that SSI payments be reduced as a result of payments made by State or local governments for medical or remedial care provided by an institution when such care could be provided under Medicaid,

Year	Event	Pertinent provisions
		--require, effective October 1, 1977, that States establish and insure enforcement of standards for group living facilities housing or likely to house, a significant number of SSI recipients, and --establish a program for the referral to and provision of rehabilitation services to SSI recipients under age 16, including a requirement for individual service plans for such disabled children.

SUMMARY OF REGULATIONS AND GUIDELINES

FOR RELEASE PLANNING

UNDER MEDICARE AND MEDICAID

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
Mental hospital	Medicare	Medical records must contain a discharge summary which includes a recapitulation of the patient's hospitalization and recommendations from appropriate services concerning followup or aftercare, as well as a brief summary of the patient's condition on discharge.	None.	Determine whether the discharge summary includes an aftercare plan.
Mental hospital	Medicaid (persons 65 or older)	Alternate plans of care must be developed, making maximum use of available resources to meet medical, social, and financial needs. Medicaid agencies must have joint agreements with mental health agencies,	The patient's record should show initial and ongoing discharge planning. The plan of care must specify what steps will be taken to place the patient in an alternative program of care suitable to his needs. Hospital discharge summaries	Independent medical review teams are to assure that the plan of care is current and complete.

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
		clearly setting forth the responsibilities for persons on whose behalf payments are made, including arrangements for joint planning and developing alternate methods of care and appropriate social services. The plan of care must include a discharge plan.	should include specific instructions and recommendations to be followed in aftercare. Social services must include planning for and selecting alternate care arrangements most appropriate to the diagnosed physical and mental condition and to personal needs. Agreements for joint planning for alternate methods of care should identify what the hospital or mental health agency staff is expected to provide in the way of posthospital followup.	
Mental hospital	Medicaid (under 21)	The plan of care shall be designed to achieve the individual's discharge from inpatient status at the earliest possible time. It shall include at an appropriate time post-discharge plans and coordination of	None.	Independent medical review teams are to assure plans of care, which include discharge plans, are current and complete.

APPENDIX II

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
		inpatient services, with partial discharge plans and appropriate related services in the patient's community to insure continuity of care upon discharge.		
Mental hospital	Medicare and Medicaid	To participate in Medicare, mental hospitals must be accredited by the Joint Commission on Accreditation of Hospitals or meet requirements equivalent to JCAH accreditation standards and must meet the requirements of section 1861(f) of the Social Security Act. To participate in Medicaid, mental hospitals (for persons under 21) must be accredited by JCAH as psychiatric facilities.	JCAH standards for psychiatric facilities require all medical records to contain a discharge summary. Discharge summaries should include recommendations and arrangements for future treatment that include a notation covering prescribed medications and followup programs. Where social work services are indicated, a brief and pertinent written plan shall be developed for each patient or group and should be used in the planning for discharge and aftercare services. The plan shall indicate	

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
			what social work services are needed for the patient.	
Institutions for the mentally retarded	Medicaid	Postinstitutionalization plans must be developed before discharge which include providing for appropriate services, protective supervision, and other followup services.	Each resident's plan of care must include an assessment of his potential for functioning outside the institution, specifying the type of care and services that will be needed to enable the individual to function in a different environment.	Review the individual plan of care to determine that it includes a postinstitutional plan that delineates the supervision and followup to be provided.
		Plans of care include discharge plans.	JCAH standards for residential facilities for the mentally retarded require planning for release to include providing for appropriate services, including protective supervision and other followup services. After the resident leaves the facility, social workers shall provide systematic followup, including	Independent professional review teams are to review plans of care to assure that they are current and complete.

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
			counseling with the resident, family, employers, and other persons significant to the resident's adjustment in the community and referral to appropriate community agencies. For residents provided vocational rehabilitation services, followup shall be provided that continues to be available to the individual for at least 1 year following placement.	
Skilled nursing facility	Medicare Medicaid	Each skilled nursing facility must: (1) have in operation an organized discharge planning program with the written designation of responsibility for discharge planning, (2) have written discharge planning procedures which includes a description of available local	Discharge planning is a service and process that identifies and evaluates the patient's needs and assists him in moving from one environment to another. The intent is to encourage the health facility to make decisions in advance about the rehabilitation goals of the patient and the overall patient care	By reviewing a random sample of records and by reviewing procedures, surveyors are to determine that SNFs follow required discharge planning procedures, including evaluation of needs,

APPENDIX II

Facility	Program	Regulation	Guidelines	Surveyor or reviewer instruction
		resources, and (3) prepare a written discharge plan that insures that each person has a planned program of post-facility continuing care which takes into account the persons postdischarge needs. Utilization review committees for each SNF are required to review such person's discharge plan to assure it meets applicable requirements.	plan, such as: What care is to be provided, how, when, for how long, and who is to provide it. There must be an individual discharge plan for each patient which reflects input from all services involved in caring for the patient. Planning procedures cover identifying and evaluating patients' needs and listing service recommendations. Each person has a discharge program that assures proper placement and a discharge summary that provides a complete picture of his or her total needs.	participation by pertinent disciplines, and involvement by utilization review committees.

