REPORT COVER
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IMPROVEMENTS NEEDED IN EFFORTS TO HELP THE MENTALLY DISABLED RETURN TO OR REMAIN IN THE COMMUNITIES IN MASSACHUSETTS

Department of Health, Education, and Welfare, et al.
Region I
Boston, Massachusetts

UNITED STATES
GENERAL ACCOUNTING OFFICE

Boston Regional Office

Contents

ABBREVIATIONS

BDD	Bureau of Developmental Disabilities
DES	The Division of Employment Security
DCA	Department of Community Affairs
DMH	Department of Mental Health
DOE	Department of Education

ABBREVIATIONS

DOL	Department of Labor
DPH	Department of Public Health
DPW	Department of Public Welfare
EOAF	Executive Office for Administration and Finance
EOHS	Executive Office of Human Services
GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
MCB	Massachusetts Commission for the Blind
MRC	Massachusetts Rehabilitation Commission
MSA	Medical Services Administration
OHD	Office of Human Development
OLTCSE	Office of Long Term Care Standards Enforcement
RSA	Rehabilitation Services Administration
SIB	Special Initiatives Branch
SRS	Social and Rehabilitation Service
SSI	Supplemental Security Income

UNITED STATES GENERAL
ACCOUNTING OFFICE REPORT

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D I G E S T

In recent years the emphasis of caring for mentally ill and retarded persons has shifted from the institutions, such as mental hospitals and schools for the retarded, to the communities. This shift is called "deinstitutionalization" and its purpose is to help people who have been released from an institution maintain themselves in the least restrictive setting possible, and minimize the institutionalization of people who can be cared for in the community.

In Massachusetts, the number of patients in state mental hospitals in 1963 was almost 21,000, but by 1975 it had been reduced nearly 66 percent to just over 7,200. The resident population at State schools for the retarded also declined from about 8,600 in 1963 to approximately 6,900 in 1975 or about 20 percent.

Placing mentally disabled people in the community enhances the opportunities to help them improve their lives, but it also increases the complexities of helping them. Generally, in an institution one organization meets a patient's needs; whereas in the community, many state and local agencies are involved. Successful deinstitutionalization requires making available a comprehensive range of services and assuring that these services are provided to the mentally disabled in the community.

GAO made this review to evaluate how deinstitutionalization has been proceeding in Massachusetts and to determine the type and range of services provided to patients discharged from State institutions.

GAO, as a legislative agency responsible to the U.S. Congress, makes recommendations to agencies of the Federal Government. Many of the findings and conclusions in this report, however, deal with matters that can be acted upon by the state agencies, the legislature, or the Governor of Massachusetts.

COMMONWEALTH OF MASSACHUSETTS

By passing several laws, such as the Comprehensive Mental Health and Retardation Services Act, Massachusetts has taken positive steps to

provide a range of services for its mentally disabled citizens and many patients have been released to the community. Despite the State's efforts, however, problems remain and must be solved, before an effective and comprehensive delivery system can be established for its mentally ill and retarded citizens. These problems are discussed below. While some could be solved with additional funding, others can be resolved within the framework of existing resources.

Lack of community services

There is a shortage of almost all types of services and facilities that are needed by the mentally disabled in order for them to live in the community. Although there has been a major shifting of patients from institutions to communities, there has not been a corresponding shift of funds and personnel to provide the required services.

Although the funds expended by the Department of Mental Health for community services have increased in recent years, most of the expenditures have been for institutional services. This was pointed out in a State Senate report which showed that $87 million of the Department's budget was spent on hospital clients, while only $20 million was spent for community service programs. Because of the shortage of community services:

--People are inappropriately admitted to institutions. It is estimated that over half of the admissions to schools for the retarded and mental hospitals could be eliminated if adequate mental health services and residences were available in the community. (See p. 40 .)

--Many patients remain in institutions who could be released if adequate community services were available. (See p. 30.)

--People who have been placed in the community are not receiving all the services they need. (See p. 41.)

--People have been placed in nursing homes because there are not enough community alternatives, such as halfway houses, or other sheltered living arrangements. Some of these nursing homes are substandard from a psycho-social standpoint. (See p. 17.)

More interagency coordination and cooperation is needed

Although the Department of Mental Health has cooperative agreements

with some agencies which identify each agency's responsibilities, coordination of services among State agencies serving the mentally disabled has been, and remains, a problem. Coordination has been fragmented and needs to be improved. As a result:

--When a patient is discharged from a State institution, it is not clear which State agency has the responsibility for follow-up to assure that aftercare services are being provided. (See p. 23.)

--Some blind mentally retarded persons and some mentally disabled persons are released from institutions without receiving available vocational services. (See p. 15.)

--Patients are not being deinstitutionalized or transferred to lower level care as recommended by periodic medical reviews. (See p. 21.)

State agencies could improve their operations

In addition to improving interagency coordination as discussed above, State agencies can do more to improve their own operations and help make deinstitutionalization a success. GAO noted that:

--The Department of Mental Health:

..has discharged people from State institutions without comprehensive discharge plans that identify total service needs. (See p. 13.)

..does not have an adequate information system to help evaluate the aftercare services provided to discharged patients. (See p. 25.)

..has placed some mentally retarded persons in State hospitals for the mentally ill; these people more properly belong in facilities that treat the retarded. (See Appendix I, p. 79.)

--The Department of Community Affairs is not providing enough community residences for the mentally disabled. (See p. 38.)

--The Division of Employment Security is not giving enough emphasis to helping the mentally disabled find suitable employment. (See p. 36.)

--The Department of Public Welfare is not fully realizing reimbursements possible under the Medicaid program for community mental health services, and is having difficulty obtaining reimbursement under Titles IVA, IVB, and VI of the Social Security Act (these have been replaced by Title XX). (See p. 33.)

Legislation not yet fully implemented

Two Massachusetts laws which have an impact on deinstitutionalization have not yet been fully implemented:

--The Comprehensive Mental Health Services Act of 1966, (see p. 6), and

--The Special Education Act of 1972 (Chapter 766), (see p. 7).

Comments of State Agencies

The Secretary of Human Services concurred with the content and accuracy of the report findings and conclusions. He stated that inadequate community mental health standards and the lack of an overall information system, to assist in evaluating and monitoring the aftercare services provided to patients, have contributed to the status quo delineated in the report.

The Secretary acknowledged that coordination among State agencies needs to be improved to bring about an integrated aftercare approach to the client. He advised that steps are being taken to address the issues in the report. Detailed work plans and timetables for task completion will be developed by lead agencies in each problem area and progress will be closely monitored (Appendix VII).

The Secretary of Administration and Finance assigned responsibility for commenting on this report to the Director, Bureau of Developmental Disabilities (now the Office of Federal State Resources) who agrees with the findings and conclusions. (See Appendix VI.) The Director stated that coordination has been a problem and the Bureau has tried to get State agencies to improve their programs, and coordinate with each other but it lacks the authority to do this. The Director also agreed that there are organizational and structural barriers that make it difficult to effectively serve the mentally retarded. (See p. 26.)

FEDERAL AGENCY REGIONAL OFFICES

Although the mentally disabled are directly served by State and local governments, there are many Federal programs that impact on mental health care and deinstitutionalization. The Department of Health, Education, and Welfare is the principal Federal agency that serves the mentally disabled primarily by providing financial assistance and setting standards of care under various Federal grant-in-aid programs such as Medicaid and Vocational Rehabilitation. The Department of Housing and Urban Development has a community development program under which services can be provided to developmentally disabled persons; and the Department of Labor has a program that requires certain Federal contractors to hire the physically and mentally handicapped.

The findings and conclusions in this report will be consolidated with those of four other States where a similar review was conducted, and a national report will be issued to the U.S. Congress. The national report will make recommendations to the Secretaries of the Departments.

GAO does have some recommendations, however, which are within the authority of the local office of these agencies to implement in Massachusetts.

GAO recommends that the Regional Director, HEW:

--Determine whether the social service needs of mentally disabled persons being released from institutions have been adequately assessed and, if not, make appropriate recommendations to the Secretary of HEW.

--Monitor State vocational rehabilitation programs to ensure that appropriate emphasis is given to persons with the most severe handicaps and that persons are not denied access to vocational rehabilitation services without an evaluation of their potential, as required by the Rehabilitation Act of 1973.

--Ensure State compliance with Medicaid discharge planning requirements for persons being released from mental hospitals and State schools for the retarded.

--Enforce HEW regulations requiring that independent professional reviews be done at least annually in intermediate care facilities and assist the State in developing procedures for resolving differences of opinion on the findings and recommendations of independent review teams.

--Ensure that the State Developmental Disabilities program places appropriate emphasis on evaluating the efforts of State agencies that provide services to persons released from State schools. Also, assist the State Bureau of Developmental Disabilities in resolving the coordination problems among State agencies.

--Consider the need for a mental health professional to evaluate the appropriateness of placement and services provided for the mentally disabled in intermediate care facilities. This could be evaluated when HEW conducts its validation survey of State utilization control programs.

--Work with State agencies to clarify the follow-up responsibilities of the Departments of Mental Health and Public Welfare for mentally disabled persons released from State institutions.

--Work with regional Labor and HUD officials, possibly through the Federal Regional Council, to coordinate Federal and State programs that can aid deinstitutionalization. For example, HEW could work with HUD to ensure that housing assistance plans adequately address the needs of lower income mentally disabled persons.

Comments of Federal Agencies

The HEW Regional Director agreed with the conclusions, particularly the status of deinstitutionalization efforts in Massachusetts and the need for better coordinated monitoring and more vigorous support on HEW's part. He agreed that the lack of cooperation among the State agencies is a key problem which seriously hampers effective deinstitutionalization.

HEW's Regional Director also stated that the report will be helpful to HEW in working with the State on deinstitutionalization. He plans to conduct a full review of regional office efforts in the area and to determine what further steps are appropriate either within the region or as recommendations for national policy changes. (Appendix VIII.) See Appendixes IX and X for comments received from HUD and DOL.

CHAPTER 1

INTRODUCTION

In the Mental Health field, a trend has developed in recent years shifting the emphasis of caring for mentally disabled[1/] persons in communities, rather than in institutions, i.e., State mental hospitals and schools for the retarded. Generally, the shift in emphasis is referred to as "deinstitutionalization" (DI). More specifically, DI means helping people who have been released from an institution maintain themselves in the least restrictive setting and minimizing the institutionalization of people who can be cared for in the community. It is a concept calling for betterment of the individual. Ideally, successful deinstitutionalization occurs when a person lives in the least restrictive environment and receives appropriate care, based on a treatment plan, which is regularly reviewed.

Many factors brought about the shift in emphasis to community-based care. Concern about poor conditions in some State institutions and the discovery of new drugs and treatment methods which helped modify the extreme behavior of the mentally ill were some of the motivating factors for the DI trend. Further impetus has been provided by increased Federal and State funding for community-level services. Also, Federal financial support programs such as Supplemental Security Income (SSI) pressures by

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1/The behavioral problems, treatment methods and service delivery system for the mentally ill and retarded are different. As used in this report the term mentally disabled refers to both mentally ill and retarded. However, when appropriate, each is discussed separately. As explained in Appendix I, we excluded alcoholic and drug abuse cases.

advocacy and other interest groups, changes in parental attitudes and recent court decisions have helped to establish the trend toward DI.

The placement of mentally disabled people in the community increases the potential for improving their lives, but it also increases the complexities of helping them. In an institution, one organization is involved in meeting a patient's daily needs (food, housing, etc.,) as well as developmental needs (psychotherapy, habilitation training, education, etc.). In the community, many agencies may be involved in providing for these same needs. Each agency has its own program objectives, eligibility requirements, range of services, and client population. The needs of a mentally disabled person are therefore usually met through the services of several agencies. These needs may change as a person progresses, or unfortunately regresses.

In Massachusetts, the Department of Mental Health (DMH) is responsible for persons in mental hospitals and schools for the retarded. Persons released to the community are required to have comprehensive treatment programs which may involve several State agencies providing the services. The principal agencies are the departments of Public Welfare, Public Health, Education, the Massachusetts Rehabilitation Commission, and the Commission for the Blind. Other State agencies that serve a particular client group, such as the elderly (Department of Elderly Affairs) or unemployed (Division of Employment Security), also serve the mentally disabled if they are eligible under the pro-

grams of these agencies. The departments of Community Affairs, Corrections, Youth Services, and the Office for Children, are also in this category.

Most State agencies that play a major role in serving the mentally disabled are organized under the Executive Office of Human Services. (See Appendix V.) The Executive Office of Human Services is responsible for planning and coordinating the activities of these agencies and making recommendations on spending levels to the Executive Office for Administration and Finance.

Many of these agencies administer Federal programs which provide funds for planning and services. For example, the Department of Public Welfare administers the Medicaid program under Title XIX of the Social Security Act and the Department of Public Health administers the Crippled Children's program under Title V of the act. The Federal role in serving the mentally disabled consists primarily of providing financial assistance and setting standards of care under Federal grant-in-aid programs such as Medicaid, Vocational Rehabilitation, etc.

OBJECTIVE AND SCOPE OF REVIEW

We made this review to evaluate how deinstitutionalization has been proceeding in Massachusetts and to determine the type and range of community services provided to patients discharged from State institutions. To do this, we randomly selected a group of patients released from two State institutions--the Metropolitan State Hospital

and the Fernald School for the Retarded. The patients traced were discharged from July through September 1974. We reviewed the selected patient's discharge plan and related records to establish what treatment and aftercare services were prescribed and received. We also interviewed caseworkers and responsible officials of the State hospital and school for the retarded as well as community, State and Federal program officials. For further details, see Appendix I.

As a legislative agency responsible to the U. S. Congress, our report recommendations are made to agencies of the Federal Government. Nevertheless, many of the findings and conclusions in this report deal with matters that can be acted upon by the State agencies, the legislature or the Governor of Massachusetts.

A draft of this report was sent to Regional officials of the Departments of Labor; Housing and Urban Development; and Health, Education, and Welfare; and, at the State level, the Executive Secretaries of Administration and Finance, and Human Services. Comments received from these officials have been considered and included in the report. Agency replies may be seen in Appendix VI to X.

We also discussed the draft report with officials of the Departments of Education, Mental Health, Community Affairs, and Public Health, the Bureau of Development Disabilities, the Division of Employment Security and the Massachusetts Rehabilitation Commission. The comments received from these officials were also considered and incorporated into the report.

CHAPTER 2

STATE DEINSTITUTIONALIZATION EFFORTS

In Massachusetts, the DI trend had its origins in the early 1950's. This trend continued through the 60's and by 1966 comprehensive ten-year plans were finalized that called for releasing mentally ill and retarded persons from State institutions to community facilities. The number of patients in State mental hospitals in 1963 was almost 21,000, but by 1975 the population had been reduced nearly 66 percent to just over 7,200. Similarly, the resident population at State schools for the retarded declined from about 8,600 in 1963 to approximately 6,900 in 1975, about 20 percent. Concurrent with the increase in discharges from the institutions, the State Department of Mental Health (DMH) increased the resources devoted to community mental health and retardation services. In 1968, an estimated $8.4 million was expended for community services, while in 1974 about $26 million was spent.