REQUIREMENTS OF OTHER PROGRAMS

RELATING TO RELEASE PLANNING

Facility	Program	Regulation
Institution or community	Developmental Disabilities	Each agency that receives formula grant funds must prepare an individual habilitation plan for each developmentally disabled person who receives services that includes (1) specific goals and objectives, (2) identifying a program coordinator responsible for implementing the plan, (3) specifying the role and objectives of all parties concerned, and (4) at least an annual review.
Institution or community	Social services IVA and VI [1]	Service plans must be developed and maintained for each person who requires services. Service plans must be responsive to the needs of each person and be reviewed at least annually to assure that they are related to the person's needs and are being effectively implemented. Foster care services must --assure placement appropriate to individual needs and in facilities approved as meeting licensing standards or licensed by the appropriate State or local authority; --assure the person receives proper care; and --determine the continued appropriateness of and need for placement through periodic reviews, at least annually.

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[1] Superseded by title XX in 1975.

Facility	Program	Regulation
Institution or community	Title XX Social Services Program	Individual service plans are not required.
Institution or community	Vocational Rehabilitation	Each recipient must have a written rehabilitation plan, reviewed at least annually, that includes a statement of long range goals and intermediate objectives related to attaining the goals and a statement of the services to be provided.
Institution or community	Education for the Handicapped	The Education for All Handicapped Children Act of 1975 requires an individual written education plan for each handicapped child which includes: (1) a statement of annual goals, including short term instructional objectives, (2) specific services to be provided, (3) criteria for evaluating accomplishments, (4) designation of responsibility for the plan, and (5) at least an annual plan review.
Community	Supplemental Security Income	Except for alcoholics and drug addicts, SSI does not generally require disabled recipients to have service plans. Disabled SSI recipients must accept vocational rehabilitation services if offered, unless they have a valid reason for not doing so. Disabled persons pursuing a self-support goal under an approved plan are permitted to exclude certain income and resources needed to fulfill such a plan when computing their SSI entitlements. In October 1976 the Social Security Act was amended to require individual service plans for certain SSI recipients under 16 years of age.

ESTIMATED HEW OBLIGATIONS FOR
THE MENTALLY RETARDED
FISCAL YEAR 1975

Major program area	Amount (millions)
Education	$ 110
Public health	36
Disability insurance	348
Supplemental security income	404
Health insurance	29
Social services	2[illegible]9
Medicaid (institutions for the retarded only) (note a)	[illegible]0
Developmental disabilities	54
Vocational rehabilitation	90
Other	1
Total	$1,531

a/Estimates of costs for the retarded under other aspects of the Medicaid program were not available.

Source: Office For Handicapped Individuals, HEW.

ESTIMATED FEDERAL
EXPENDITURES RELATING TO
MENTAL ILLNESS IN 1971

Agency	Amount (millions)
National Institute of Mental Health, Department of Health, Education, and Welfare	$ 359.8
Other Public Health Service, HEW	72.9
Medical Services Administration	816.6
Other Social and Rehabilitation Service, HEW	622.0
Office of Education, HEW	16.6
Department of Defense	175.4
Department of Justice	7.3
Veterans Administration	1,492.9
Other	450.7
Total	$4,014.2

Source: National Institute of Mental Health, HEW.

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

November 3, 1976

Mr. Gregory J. Ahart
Director
Human Resources Division
General Accounting Office
Washington, D. C. 20548

Dear Mr. Ahart:

This letter responds to your request for OMB comments on the draft GAO report entitled "Improvements Needed in Efforts to Help the Mentally Disabled Return to and Remain in Communities." We appreciate this opportunity to express our views on this report, which we have carefully reviewed. Our comments address the broad policy issues raised by the study. Other Federal agencies will address programmatic issues relevant to their specific programs.

We endorse the goal of appropriate care and treatment of the mentally disabled, with a full range of community care as an alternative to institutional care. The responsibility for assessing and addressing the needs of the mentally ill and mentally retarded, however, legitimately resides at the State and local level--and with the communities themselves.

There is indeed a complicated array of Federal programs designed to provide assistance to States and localities responding to the needs of these individuals. Your report noted some 135 programs in 11 agencies providing services in this area. As long as the Congress mandates some 135 separate narrow categorical programs and provides substantial funding for each of them, Federal coordination, State coordination and the ability of the communities themselves to integrate services will be virtually impossible. In recognition of these difficulties, and in an attempt to solve some of these problems, the Administration proposed to Congress in 1976 the "Financial Assistance for Health Care Act," which would have consolidated 16 of the categorical Federal health programs into a $10 billion block grant to the States. This proposal would have enabled States and localities to restructure and integrate their health services delivery system to more effectively meet community needs and priorities.