Federal and State legislation enacted during the 1960's and 1970's has had a substantial influence on the decline in the resident population at Massachusetts mental health institutions. Federal mental health planning funds made available in 1963 and the Federal Community Mental Health Centers Act of 1963 have been cited as providing impetus for DI. Also influencing the DI trend was State legislation such as the Comprehensive Mental Health and Retardation Services Act of 1966, and the Mental

Health Reform Act of 1970. Advocacy group efforts and various court decisions concerning a patient's right to treatment, and not just custodial care, have also helped this trend.

LEGISLATION TO AID THE MENTALLY DISABLED

To effectively serve the mentally disabled in the community, the Massachusetts Legislature in 1966 passed the Comprehensive Mental Health and Retardation Services Act (Chapter 735). The Act required DMH to establish a comprehensive program of community-based mental health and retardation services. Under the Act, the State was divided into 39 catchment areas,[1/] each with a director who would be responsible for assuring that persons released to his catchment area receive the care and services required. The five comprehensive services required under the Act are: inpatient; outpatient; 24-hour emergency services; partial hospitalization (i.e., intensive clinical treatment, but not 24-hour care); and, consultation and education. Although not yet totally implemented, some of the positions and services authorized under the Act have been funded. (See p. 32.)

Another State law which contributed to the decline in the resident population of State mental hospitals is the Mental Health Reform Act of 1970 (Chapter 123). The Act provides that (1) DMH perform comprehensive evaluations of patients at specific intervals, and (2) no

1/The Secretary of Human Services advised that there are now 40.

person can be involuntarily committed to a mental institution unless it is found likely that the person will harm himself or others. The limited availability of community services contributed to the increase in readmission rates. As Appendixes II and III show, the readmission rate for both the mentally ill and retarded has increased over the past ten years.

In 1972, an act regulating special education (Chapter 766) was passed which requires that each local school system provide a suitable educational program to all persons aged three to 21 even if they are determined to have "special needs". The Act requires that (1) each child entering kindergarten be screened by qualified personnel with experience and training in working with three, four, and five-year olds, or children of kindergarten entry age, and (2) each local school system have a Core Evaluation Team. Children of any grade found to have special needs are referred to the Team which is responsible for developing a program to meet the child's needs. The Team must include a doctor, nurse, social worker, psychologist, the student's teacher, and the special education coordinator of the school department.

According to a Department of Education (DOE) official, this law should help identify the educational services needed to allow more residents to move from State institutions to the community and focus attention on any shortage of appropriate educational options. He pointed out that the State is presently paying transportation and

tuition to send over 300 children to out-of-state schools because the needed specialized services are not available in Massachusetts. DOE's Director of Special Education told us that prior to the enactment of Chapter 766, there were over 750 children attending specialized out-of-state schools.

Chapter 766 went into effect in September 1974. At the time of our field work, most cities and towns had not yet fully implemented the Act and according to a DOE official, it is too early to make any meaningful program evaluations. DOE's Director of Special Education estimated that by June of 1976 over 800 institutionalized children will be in special education programs over half of them in public schools.

Massachusetts also has a law which requires a minimum of 5 percent of certain public housing constructed after August 1971 be set aside for the handicapped. Under this law, public housing developed for the handicapped has been primarily for the physically handicapped.

ESTABLISHMENT OF THE STATE BUREAU OF DEVELOPMENTAL DISABILITIES (BDD)

The Federal Developmental Disabilities program was enacted to assist States in planning and providing comprehensive services for the developmentally disabled.

The BDD[1/] administers Massachusetts' Developmental Disabilities

1/The BDD has since been merged with the newly established Office of Federal/State Resources.

Program. One of its responsibilities is to coordinate interagency planning for persons with developmental disabilities, which includes the mentally retarded (but not the mentally ill), epileptics, and persons with cerebral palsy.

The BDD does not directly provide services to the developmentally disabled, but rather fills gaps in services by providing grant funds to both public and non-profit private agencies for programs that meet the goals and objectives identified in the plan.

The BDD is part of the Executive Office for Administration and Finance (EOAF), which is responsible for administering and controlling the financial policies and programs of Massachusetts. The BDD was placed within the EOAF to give it the needed influence to carry out its duties. Some of BDD's activities include:

--Undertaking a multi-agency project to qualify the State schools for the retarded as Intermediate Care Facilities for the Mentally Retarded. This effort stemmed from Planning Grants awarded by the Federal Government.

--Providing grant funds to the Department of Public Health to help train pediatric nursing home staff to care for retarded persons that also have other handicaps.

--Providing grant funds to the Department of Mental Health to help establish 50 community residences for the mentally retarded.

BDD's director told us that other activities include: developing legislation to provide housing, transportation, education and community

residences for the retarded; assisting in the development of legislation and regulations to permit handicapped children under age 16 to obtain skilled and intermediate nursing care. BDD also provided legal research when the Special Education Act (Chapter 766)was drafted.

BDD's director advised us that it does not have enough resources to evaluate how effectively state programs are serving the developmentally disabled; and that this is considered to be a responsibility of the state agency administering the program. We were advised that BDD has not placed emphasis on program evaluation, but, in the future, more of its resources will be devoted to monitoring and evaluation.

PROBLEMS IN IMPLEMENTING DEINSTITUTIONALIZATION

Massachusetts has taken positive steps to pass the necessary laws to provide a full-range of services for its mentally disabled citizens. Despite the State's efforts, many problems remain and must be resolved before an effective mental health care delivery system can be established. The following two chapters discuss the problems being encountered by Massachusetts in its attempt to establish a comprehensive community-based program to serve the mentally disabled.

CHAPTER 3

NEED TO IMPROVE AND COORDINATE STATE PROGRAMS THAT SERVE THE MENTALLY DISABLED

Caring for the mental health needs of the residents of Massachusetts is the responsibility of the Department of Mental Health (DMH). Under the Comprehensive Mental Health and Retardation Service Act, DMH is required to provide a comprehensive mental health program in pre-established catchment areas so that people can receive mental health services in local communities.

In addition to mental health services, mentally disabled people frequently need other services such as vocational rehabilitation, job placement, housing, income supplements and medical services which are provided by other State agencies.

Clearly then, successful deinstitutionalization requires not only having available the range of services needed to help the mentally disabled in the community, but assuring that these services are accessible and are provided when needed. Because many agencies may be involved, a system is needed to marshal resources and apply them effectively. A focal point is needed in this sytem to act as an advocate and coordinator for deinstitutionalization. More importantly, however, other State agencies must be willing to cooperate and provide the needed resources to the mentally disabled.

Although DMH has cooperative agreements with some agencies which identify each agency's responsibilities, coordination of services has been, and remains, a problem. A number of different agency officials stated that coordination is one of the principal problems hindering the State's deinstitutionalization program. One official from the Executive Office of Human Services said that clients find their way through the human services system depending on how well their case worker knows the system.

In addition to the inadequate coordination among the various agencies, we found the following areas in need of improvement:

1. Inadequate discharge planning for patients released from State institutions,
2. Patients not receiving available services,
3. Patients being placed into substandard nursing homes,
4. Patients not being deinstitutionalized or transferred to lower level care as recommended by periodic medical reviews,
5. Inadequate follow-up of patients released from mental health institutions, and
6. Lack of an overall information system to help evaluate the after-care services provided to discharged patients.

Each of these matters is summarized below. Additional details are presented in Appendix I, which deals with tracing patients who have been released from two institutions to the community to determine what services were prescribed and received.

COMPREHENSIVE DISCHARGE
PLANS NOT PREPARED

Federal Medicaid and Social Service regulations required comprehensive treatment plans for patients released from mental institutions. In a joint agreement between DMH and The Department of Public Welfare (DPW), each agency's responsibilities for treatment planning are spelled out. DMH is responsible for preparing a comprehensive plan that provides for all the patients' needs including medical, social, psychiatric, and vocational services. Under the agreement, DPW is required to provide financial support to those who are eligible.