In response to the three specific GAO recommendations to Congress and OMB in the report's cover summary, the Administration will continue to support appropriate services to the mentally ill and the mentally retarded in the following ways:

-- requesting appropriate levels of Federal resources to support State and community efforts to develop appropriate service alternatives for the mentally disabled;

-- supporting the State and local decisionmaking responsibilities in this area; and

-- proposing consolidation into block grants of narrow categorical health and related service programs which, as currently designed, make program integration and coordination at the State and local level extremely difficult.

We believe that this approach is responsive to the problems identified in the GAO report and constitutes an appropriate Federal role. The additional Federal activities recommended in the report are unwarranted. Such activities would constitute an unjustifiable intrusion into traditional and appropriate State and local control over the development and delivery of a comprehensive range of services for the mentally disabled.

In sum, the answer to improving coordination is to remove the impediments to the local coordination, not to try to solve local problems from Washington.

Sincerely yours,

Paul H. O'Neill
Deputy Director

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
OFFICE OF THE SECRETARY
WASHINGTON, D.C. 20201

October 6, 1976

Mr. Gregory J. Ahart
Director, Human Resources Division
United States General Accounting Office
Washington, D. C. 20548

Dear Mr. Ahart:

The Secretary asked that I respond to your request for our comments on your draft report, "Improvements Needed in Efforts to Help the Mentally Disabled Return to and Remain in Communities."

We have furnished members of your staff with several staff papers prepared by various HEW components as a preliminary to developing a coordinated Department response to the report. They show that while the Department agrees with the thrust of the report, there are areas which we believe require changes or modifications. Also, there are many issues that cut across a number of programs which require further in-depth analyses.

The Under Secretary has asked the Assistant Secretary for Planning and Evaluation to be the focal point in coordinating our responses to the specific recommendations in the report and to develop a plan for implementing those with which we concur.

We will provide you with our conclusions and the action plan within sixty days following the issuance of your final report.

Sincerely yours,

John Young

John D. Young
Assistant Secretary, Comptroller

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT
WASHINGTON, D.C. 20410

OFFICE OF THE ASSISTANT SECRETARY
FOR CONSUMER AFFAIRS AND REGULATORY FUNCTIONS

IN REPLY REFER TO:

October 6, 1976

Mr. Henry Eschwege
Director, Community and
Economic Development Division
U. S. General Accounting Office
Washington, D. C. 20548

Dear Mr. Eschwege:

This is in response to your letter of July 7, 1976, transmitting a copy of the GAO draft report on "Improvements Needed in Efforts to Help the Mentally Disabled Return to and Remain in Communities".

As requested, we have reviewed the report and find that it is a generally accurate reflection of many of the problems historically associated with attempts to use the programs of the Department of Housing and Urban Development to provide appropriate housing for mentally disabled persons.

Despite the lack of a more substantive mandate, including increased resources, the Department has responded to the Federal deinstitutionalization effort.

Initially, the Department's General Counsel undertook a detailed study in 1971 to determine whether or under what conditions mental retardation could be considered an eligibility factor for housing for the handicapped. He concluded: "Although this Department's earlier position was that the statutory definition of handicap, which was based on 'physical impairment' did not include the mentally retarded, the Department's position is now that if the mental retardation of an individual can be determined to be the result of a physical impairment, such as a brain damage problem, or chemical or neurological physical impediment to normal growth, then that individual legally could be considered 'handicapped' for purposes of determining (tenant) eligibility......"

In early 1972, HUD established the Office of the Assistant to the Secretary for Programs for the Elderly and Handicapped in order to give special focus to the particular needs of these persons, including the mentally disabled.

One of the first activities undertaken by this new office was the designation of Elderly and Handicapped Specialists in all HUD field offices. While the decision of the General Counsel referred to above was not formally transmitted to all field offices, the substance of the decision was communicated to Regional level Specialists during Central Office training in mid 1972, and to persons and organizations active in the field of housing for the handicapped through speeches delivered by Departmental representatives.

The expanded definition of handicapped issued by the General Counsel enabled HUD to approve several State-Federal financing plans for the development of group homes for mentally retarded adults capable of an independent lifestyle in their communities. These homes received supportive services from local, private and government agencies and mortgage insurance from the state.

In January 1973, the Department suspended new approvals under its major subsidized programs in order to conduct an intensive and comprehensive evaluation of their effectiveness in meeting the National housing goal.

The results of this evaluation are reflected in the new housing programs and community development strategy contained in the Housing and Community Development Act of 1974. This Act also includes the developmentally disabled within the statutory definition of "handicapped" as it pertains to HUD programs. In addition, a recent amendment to the Act has included "centers for the handicapped" as a specifically eligible activity under the Community Development Block Grant Program. Proposed regulations implementing this new authority will be published shortly.

In September 1974, HUD played an active role in a three-day National conference on housing and the handicapped convened in Houston, Texas. For the first time, more than 150 representatives of government and volunteer groups concerned with the needs of the handicapped assembled to discuss the various housing problems facing handicapped individuals and the HUD programs which could be brought to bear on them.

The new emphasis on the handicapped contained in the 1974 Act prompted the Department to issue instructions to its field offices in early 1975. Regional Administrators were directed to take appropriate steps to give adequate and full support to increasing the Department's responsiveness to the special needs of the elderly and handicapped. Additionally, they were advised that providing improved housing is but one part of the overall objective of integrating State, local and Federal efforts and maximizing the timeliness and effectiveness of program delivery to handicapped citizens.

HUD's monthly journal, Challenge, reaches a wide variety of subscribers, including, among others, housing authorities, builders and developers, public officials and architects. In March 1975, the entire issue was devoted to the handicapped. Articles covered a range of special subjects, from HUD-assisted housing for the handicapped, including a five page article on housing the mentally handicapped, to what other countries are doing for their handicapped citizens. The issue received such good response that it was reprinted in several thousand copies. In addition, further public attention was directed toward housing the mentally disabled by the article, "Living Centers for the Mentally Retarded", featured in the December 1975 issue of Challenge.

The Department is aware that its low income housing production procedures should be revised, in line with the emphasis in the 1974 Act, to insure that they address the housing needs of the mentally disabled, as well as those of the elderly and physically handicapped; and HUD fully intends to make every effort to do this as quickly as possible. For example, existing low-income processing handbooks contain special provisions relative to elderly and handicapped housing, with particular attention on designing for accessibility. An early effort will be undertaken to up-date these provisions by expanding instructions in a way that will increase the production of such facilities for the entire range of elderly and handicapped persons, including the mentally disabled.

In a very positive sense, HUD has been encouraged in its efforts to increase the number of handicapped housing units through its recent experience with the Section 202 Direct Loan Program. In response to the 1975 invitation to non-profit sponsors, a substantial number of applications were received from groups interested in serving the mentally retarded. Responses were particularly heavy from states such as Illinois, Massachusetts and New York, which are emphasizing deinstitutionalization of the mentally retarded.

Applications were reviewed in HUD Central Office, and those projects selected were announced by the Secretary on April 22, 1976. Among the selectees were ten applicant groups whose projects should provide approximately 450 units for the developmentally disabled. Monitored by Central Office and coordinated with the Department of Health, Education and Welfare, these cases will serve as a basis for establishing standards for this type of project and should permit greater use of HUD programs for providing such facilities. Additional units for the mentally disabled will be approved out of the 1976 Section 202 supplemental appropriation.

In addition, the Department is considering including in final regulations regarding Admission to and Occupancy of Low-Income Housing special mention of retarded or mentally ill, as defined in the Act, as groups to which LHA's cannot automatically deny admission.

Management of handicapped housing is also an on-going concern of HUD. The Office of Housing, for example, is currently working with Temple University on plans to set up a feedback conference to be held this fall for the managers of housing for the handicapped. This will be one of the few forums whereby managers from across the United States can get together to discuss their management problems and to exchange ideas and learn of new concepts which will enhance the development and delivery of housing for the handicapped.

To further assist with the feedback process, invitations will be offered to one representative, as well as the architect, from the selected Section 202 applicants who intend to construct housing for the handicapped. All proceedings will be recorded and transcripts published for dissemination to conference participants. Also, curriculum materials will be developed for distribution to a number of schools and training facilities for the handicapped.

Even sharper focus on the concept of small group homes is to be provided this year through the Office of Policy Development and Research. It will sponsor a demonstration and evaluation of small group homes which will result in guidelines for HUD staff and for sponsors on how to develop such facilities for the handicapped using HUD resources.

With respect to the Community Development Block Grant Program, and the required Housing Assistance Plan in particular, it should be noted that Housing Assistance Plans are prepared by units of general local government and not local housing authorities. The degree of participation by local housing authorities varies at the discretion of the unit of general local government.

The program regulations and instructions to applicants regarding housing assistance plans conform to the 1974 Act. Applicants are required to accurately assess the housing assistance needs of lower income persons, including the handicapped, in their community. Moreover, the statute further requires that the Secretary shall approve an application "...unless on the basis of significant facts and data, generally available and pertaining to community and housing needs and objectives, the Secretary determines that the applicant's description of such needs and objectives is plainly inconsistent with such facts or data ..."

The Department does not make an affirmative judgement on the consistency of an applicant's data. Rather, it must be accepted unless plainly inconsistent with generally available data. Although some communities have developed more complete data from other, not totally reliable sources, in most cases the only data generally available is the Federal Census, which contains only limited information on disabilities affecting the ability to work.

Thus, in the absence of generally available data of a more complete nature regarding handicapped needs, it is difficult for the Department to make a finding of inconsistency. Nevertheless, program regulations do provide a means for groups representing the handicapped to present the

Department with evidence of an application being inconsistent. Moreover, HUD field offices are now being directed to screen more carefully all Community Development applications to insure strict compliance with the requirement to assess the housing needs of the handicapped.