Under the single State agency concept, the DPW is the State Medicaid agency, and as such, is responsible for providing medical and public assistance to the State's needy, including the qualified mentally disabled. Frequently, mental hospital patients are discharged to intermediate care facilities (ICF's) and their medical expenses are covered under the Medicaid program. About half of the cost of keeping them in the ICF is reimbursed by the Federal Government. Medicaid also covers eligible patients that are 65 or older in State mental hospitals. DPW is also the State social services agency and provides services to the mentally disabled. These services are 75 percent reimburseable under Title IVA, IVB, and VI of the Social Security Act.1/

1/During our review these titles were replaced by Title XX.

At the two institutions where patients were selected for tracing--Metropolitan State Hospital and the Fernald School--discharge plans did not identify all the patients' needs. The State Department of Public Health conducts medical reviews of State institutions and nursing homes. A recent Public Health review of Medicaid patients at Metropolitan disclosed that medical and social service plans were not comprehensive and recommended that a written plan be prepared, based on each patient's needs. Hospital officials agreed that discharge plans are not always comprehensive, and explained that in most cases some of the services needed by the patient were not available, and therefore, there was no point in including this information in the discharge plan.

At the Fernald School, formal discharge plans were not prepared for patients being released. Only general background data such as a brief social history, and the level of retardation were provided to the agency or facility to which the patient was being referred.

We believe that the needs of the patients should be identified in the discharge plans even if they may not be available in the community. Without a discharge plan which identifies the medical, social, psychiatric, vocational, housing and other service needs of the client, an evaluation of the effectiveness of aftercare is incomplete and will not show whether the prescribed services were received by the discharged clients. The Secretary, Executive Office of Human Services, advised us that this condition has been corrected and evaluations and discharge plans have been prepared, see p. 27 .

PATIENTS NOT RECEIVING AVAILABLE SERVICES

Some patients have been released from State mental hospitals and schools for the retarded without adequate referral for services.

Mentally ill patients not referred to the Massachusetts Rehabilitation Commission

Our tracing results at Metropolitan showed that some patients who were reported to be suitable candidates for vocational rehabilitation training were not referred to the Rehabilitation Commission. Provision for referral of such patients is included in a cooperative agreement between DMH and the Commission. The agreement states that individuals in State institutions including those being released, should be screened for vocational rehabilitation potential and that the Commission will evaluate all persons recommended by the screening team. Commission officials agreed that if a Commission counselor were included as a part of the interdisciplinary discharge committee, the likelihood of a patient being overlooked for vocational rehabilitation evaluation would be minimized.

Mentally retarded persons may not be receiving services of Massachusetts Rehabilitation Commission

At Fernald School for the Retarded, we found that patients with an I.Q. of 50 or below were not referred to the Massadhusetts Rehabilitation Commission for vocational rehabilitation because a local Commission counselor considered them untrainable. The President's Committee on

Mental Retardation does not consider a person severely retarded unless his I. Q. is 35 or below. Accordingly, the Commission may not be focusing on the severely retarded as required by the Rehabilitation Act of 1973. Commission officials stated that this situation may be caused by a subjective interpretation of its policy which states in part: "...below I. Q. 50, a client, while eligible, may not be susceptible to rehabilitation services."

A Department of Mental Health official stated that he does not believe the Commission is fulfilling its responsibility in serving the severely retarded and that they are interested in clients with higher potential. A Commission official told us that if emphasis is placed on the severely disabled, as required by the Rehabilitation Act of 1973, it will require them to devote a disproportionate amount of resources to a smaller number of clients. This will result in fewer people being served and possibly fewer rehabilitations, which is one of the criteria used by the Federal Government to fund rehabilitation programs. The Secretary, Executive Office of Human Services, plans to rectify this, as discussed in the agency comments. (See p. 27.)

Patients referred to the Massachusetts Commission for the Blind not followed-up

Patients discharged from Fernald and referred to the Massachusetts Commission for the Blind were not followed-up by either agency. Commission officials stated that they do not follow-up persons who are both blind and mentally retarded; but provide services to the blind who are not otherwise handicapped and have a better chance of becoming gainfully employed.

The Commission and the Department of Mental Health were formulating an interagency agreement for providing services to blind, mentally retarded persons. At the time of our review, the agreement had not been finalized.

PATIENTS RELEASED TO SUB-STANDARD NURSING HOMES

Since the advent of the Medicaid program, many mental patients and retarded persons have been discharged to nursing homes, primarily intermediate care facilities (ICF's) which provide medical and social services in addition to domiciliary care. It is not known how many discharged mental patients have been placed in nursing homes; however, various estimates are available. A Boston State Hospital study of patients discharged between 1965 and 1968 showed that about 26 percent were discharged to nursing homes. Another study done at Grafton State Hospital showed that 43

percent of the discharged patients went to nursing homes and 19 percent to rest homes. More recently, a Department of Public Health study of 39 ICF's found that 13.5 percent of the patients were former mental patients. Another recent study which accounted for over 90 percent, or about 38,000 of the total nursing home beds in Massachusetts showed that about one out of every five,or about 8,400, ICF beds are occupied by a mentally disabled person.

There is a financial incentive for the State to discharge patients to nursing homes because, under the Medicaid program, some of the financial burden is transferred to the Federal Government which reimburses the State for about fifty percent of nursing home costs.

Just how well ex-mental patients and retarded persons are being cared for in nursing homes is difficult to assess. A State official advised us that ex-mental patients tended to be placed in those nursing homes where the quality of patient care tended to be poorer and safety standards may not be complied with. He also said that the poorer quality nursing homes had many ex-mental patients and that, generally speaking, the more mental patients in a nursing home, the worse its condition.

In June 1975, the Executive Office of Human Services decertified from the Medicaid program or issued warnings to 60, or about 10 percent, of the State's ICF's. These were homes that failed to comply with the Federal Life Safety Code or with minimum standards of patient care. The following action was taken against these homes:

Decertified from the Medicaid program because of patient care or Life Safety Code deficiencies	25
Two-month provisional certification	2
Interim certification for 90 days	10
Dropped to Rest Home status[1/]	13
Voluntarily closed	10
	60

1/This makes the facility ineligible for Medicaid, however, it is not known whether the deficiencies have been corrected.

By means of a questionnaire sent to these homes, we determined that many persons from State mental hospitals and schools for the retarded were in problem nursing homes. The following table shows that 31 of the 46 homes that responded and were still operating had an average of 28 percent of their total bed capacity occupied by mentally ill and retarded patients who were formerly in State institutions. Moreover, 76 mentally disabled patients were placed in 13 of these homes, while they were being decertified.

Bed capacity occupied by mentally disabled patients	Number of homes[1/]	Total bed capacity	Number of mentally disabled patients	Percent of beds occupied by mentally disabled patients
Over 90%	1	24	24	100%
75 - 90%	4	121	96	79
51 - 74%	3	128	70	55
26 - 50%	7	299	106	35
11 - 25%	8	220	41	18
1 - 10%	8	464	13	03
	31	1,265	350	28%

1/Nine other homes that responded and were still operating indicated that they had no mentally disabled patients. Six other homes indicated that they were no longer in business.

The Secretary of Human Services stated that it is against DMH policy to place a patient in a nursing home that is more than 50 percent occupied by former mental patients. We noted that 5 of the above 31 problem nursing homes are more than 50 percent occupied by former mental patients.

There is inadequate communication between the Department of Public Health and DMH regarding the certification status of nursing homes in the State. The Assistant Commissioner for mental health services in DMH stated that occasionally he learned of an action taken against a nursing home by reading about it in the newspaper. We believe that inadequate communication between the Department of Public Health and DMH is one cause for patients being placed in substandard nursing homes. DMH officials stated that other factors contributing to this problem include a general shortage of nursing home beds as well as the reluctance of some nursing homes to admit mentally disabled patients.