It is also important to note that the Department is unable to issue guidelines for the purpose of insuring the provision of adequate facilities and supportive services to the mentally disabled through the Community Development Block Grant Program. Such action would be in conflict with Congressional intent that local elected officials, rather than special purpose agencies, have principal responsibility for determining Community Development needs, establishing priorities, and allocating resources. Imposition of Departmental guidelines abridging this local responsibility would, therefore, violate one of the basic purposes of the statute.

Further, Title I of the 1974 Act also sets forth specific criteria which must be met in order for certain supportive services to be eligible for Community Development Block Grant assistance. For example, the statute requires that public services be necessary or appropriate to support assisted physical development activities being carried out in a concentrated manner. Thus, under the present construction of the statute, freestanding supportive services are not eligible for assistance.

Nevertheless, there are a number of action steps which can be taken within the framework of existing statutory authority. As the Assistant Secretary for Consumer Affairs and Regulatory Functions, I have incorporated a number of these into the operating plan under the Goals Management System for FY 1977.

Among the objectives which my Office has selected for accomplishment during this period is the prevention of unnecessary institutionalization of mentally and physically handicapped persons by encouraging the provision of alternative housing.

The tasks necessary to accomplish this objective include a review of the applicability of existing HUD Minimum Property Standards to the development of small group homes and similar supportive type living arrangements, a management meeting with HUD field personnel to enhance their capability to assist sponsors in utilizing HUD resources to meet the special housing needs of the handicapped and coordinating the publication and distribution of an updated management guide for congregate housing facilities.

Another objective adopted by the Office of Consumer Affairs and Regulatory Functions, that of assuring the delivery of adequate social and other services in coordination with other Federal government agencies, would also directly benefit those mentally retarded persons who wish to reside in the community.

This Office will also be coordinating consumer input with regard to the formulation of Departmental policy on Section 202 Selection Criteria. The goal is to insure that small, non-profit community based organizations seeking to develop group homes for the mentally retarded are afforded an opportunity to receive 202 funding equal to that of larger, more experienced applicants.

Perhaps the most important indication of HUD's commitment to handicapped citizens is, even though actual implementation of Section 504 of the Rehabilitation Act of 1973 will have to await the issuance of guidelines by the Department of Health, Education and Welfare, a Departmental action force has already been established to plan for such implementation.

The Department hopes that these comments will be of assistance in the preparation of the final GAO Report.

Sincerely,

Constance Newman

Constance B. Newman
Assistant Secretary

U.S. DEPARTMENT OF LABOR
OFFICE OF THE ASSISTANT SECRETARY
WASHINGTON

August 10, 1976

Mr. Gregory J. Ahart
Director
Human Resources Division
U. S. General Accounting Office
Washington, D. C. 20548

Dear Mr. Ahart:

Thank you for the opportunity to review the draft report, "Improvements Needed in Efforts to Help the Mentally Disabled Return to and Remain in Communities."

We have provided your staff with oral comments on the report.

If we can be of further assistance to you, please let us know.

Sincerely yours,

for FRANK A. YEAGER
Director of Audit
and Investigations

UNITED STATES DEPARTMENT OF JUSTICE

WASHINGTON, D.C. 20530

Address Reply to the
Division Indicated
and Refer to Initials and Number

September 22, 1976

LMT:mvr

Victor Lowe, Esq.
Director, General Government Division
General Accounting Office
441 G Street, N. W.
Washington, D. C. 20548

Dear Mr. Lowe:

I am writing concerning the draft GAO report entitled: Improvements Needed in Efforts to Help the Mentally Disabled Return and Remain in Communities. Let me first of all commend you and your staff in a truly monumental enterprise.

As your draft report at page 35 notes, the Department of Justice is taking a very active role in litigating in the federal courts throughout the country concerning the constitutional rights of persons who are subject to civil commitment to institutions. Much of our effort is directed toward establishing as a constitutional principle the right to receive treatment in that setting which is less restrictive of personal liberty consistent with the treatment needs of such persons. As the GAO draft report well substantiates, there is little controversy over the obvious conclusion that there are many persons institutionalized in the United States who would benefit from deinstitutionalization and treatment in a much less restrictive setting.

I believe that it is important that GAO be advised that one of our major cases, United States v. Solomon, C.A. No. N-74-181 (D. Md.) has recently been dismissed on the grounds that there is no specific statutory authorization for the Attorney General to bring such suits. As you know, the Solomon case is a right to treatment case concerning the conditions of confinement of the mentally retarded residents of the Rosewood State Hospital in Maryland. The Department has filed a notice of appeal in that case. While it is our position that a specific statute authorizing the Department of Justice to bring such suit is not necessary in order for the Attorney General to sue to enjoin widespread and severe deprivations of constitutional rights (as we allege has occurred at the Rosewood facility), nevertheless such a statute would assist in gaining acceptance by state and local governments of the rights of the institutionalized throughout the country. A proposed statute has been submitted to Congress which would so authorize the Attorney General to bring such suits. This bill, H.R. 12008, was introduced into the 94th Congress by Representative Railsback.