In another GAO review, we found another effect of the nursing home bed shortage in Massachusetts. For a six-month period we noted delays in transferring medically ready Medicaid patients from hospitals to lower cost health care facilities such as skilled nursing and intermediate care facilities. Our findings indicate that in addition to paying one-half of the cost for medically necessary inpatient hospital days, the Federal Government will pay over $500,000 in Medicaid reimbursement for about 10,000 inpatient hospital days approved for reasons other

than medical necessity. About one-half of the unnecessary hospital days were authorized because the medical recipients were awaiting a bed in a skilled nursing or an intermediate care facility.

PERIODIC MEDICAL REVIEWS

Federal Medicaid regulations require that a Periodic Medical Review (PMR) be made annually at hospitals and skilled nursing facilities. They also require an Independent Professional Review at intermediate care facilities to determine the adequacy of services, the necessity and desirability of continued placement of patients in such facilities and the feasibility of meeting their health care needs by alternative means. Under an agreement with the DPW, DPH is responsible for licensing and inspecting health care facilities in the State.

Our review at Metropolitan State Hospital did not include an assessment of the quality of patient care, but the Department of Public Health completed a PMR report at the hospital in August 1974, that cited several deficiencies in the quality of patient care. The report also noted that psychiatric care was difficult to evaluate because of the poor quality of record keeping. Some of the more serious findings were:

--medical care was described as fair to poor,

--medical care is crisis-oriented, rather than preventive,

--laboratory tests which showed abnormal results were not repeated to verify them, nor were additional tests and recommendations for appropriate treatment noted,

--the nursing staff was assuming a great deal of responsibility for medical care that more appropriately belonged to the physician,

--the quality of the social services was difficult to assess because of inadequate documentation,

--of the 114 patients included in the PMR, only 22 had any documentation of social service plans and goals,

--only one patient's record was found to have a social service progress note although all had a social service history.

The Department of Public Health began making periodic medical reviews in the State mental hospitals and skilled nursing facilities in December 1972. Officials advised that as of July 1975, Public Health had not completed its review of these facilities due to staffing limitation.

Because hospitals and skilled nursing facilities were focused on initially, independent professional reviews have been made at only three intermediate care facilities. We were advised that Public Health only has about one-half of the staffing needed to complete the number of independent professional reviews required by Federal regulation and the State faces a serious non-compliance problem in this area. A Public Health official further advised us that the licensing teams will not include a mental health professional. Because so many intermediate care facilities have mentally disabled patients, we believe that the licensing team should include a mental health professional.

PMR reports are submitted to the Department of Public Welfare for corrective action. Welfare officials advised us, however, that they have little authority in getting DMH to act on PMR recommendations. The

PMR report for Metropolitan State Hospital recommended that seven patients be transferred and 16 reevaluated for transfer to a lower level facility. The hospital superintendent, who is responsible for the patients, did not agree with the recommendations and only four patients were discharged--two of the seven patients recommended for transfer and two recommended for reevaluation.

The Departments of Public Welfare, Public Health, and DMH are peer agencies and have no authority over one another. Therefore, DMH is not required to adopt Public Health's recommendations if they do not agree with them. We were also advised that DPW is reluctant to cut off Medicaid payments to a State institution in order to enforce compliance.

If PMR reviews at mental hospitals are to be effective, a method should be established to resolve these differences. Apparently the Executive Office of Human Services, the organization to which these agencies report, is either unaware of the problem or is not able to get them to work together.

INADEQUATE FOLLOW-UP OF PATIENTS RELEASED FROM MENTAL HEALTH FACILITIES

Follow-up is designed to assure that needed services are being received and to assess the discharged patient's progress. Follow-up procedures for the mentally disabled vary according to the aftercare provider. Mental patients placed into nursing homes are generally followed-up for one year by DMH personnel. After one year, operating

personnel were unclear as to their responsibility for follow-up and many patients are not being followed-up.

DMH representatives said that during the first year a mental patient is in a nursing home, it is their responsibility to follow-up. After the first year, we were advised that the Department of Public Welfare follows-up, but only to provide financial assistance to the patient. The Secretary of Human Services advised us that according to policy, DMH is responsible for providing follow-up indefinitely, but that this policy has not been effectively implemented.

At Metropolitan, we traced six patients that were placed in nursing homes and found that the patients' files contained no documentation indicating that they were being followed-up. Nursing home personnel contacted stated that patients were visited by the hospital staff, but could not recall how frequently. We traced 18 patients discharged from the Fernald School and found that follow-up visits to patients placed in nursing homes were generally made for only one year.

The Commissioner of Mental Health advised us that because of their special needs, the mentally disabled require follow-up for extended periods, sometimes for the rest of their lives. However, the various agencies to which they are referred provide only limited follow-up. For example, MRC follows-up clients for only 60 days after they have been placed on a job, regardless of the client's disability category. See Appendix I for more information on the follow-up of patients discharged from two institutions.

NEED FOR INFORMATION SYSTEM TO EVALUATE EFFECTIVENESS OF AFTERCARE SERVICES

Identifying those mentally disabled people who are actually receiving services from agencies other than DMH is extremely difficult and in a realistic timeframe nearly impossible. Generally, State agencies do not identify the mentally disabled as a distinct population because mental illness, per se, is not a basis for qualifying for services. For example, the Crippled Children's Services program administered by the Department of Public Health provides services to children with certain physical handicaps, some of whom may be mentally retarded, but the number of retarded children being served is not known. Similarly, the Department of Public Welfare records do not identify how many mentally disabled patients in nursing homes are on Medicaid.

In addition to not having a system which keeps track of where the mentally disabled patients have gone, there is no system which lists the services which are needed by these discharged patients and who is providing them. Because of the lack of an information system, it is impossible to evaluate the effectiveness of the aftercare network into which the mentally disabled are placed.

In order to evaluate aftercare for discharged patients, a system is needed that shows where the ex-patients are, what services are needed, what services are being provided, and who should be providing them. The

need for such an information system is important because of the current trend toward caring for the mentally disabled in the community.

The Bureau of Developmental Disabilities (BDD) is currently trying to establish a client information system that will be used by State agencies serving the developmentally disabled to identify resources for their clients. The BDD system will serve as a focal point for the developmentally disabled, which includes the mentally retarded, but not the mentally ill, and is expected to provide client information to aid in assessing their progress.

STATE AGENCY COMMENTS

Executive Office for Administration and Finance

BDD has identified coordination as a major barrier to deinstitutionalization and has tried to get agencies to improve their programs, but it does not have the authority to require other State agencies to do this. The BDD Director advised us that there are organizational and structural barriers that make it difficult to effectively serve the mentally retarded.

Executive Office of Human Services

The Secretary of Human Services reviewed our draft and agreed with its content and accuracy. In particular, the Secretary indicated that the following conclusions were worth highlighting:

--Many people have been released without adequate services and without comprehensive discharge plans,

--Mentally ill and retarded persons have been discharged from State institutions to nursing homes which in certain cases are probably substandard from a psycho-social standpoint.

--Many people are inappropriately admitted to institutions because of a lack of community services.

--Many patients are not being deinstitutionalized to lower level care facilities as recommended by periodic medical reviews, in certain cases due to lack of community alternatives.

--There is a lack of an overall Department of Mental Health information system to assist in evaluation of aftercare services provided to patients.

--The quality of health services in our institutions is substandard in many respects.

--Coordination among state agencies serving the mentally disabled needs to be improved to bring about an integrated aftercare approach to the client.

--The Department of Mental Health/Massachusetts Rehabilitation Commission agreement which calls for every discharged patient to be evaluated by the Rehabilitation Commission is only partially implemented.

The Secretary considered the following observations to be particularly sound and agreed with the need to:

--Develop a centralized tracking system for patients discharged from mental hospitals.

--Revise the Massachusetts Rehabilitation Commission's policy manual which presently considers persons with I.Q. below 50 as untrainable and therefore ineligible for services.