For a more complete statement of the litigative activities of the Department in this area, you may wish to review my testimony which is reported in the Report of Proceedings of the Joint Hearing before the Subcommittee on Long-Term Care and the Subcommittee on Health of the Elderly of the Special Committee on Aging, United States Senate, 94th Congress, First Session, Mental Health and the Elderly, at pages 48 through 52 (September 29, 1975).

If I can provide you any further information in this regard, please do not hesitate to ask.

Sincerely,

LOUIS M. THRASHER
Director
Office of Special Litigation
Civil Rights Division

Phone (202) 554-7807

1001 3rd Street S.W.
Washington D.C. 20024

NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

October 13, 1976

Gregory J. Ahart
Director of the
Human Resources Division
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart,

This is in response to your letter of August 25th and constitutes in a preliminary way, a reaction of the leadership of the NASMHPD to the GAO draft report on "Improvements Needed in Efforts to Help the Mentally Disabled Return to and Remain in Communities".

First of all, the enormous breadth and size of the report necessarily makes our first reaction, in a sense, an incomplete one and we do intend to present to you further comments in the near future as we continue our study of your report.

Second, because of the "limitation" imposed on the use of the draft, we have necessarily confined our consultations on the document to the officers and board of our association. Thus this response, obviously, does not carry with it the total concurrance of all 50 state governments. From our general discussions with the other state mental disability agency executives, however, we know that what we submit to you here does constitute a substantial consensus.

Also, in-as-much as NASMHPD functions under the aegis of the National Governors' Conference, a copy of these comments to you is being made available to NGC in the event they consider that further comment is necessary.

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The report to the Congress of the United States by the Comptroller General's Office represents a new milestone toward the development of modern public policy for treating mentally ill and developmentally disabled persons.

The report is particularly remarkable in its frankness in describing some of the failures of the piecemeal program approaches now in process and the report emphasizes in numerous ways the need for a holistic approach.

COOPERATING AGENCY — COUNCIL OF STATE GOVERNMENTS

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It is one of the best documents prepared by any group in many years in systematically reviewing the problem areas in the mental health/mental retardation delivery system.

Although a good number of the observations have been known to most of the state mental health and mental retardation program directors for years, this report concisely delineates the problems and arrives at an insightful group of conclusions and recommendations.

Although only five states were studied intensively, the GAO staff interviewed many people in other states.

From our experience, most of the comments made regarding Federal/State arrangements, both programmatic and fiscal, are as appropriate to the other 45 states as they are to the five states studied.

We strongly believe this report represents the experiences of a vast majority, if not all, the states.

The GAO staff is, therefore, to be strongly commended for a most worthwhile effort.

I. GENERAL COMMENT AND RECOMMENDATIONS:

(1)

- The compilation in summary form of the major events in the growth of federal involvement in deinstitutionalization beginning with the National Mental Health Act of 1946 is a most valuable document.
- It is of major significance in that since the Social Security Amendments of 1972, major changes have come about directly or indirectly, through actions of the judicial branch of government, beginning with the landmark Wyatt v. Stickney "Right to Treatment in the Least Restrictive Setting."
- All of the recent court decisions emphasize the constitutional right to treatment and when these decisions are combined it means the legislative and executive branches are mandated to provide treatment to - in effect - guarantee treatment which must in effect be carried out within a community setting in most cases.
- In addition, communities are ordered not to confine nondangerous persons.
- The impact of these decisions on our communities may well be much the same as great as the impact of court decisions on desegregation.

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- In this area we believe the report to be lacking.
- We are unable to find adequate consideration given to the impact of deinstitutionalization on the <u>community</u> and of the steps necessary to prepare <u>communities</u>.
- The state governments have made significant advances in this area since the mid-1950's.
- The state mental disability agencies have concentrated, particularly in the last few years, in building a true community base for mental disability programming.
- We look forward to the boost a major report such as this will give our programs, particularly as this report recognizes the increasing necessity for the federal government to assume direct financial assistance to state governments in funding mental disability programs related to deinstitutionalization.

(2)

- The federal government programs should not by-pass state, county and city governments.
- Money must flow to smaller levels of government <u>through</u> larger levels of programs or they will never be coordinated.
- The federal government's role should be to monitor and implement such a structure.

(3) Non-governmental structures should not be created by the federal government to by-pass state and local governmental structures.

(4) The federal government's money should not be "seed money" or "time-limited" money at a time of fiscal problems at state and local levels. Limited federal monies end up as a "buck-passing-mortgage".

(5) Coordination is not effected by more "committees", "regional councils", etc. It is effected by simplification of money flow.

(6)

- Current federal regulations are focused primarily on cost containment.
- Lack of coordination among federal regulation drafters leads to poor service, duplication, internal contradiction between different funding sources and exorbitant administrative costs.
- Federal regulations need to be monitored from "below" as well as from "above".