--Develop DMH regulations on aftercare and follow-up.

The Secretary advised that steps are being taken to address the issues in this report. For example, Title XIX evaluations and client plans includ-

ing comprehensive discharge plans have been developed for each resident of every state school for the retarded. Detailed work plans and timetables for task completion are to be developed by lead agencies in each problem area and progress is to be closely monitored. These actions include:

--Clarifying the Area Director's responsibility for the aftercare of each client, thereby making one person accountable for the client's progress. Each Area Director will likewise be assigned responsibility for a geographic unit at the State Hospital, thereby insuring continuity of care between the institution and the community.

--Developing standards for community services which will focus on the aftercare problems experienced by clients discharged from institutions.

--Developing a system to monitor the quality of care provided clients, drawing upon the expertise of professionals and citizens.

--Developing a management information system that will facilitate the monitoring of services to clients as well as generate management information to ensure that scarce resources are used effectively.

--Reviewing the health services provided at institutions with the expectation that glaring deficiencies will be rapidly corrected. A contractual strategy involving the resources of Boston's major teaching institutions is being used to achieve this goal.

--Developing cooperative approaches between the Massachusetts Commission for the Blind and the Department of Mental Health. Service systems are being developed for formalization in an interagency agreement. The Commission previously viewed rehabilitation efforts as DMH's responsibility and only 50 blind-retarded persons were officially acknowledged to be in state institutions. Currently, the Commission estimates that there are about 500 to 600 blind persons in state institutions and views deinstitutionalization as a cooperative effort with DMH.

The Secretary's letter is in Appendix VII.

HEALTH, EDUCATION, AND WELFARE COMMENTS

The HEW Regional Director advised us that the report very accurately points out a key problem which seriously hampers effective implementation of deinstitutionalization--the lack of cooperation among the State agencies involved. He stated that there must be stronger interagency cooperation than has been the case in Massachusetts thus far, and acknowledged that Massachusetts badly needed a comprehensive evaluation system. Further, he stated that a performance review of the Massachusetts Rehabilitation Commission has been scheduled for fiscal year 1976 and particular emphasis will be placed on examining its work with the severely handicapped in light of the policy reflected in the Rehabilitation Act of 1973.

The Regional Director's letter is in Appendix VIII.

CHAPTER 4

SHORTAGES OF COMMUNITY SERVICES

Various studies and estimates by Massachusetts mental health officials recognize that many more institutionalized patients could be released if additional services were available in the community. There is a shortage of almost all types of services and facilities that are needed by the mentally disabled in order for them to live in the community. This has both prevented patients from being placed in the community, and has resulted in those who have been placed not receiving all of the services they should be receiving.

The following conditions contributed to this problem:

--A major shifting of patients from institutions to communities without a corresponding shift of funds and personnel to provide the services,

--Not fully implementing the requirements of the Massachusetts Comprehensive Mental Health Services Act of 1966,

--Not fully realizing reimbursements possible under the Medicaid program for community mental health services,

--Difficulty in obtaining reimbursement under Titles IVA, IVB, and VI of the Social Security Act,[1/]

--Not being able to qualify for SSI benefits those patients with a history of recurring short-term mental illness,

--Not giving enough emphasis to helping the mentally disabled find suitable employment,

--Not yet fully implementing the Special Education Act of 1972 (Chapter 766),

--Not providing enough community residences for the mentally disabled.

1/During our review these titles were replaced by Title XX.

While some of the problems would be solved with additional funding, there is much that can still be done within the framework of existing resources.

Experts have estimated that over half of the admissions to State hospitals and schools for the mentally retarded could be eliminated if adequate residences and mental health services were available in the community. Also, the Secretary of Human Services stated that the number of in-patient hospital days could be reduced by as much as 90 percent because of the shorter lengths of stay made possible through out-patient and partial hospitalization programs.

FUNDING MENTAL HEALTH INSTITUTIONS

The DMH operates 23 mental health facilities including 10 State mental hospitals and 6 State schools for the retarded. DMH statistics show that these institutions housed slightly more than 14,000 patients as of July 1, 1975. Although the cost of operating these institutions is declining in terms of its percentage of the total DMH budget, it is still consuming an overwhelming share of the budget. This was pointed out in a State Senate report which showed that in 1974, $87 million of DMH's budget was expended to serve State Hospital clients, while only $20 million was expended for community mental health service programs.

Because community services are inadequate, it is necessary to operate and maintain these institutions while the community based care system is being improved. Officials stated that reallocating resources from the institutions to the community is a very difficult and slow

process. The State's civil service system presents a major obstacle to deinstitutionalization because services are difficult to restructure on a community-based delivery system. For example, some employees' positions are tenured at the institutions and State officials said that if State hospital staff positions were eliminated, in many cases, doctors and nurses would be lost while maintenance and other support personnel would be retained. A Department of Public Welfare official pointed out that during the transition from institutional to community-based care the State must fund both the institutions and start up costs for community programs which are very high.

In addition to DMH's problem in shifting resources from institutions to community programs, its fiscal year 1976 budget request has been reduced by the Governor and the Legislature. These budget reductions may affect the amount of Federal funds reimbursed to the State under Federal programs such as medicaid.

REQUIREMENTS OF THE COMPREHENSIVE MENTAL HEALTH AND MENTAL RETARDATION SERVICES ACT OF 1966

Under Massachusetts' Comprehensive Mental Health and Mental Retardation Services Act of 1966, DMH is required to provide five essential mental health services in each of the State's 39 catchment areas. Although the position of Area Director is provided for in the Act, only 8 of 39 positions were funded in 1975. The Area Director is an integral part of the aftercare network since he is responsible for planning, developing, and supervising all clinical programs in his catchment area and getting the cooperation of other

public and private agencies to serve the mentally disabled.

A recent mental health planning study recognizes that full implementation of the Act is not possible without filling all 39 positions. According to the Massachusetts Mental Health Plan, only 13 of the 39 catchment areas provide all full essential services; 10 provide most of the services and the remaining 16 offer very limited services. We were advised that the greatest need is for partial hospitalization and 24-hour crisis intervention service.

Community Mental Health Centers (CMHC's) play a key role in providing follow-up and aftercare to patients discharged from state hospitals and schools for the retarded. Our tracing revealed that discharged patients that were referred to CMHC's were generally receiving prescribed aftercare and follow-up. (See appendix I.)

MEDICAID REIMBURSEMENT FOR COMMUNITY SERVICES

The Massachusetts Medicaid Plan covers a wide range of mental health services that can be provided in mental health clinics and are eligible for reimbursement under the Medicaid program. In addition, outpatient services provided in State mental hospitals are covered in the plan and reimbursable under the Medicaid program.

Financial data provided by the Department of Public Welfare, the State Medicaid agency, indicates that most of the reimbursement for mental health services has been for inpatient services in State mental hospitals. For example, the Department estimated that in fiscal year 1976 between $16 and $17 million will be spent under the Medicaid program

for care in State mental hospitals, but only about $1 million will be spent for mental health clinic services.

A Department of Public Welfare official stated that many of the outpatient services being provided in State mental hospitals and mental health clinics could be reimbursed, thus freeing up funds to expand critically needed community programs. He stated that the primary reason why these services are not being reimbursed is that DMH has not established a system for claiming community services and as a result claims are not being submitted.

A joint agreement between DMH and the Department of Public Welfare calls for Public Welfare to assist in training DMH staff who are responsible for filling out claims for reimbursement for mentally disabled persons released to the community. The Secretary, Executive Office of Human Services acknowledged that the State is not submitting Medicaid claims for all eligible CMHC services. (See p. 41.)