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(7)

- A clear distinction needs to be made between what constitutes "medical care" and what constitutes "support system" funding.
- Medical care funding should be restricted in use to certain S.S.A. titles (e.g. XVIII and XIX), and support system funds should be restricted to other titles (e.g. XVI and XX).
- Programs such as halfway houses should be funded under "support systems" exclusively, rather than permitting the funding to be distorted to get covered under two systems.

(8)

- Federal government "health" programs and statutes should be mandated in all instances, to make a specific reference to, and dollar allocation to "mental health".
- Public "mental health" programs represent forty-percent (40%) of all public "health programs".
- Yet, despite well intentioned assurances to the contrary, "mental health" can be almost certain to be ignored in the implementation of the program.

II. SPECIFIC COMMENT AND RECOMMENDATIONS:

(1) To the Congress .....

(a) We concur in the idea of designating a committee with overall responsibility to oversee all Federal efforts toward deinstitutionalization.

(b)
- The report appropriately points out that the CMHC program although extremely important, is only one of a vast array of federal programs, emphasizing the overall problem of deinstitutionalization (Medicare, Medicaid, Title XX, HUD programs, etc.).
- The recommendation that Congress consider consolidating funds earmarked for mental health (out of special revenue sharing and CMHC programs) into block grants to the state mental health agencies has a great deal of appeal.
- An alternative which may be equally appealing to some and possibly more practical at this time would be Federal-to-State contracts possibly monitored by NIMH to include the two funding systems mentioned above.
- Project grants from NIMH to localities have run their course and should be replaced by some mechanism allowing the state (which has probably the greatest responsibility in the area) more flexibility in establishing and operating, either directly or by contract, the community mental health programs of the Nation.

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(2) To OMB ..... we concur in the GAO recommendations.

(3) To HUD and LABOR ..... we concur in the GAO recommendations.

(4) To HEW ..... we concur in all of the GAO recommendations to the Secretary of HEW with the exception of those comments regarding medicaid relative to the age group between 21 and 65. It may be that the exclusion for this age group will have to continue for various fiscal reasons, however, we think there should be some reconsideration as to whether or not exclusion of medicaid for this age group who are mentally ill should be discontinued.

(5) Chapter Three --- "Federal Coordination" .....

- The recommendations for interdepartmental coordination, though on the side of the angels, will not lead to improvement unless structures are devised to simplify coordination at the program delivery level.

(6) Chapter Five --- "Impact of CMHC's on Deinstitutionalization" .....

- The 1975 amendments to the CMHC Acts are counter-productive because the mandate increases services without adequate funding and vastly complicates administrative tasks.
- The catchment area concept is not useful in high density areas in our cities. The concept of CMHC becomes workable only if there is a single system of mental health care.
- Because the CMHC program by-passes state governments, it inevitably results in a dual system.
- The current failure of the CMHC program to impact deinstitutionalization is the direct consequence of its original design.

(7) Chapter Six --- "Medicaid" .....

- The implication that federal medicaid monies increases state resources for deinstitutionalization and improves quality of care is simply incorrect. Medicaid has been a drain on state dollars. Medicaid for delivering state services has not added to the flexibility of state resources.
- We agree that priority decisions between the up-grading of institutional care and development of community care need to be made. However, current federal regulations or limitations by judicial actions require states to implement both simultaneously, without additional resources.

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(8) Chapter Eight --- "Medicare" .....

- Medicare coverage for psychiatric patients in non-general hospitals should not be required to meet general hospital standards.

(9) Chapter Nine --- "SSI" .....

- SSI should not have service program requirements attached.
- It should remain an "income support" program.
- Adding a service program to it only further complicates an already excessively complicated system.
- The proposed definition of an ICF as the cut off point for full client eligibility under SSI, if implemented, would result in disincentives to the use of the "least restrictive alternative."

(10) Chapter Ten --- "Social Services" .....

- Fifty-percent (50%) categorical eligibility in nursing homes is a disincentive to deinstitutionalization as well as leading to poor quality programs for both psychiatric and non-psychiatric patients.

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We appreciate the opportunity to comment on what we consider to be a "landmark" mental health report of the federal government.

We are hopeful that the fruits of this report will be fast coming and long-enduring and we pledge the support of the state mental disability agencies in implementing the report's recommendations as amended by this communication.

As the various state agencies develop additional ideas we will be forwarding them to you.