IMPACT OF SOCIAL SERVICE PROGRAM

Community-based social service programs are an integral part of the aftercare of the mentally disabled. Social services helps persons discharged from mental hospitals and schools for the retarded to return and remain in their communities. Also, persons in the community may avoid being institutionalized if social service programs are available. Prior to the enactment of Title XX, social services for the mentally disabled were provided under Titles IVA, IVB, and VI of the Social Security Act. Services covered in the State social services plan include daycare, foster

care, homemaker services, as well as referral services, services to aid a person's return to community living and self-support services.

We were advised that Massachusetts social services claims were not reimbursed by Health, Education, and Welfare (HEW) because they were not properly submitted. For example, claims for institutional medical services were disallowed because these services are not reimbursable under the social services program. Also, the submitted claims were based on projections and not actual caseloads. Actual reimbursement from HEW for the two fiscal years has been limited to less than $3.6 million of the $86.6 million submitted.

Claims for reimbursement under Titles IV and VI of the Act amounted to about $50.7 million in fiscal year 1973 and about $35.9 million in fiscal year 1974. As shown below, a total of 15,700 and 6,900 clients were served during these years.

	Community	Institution	Total
1973			
Clients served	3,000	12,700	15,700
Expenditures (in millions)	$10.3	$40.4	$50.7
1974			
Clients served	1,200	5,700	6,900
Expenditures (in millions)	$3.6	$32.3	$35.9

A DMH official stated that past problems in obtaining Federal reimbursement for social services may hinder the State's deinstitutionalization effort in the future, and explained that this contributed to the decline of clients served.

IMPACT OF SUPPLEMENTAL SECURITY INCOME (SSI)

Many patients released to the community from State mental hospitals and schools for the retarded receive SSI benefits. SSI was designed to establish uniform eligibility requirements to replace the varying requirements that existed under the public assistance programs for the aged, blind, and disabled that preceded SSI. Both HEW and State officials advised us that the disability requirements under the SSI program are more stringent than they were under the earlier program for the disabled. Under the SSI requirements, to be considered disabled, a patient's mental illness has to be expected to last for at least one year; those patients afflicted with short-term sporadic mental illness that recurs for prolonged periods, usually do not qualify for SSI. Since these patients may not qualify for SSI, there is often no other alternative but to keep them in mental hospitals.

FINDING SUITABLE EMPLOYMENT

Various officials advised us that the need for suitable employment for the mentally disabled is critical and hinders deinstitutionalization efforts. Section 503 of the Rehabilitation Act of 1973 is aimed at alleviating discrimination in hiring the mentally disabled and requires each Federal contractor, with a contract exceeding $2,500, to take affirmative action to hire qualified handicapped persons. Officials of the Division of Employment Security (DES) said that Section 503 regulations have not been fully implemented yet.

The Department of Mental Health has an agreement with the DES--the State employment agency--and the Massachusetts Rehabilitation Commission--the State rehabilitation agency--to help the mentally disabled find suitable employment. The agreement calls for the three agencies to coordinate their services and cooperate in implementing joint programs. It also provides for a committee made up of representatives from each agency to analyze, evaluate and review cases of mentally disabled patients who need the services of the Rehabilitation Commission or DES. Under the agreement, DES is to assign counselors to serve on case conference committees at Department of Mental Health facilities.

Our review showed that no DES representatives were assigned at either Metropolitan or Fernald. According to DES officials there are official procedures for referring mentally disabled patients to DES, and some which have been referred, have not been ready for competitive employment. A DES official stated that the cooperative efforts called for in the agreement were being implemented only in a few area offices. We were advised by DES officials that although an individual in each DES office has been designated as a specialist for services to the handicapped, it is a part-time position which has had limited impact in many offices. DES officials also said that because the formula used by the Department of Labor to determine DES funding levels emphasizes the number of job placements made, emphasis is given to the non-handicapped so that more placements can be made.

LACK OF EDUCATIONAL PROGRAMS
FOR THE MENTALLY DISABLED

A State Education official informed us that many children are admitted to State institutions because of a lack of specialized educational programs. In an attempt to provide a suitable educational program for children with special needs, the Massachusetts Legislature adopted an education act, (Chap. 766 of the Acts of 1972), which requires each local school system to provide an educational program suitable to each child's particular needs.

Implementation of Chapter 766 and the corresponding emphasis on children with special needs began in September 1974 and it is too early to assess its impact on deinstitutionalization. However, if the requirements of the law are met, more educational opportunities should be available to the mentally disabled and this should reduce admissions to State institutions and permit the discharge of many institutionalized children.

SHORTAGES OF HOUSING FOR
THE MENTALLY DISABLED

Community living arrangements are one of the mentally disabled's most critical needs. Although a State law requires that priority be given to handicapped persons and their families in at least 5 percent of the units in certain public housing projects initiated after January 1, 1971, no special emphasis has been given to the mentally disabled versus the physically disabled.

The Department of Community Affairs (DCA), the State agency overseeing the development of public housing, has established a Bureau of Housing for the Handicapped and has issued guidelines to local housing

authorities and other sponsors for the development of community residences. In a letter attached to the guidelines, the Commissioner recognizes the need to develop community residences in order to prevent unnecessary institutionalization and remove persons already inappropriately placed in institutions.

Although DCA recognized the needs of the handicapped, more emphasis has been directed to the physically rather than the mentally handicapped. For example, DCA has financed 631 housing units for the physically handicapped, but only 7 community residences which can house 84 mentally disabled persons. A DCA official advised that in late 1975 a state law was passed that will make available up to $10 million to the DCA. He stated that this should provide some of the community housing needed for the mentally disabled, since they are scheduled to occupy about one-half of the units planned for construction.

Our review at two local housing authorities (Boston and Waltham) disclosed that no special attention is given to the housing needs of the mentally disabled residing in the community, and these needs are not addressed in their housing assistance plans submitted to HUD. (See p. 62.)

The Program Manager of the DCA Bureau of Housing for the Handicapped acknowledged that not all the local housing authorities have provided housing to the handicapped. However, he added that some cities and towns independently fund housing for the mentally disabled. He said that community resistance and local zoning laws are two significant barriers to developing community residences. DCA has issued guidelines to local

communities to reduce this resistance, but recognizes that greater effort is needed to educate communities on the goals and objectives of community residences.

IMPACT OF SHORTAGES OF COMMUNITY SERVICES

In 1973, a DMH sponsored study concluded that between 50-75 percent of inpatient institution admissions could be avoided if adequate community services were available. The Commissioner concurred saying that about two-thirds of admissions to state mental hospitals could be eliminated if comprehensive community services such as 24-hour crisis intervention were available. The Commissioner made a similar estimate regarding admissions to schools for the retarded, stressing the underlying need for sheltered housing, such as half-way houses and cooperative apartments. Also, clinical surveys in the State hospitals have indicated that at least half of the patients now institutionalized could be discharged if adequate supportive community housing were available.

Suitable housing is recognized as vital to the community-based care of released patients. Only 4 of the 39 catchment areas in Massachusetts had cooperative apartments, at the time of our review. One catchment area served by the Metropolitan State Hospital has no half-way houses which has prevented some patients from leaving the institution. For example, our tracing revealed that one patient was ready to leave the hospital in July 1974, but because there was no available space in a half-way house, he remained hospitalized for an additional 8 months. Several other cases were noted where patients were released to their own

home due to lack of community residences, although it was considered an inappropriate setting for the patient.

A Fernald School official estimated that over 40 percent of the mentally retarded patients could be released if community alternatives were available. Community residences and group homes were cited as a critically needed service for mentally retarded patients.

Officials from DMH and various state agencies said that in addition to alternative living arrangements, there is a critical shortage of general social support services, employment opportunities, education and community medical services.

STATE AGENCY COMMENTS

Executive Office of Human Services

The Secretary of Human Services acknowledged that:

--Many people remain in institutions who do not need such care, in large part, because of lack of community placements and suitable housing in the community.