Sincerely,

William S. Allerton

William S. Allerton, M.D.
Director, Division of MH/MR
Dept. of Human Resources
State of Georgia
and
President, NASMHPD

cc: Mr. Stephen B. Farber
Director
National Governors' Conference

PRINCIPAL OFFICIALS RESPONSIBLE FOR THE ADMINISTRATION OF ACTIVITIES DISCUSSED IN THIS REPORT

	Tenure of office	
	From	To
DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE		
SECRETARY OF HEALTH, EDUCATION, AND WELFARE:		
David Mathews	Aug. 1975	Present
Caspar W. Weinberger	Feb. 1973	Aug. 1975
Frank C. Carlucci (acting)	Jan. 1973	Feb. 1973
Elliot L. Richardson	June 1970	Jan. 1973
ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT:		
Stanley B. Thomas, Jr.	Aug. 1973	Present
Stanley B. Thomas, Jr. (acting)	Apr. 1973	Aug. 1973
ASSISTANT SECRETARY FOR HEALTH:		
Theodore Cooper	May 1975	Present
Theodore Cooper (acting)	Feb. 1975	Apr. 1975
Charles C. Edwards	Mar. 1973	Jan. 1975
Richard L. Seggel (acting)	Dec. 1972	Mar. 1973
Merlin K. Duval, Jr.	July 1971	Dec. 1972
ADMINISTRATOR, SOCIAL AND REHABILITATION SERVICE:		
Robert Fulton	June 1976	Present
Don I. Wortman (acting)	Jan. 1976	June 1976
John A. Svahn (acting)	June 1975	Jan. 1976
James S. Dwight, Jr.	June 1973	June 1975
Francis D. DeGeorge (acting)	May 1973	June 1973
Philip J. Rutledge (acting)	Feb. 1973	May 1973
John D. Twiname	Mar. 1970	Feb. 1973
COMMISSIONER, SOCIAL SECURITY ADMINISTRATION:		
James B. Cardwell	Sept.1973	Present
Arthur E. Hess (acting)	Mar. 1973	Sept.1973
Robert M. Ball	Apr. 1962	Mar. 1973

	Tenure of office	
	From	To
DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT		
SECRETARY OF HOUSING AND URBAN DEVELOPMENT:		
Carla A. Hills	Mar. 1975	Present
James T. Lynn	Feb. 1973	Feb. 1975
George W. Romney	Jan. 1969	Feb. 1973
ASSISTANT TO THE SECRETARY FOR PROGRAMS FOR THE ELDERLY AND THE HANDICAPPED (note a):		
Helen F. Holt	Apr. 1974	Mar. 1976
Robert F. Sykes (acting)	July 1973	Apr. 1974
Mercer L. Jackson	Mar. 1972	July 1973
ASSISTANT SECRETARY FOR CONSUMER AFFAIRS AND REGULATORY FUNCTIONS:		
Constance B. Newman	Feb. 1976	Present
ASSISTANT SECRETARY FOR COMMUNITY PLANNING AND DEVELOPMENT:		
David O. Meeker, Jr.	Aug. 1973	Present
ASSISTANT SECRETARY FOR HOUSING PRODUCTION AND MORTGAGE CREDIT AND FEDERAL HOUSING COMMISSIONER (note b):		
David S. Cook	Aug. 1975	June 1976
David DeWilde (acting)	Nov. 1974	Aug. 1975
Sheldon B. Lubar	July 1973	Nov. 1974
Woodward Kingman (acting)	Jan. 1973	July 1973
Eugene A. Gulledge	Oct. 1969	Jan. 1973
ASSISTANT SECRETARY FOR HOUSING MANAGEMENT (note b):		
James L. Young	Mar. 1976	June 1976
Robert C. Odle, Jr.	Jan. 1976	Mar. 1976
H. R. Crawford	Apr. 1973	Jan. 1976
Abner D. Silverman (acting)	Jan. 1973	Mar. 1973
Norman V. Watson	July 1970	Jan. 1973
ASSISTANT SECRETARY FOR HOUSING-FEDERAL HOUSING COMMISSIONER		
James L. Young	June 1976	Present

	Tenure of office	
	From	To
DEPARTMENT OF LABOR		
SECRETARY OF LABOR:		
W. J. Usery, Jr.	Feb. 1976	Present
John T. Dunlop	Mar. 1975	Jan. 1976
Peter J. Brennan	Feb. 1973	Mar. 1975
James D. Hodgson	July 1970	Feb. 1973
ASSISTANT SECRETARY FOR EMPLOYMENT STANDARDS:		
John C. Read	May 1976	Present
Bernard E. DeLury	May 1973	Apr. 1976
Vacant	Jan. 1973	May 1973
Richard J. Gruenwald	Jan. 1972	Jan. 1973
Horace E. Menasco (acting)	Oct. 1971	Jan. 1972
ASSISTANT SECRETARY FOR EMPLOYMENT AND TRAINING (note c):		
Willian H. Kolberg	Apr. 1973	Present
Paul J. Fasser, Jr. (acting)	Jan. 1973	Apr. 1973
Malcolm R. Lovell	July 1970	Jan. 1973

a/In March 1976, this position was changed to Assistant for Programs for the Elderly and Handicapped and became part of the office of the Assistant Secretary for Consumer Affairs and Regulatory Functions.

b/In June 1976, these positions were combined and the position of the Assistant Secretary for Housing-Federal Housing Commissioner was established.

c/Before November 12, 1975, the position title was Assistant Secretary for Manpower.