--The absence of adequate community mental health standards, as well as the absence of a full-fledged monitoring system have contributed to maintaining the status quo delineated in this report.

--The state is not submitting claims for all eligible CMHC services.

The Secretary also advised us that DMH is taking the following corrective actions to remove some of the fiscal limitation which have been partially responsible for the inadequacy of the aftercare services stressed in this chapter.

--Certain state mental hospitals are being consolidated with Public Health hospitals to reduce the resources spent on the physical plant. Subject to the State Legislature's approval, the savings generated from consolidation as well as the additional revenue generated are scheduled for developing community services.

--A working document is being developed which advocates a change in the Medicaid retention formula which would permit community

mental health clinics to retain 100 percent of their Medicaid collections.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE COMMENTS

The HEW Regional Director agreed with the community shortages and added that the conditions cited have also been verified in HEW site visits and contacts with State mental health facilities, State hospitals and Community Mental Health Centers. The Regional Director said that some of these problems have been influenced adversely by the State's line-item budgetary mechanisms, the lack of flexibility to transfer funds from State hospitals to community programs and the reluctance on the part of the legislature to accept this procedure.

He also advised us that even more emphasis could have been given to the inhibitions to deinstitutionalization posed by the restrictions placed on fiscal and personnel flexibility by the legislature. Retraining, replacing, and deploying permanent State employees in the institutions is extremely difficult and transferring funds without legislative approval is impossible. Moreover, he stated there is a need to improve planning, management, and evaluation capacity at the State level.

Further, the Regional Director stated that Medicaid reimbursement for mental health services may be further restricted because of the State's current financial crisis which has resulted in Medicaid cutbacks. He stressed the difficulties and delays in getting mental health centers and clinics certified for outpatient and partial hospitalization services. He explained that this is a complicated process involving several State

agencies and, unfortunately, other third-party reimbursement practices follow the pattern established by Medicaid, further restricting the funds available for community mental health services.

CHAPTER 5

NEED FOR MORE EFFECTIVE FEDERAL MONITORING OF STATE PROGRAMS FOR THE MENTALLY DISABLED

The Federal Government, principally through HEW, supports many State programs that serve the mentally disabled. Through these programs the Federal Government has a substantial impact on a state's ability to provide a full range of health services. Without Federal support, states could not provide some services.

At the Federal level, the treatment of the mentally disabled in the community was established as a national objective in 1963, when funds were made available to the States to plan the development of comprehensive, community-based services. In that same year, the Community Mental Health Centers Act was passed which highlighted the need for community-based treatment centers. Under the Act, grant funds are provided to states for construction and staffing of community treatment centers. Community Mental Health Centers (CMHC's) make it possible for the mentally ill and retarded to be treated in their own communities rather than in institutions.

The special needs of the mentally retarded were again recognized in 1966, when an Executive Order established the President's Committee on Mental Retardation. In 1971, a presidential statement called for the return to the community of one-third of the more than 200,000

retarded persons in the nation's public institutions. The statement also called for Federal agencies to provide maximum support for a national coordinated effort to return the mentally retarded to their own communities. In this statement, the President also directed the Department of Housing and Urban Development (HUD) to assist in developing special housing arrangements to facilitate independent living for the retarded in the community.

The Developmental Disabilities program also addresses the needs of the mentally retarded. The program provides for establishing developmental disabilities councils in each state to identify and fill the unmet service and treatment needs of the mentally retarded, including community-based needs.

Despite the stated presidential and congressional concern for the special needs of the mentally disabled and the expressed preference for community-based treatment whenever possible, in Region I we found that neither HEW, HUD, nor the Department of Labor (DOL) had established a DI program. Other than HEW, which had established a Committee on DI, neither agency had taken any specific action directed toward mentally disabled persons released to the community.

Although Massachusetts had a DI program, HEW agencies have done limited coordinating or monitoring of its impact on mentally disabled persons released to the community. The HEW Regional Director advised us that there is insufficient staff to monitor and coordinate activities to the extent desired.

In Region I, HUD had not taken any steps to assure that suitable community housing was being made available to the mentally retarded. DOL had not taken any action to direct the State Employment Service to work with interested employers to hire the mentally retarded, nor had the legislation requiring Federal contractors to take affirmative action to hire the mentally disabled been fully implemented.

In 1972, Federal Regional Councils were established to develop closer working relationships between Federal agencies and State and local governments and to improve coordination of grant-in-aid programs. The councils are comprised of representatives from the major Federal agencies in each of the ten Federal regions. The Staff Director of the Council in Region I stated that it had not undertaken any project concerning the DI of the mentally disabled because none had been proposed.

HEALTH, EDUCATION AND WELFARE (HEW)

HEW administers numerous programs that affect the State's DI efforts. Because of this, HEW's Regional Director established a DI Committee comprised of various program personnel and a representative of the Regional Director's Office. The Committee's stated objective is:

> "To review deinstitutionalization strategies in Region I; to explore opportunities, where appropriate, for HEW to be supportive of these strategies and to seek changes in HEW policies and procedures which may impede the DI objective."

The Committee did not address many specific actions that could be taken under current regional programs, such as the coordination required by existing state interagency agreements, under the Medicaid program.

Other than establishing the DI committee, HEW Region I has done limited coordinating and monitoring of programs that impact on DI. The reasons given for the lack of emphasis is that there has been no HEW headquarters direction or mandate to undertake specific DI-related initiatives. Also, Regional program officials cited a lack of staff and other priorities as primary reasons for not evaluating programs that could help facilitate the DI of the mentally disabled to community-based programs. The Regional Director stated that some HEW programs encourage DI, but at the national level the agency has no overall plan of action.

Some of the HEW programs that directly impact on DI are Medicaid, Vocational Rehabilitation, and Social Services. A more detailed discussion of these programs follows.

Need For More Effective
Monitoring of Medicaid Programs

The Medicaid program has played a major role in releasing people from institutions into the community. As discussed in Chapter 3, many patients are being released from institutions to nursing homes without comprehensive discharge plans for aftercare and other needed

services. Some of these homes were decertified from Medicaid because patients were not receiving proper care. The Commissioner of Mental Health advised us that other nursing homes in the Medicaid program are still operating that have some problems similar to those homes that have been decertified. Federal regulations call for periodic Federal evaluations of State Medicaid programs, but there is no emphasis placed on DI or mental hospitals.

Medical Services Administration

The prime responsibility for the Medicaid program rests with the Medical Services Administration (MSA) of the Social and Rehabilitation Service, although the Office of Long Term Care Standards Enforcement (OLTCSE) and the Special Initiative Branch (SIB) also have some program responsibility.

Monitoring the Medicaid program is important to DI because many mentally disabled patients who are eligible for Medicaid are discharged to intermediate care facilities (ICF's). Patients over 65 years of age in mental hospitals are also covered by Medicaid. In Massachusetts at the time of our review, residents of State schools for the retarded were ineligible for Medicaid until they were discharged. During our review, State schools were converted to ICF's for the mentally retarded and became eligible for Medicaid. (See Appendix I, p. 79.)

There are several Federal regulations that are designed to assure that Medicaid patients in State mental hospitals and ICF's are receiving proper medical care. Section 1903(g) of the Social Security Act requires that States have an effective utilization review program to control medical services provided to Medicaid patients. Utilization reviews are designed to assure that patients receive the proper level of quality care for as long as necessary.

Under the single State agency plan, the Department of Public Welfare administers the Medicaid program. Federal regulations require that on-site validation surveys be conducted to assure that the program is effectively delivering health care to Medicaid patients. In 1973, MSA conducted an on-site survey at selected Massachusetts intermediate and skilled nursing facilities, and hospitals and noted several deficiencies:

—at the only mental hospital visited, there was no utilization review of Medicaid patients (age 65 and over),

—plans of care for patients in ICF's were generally not developed on a comprehensive interdisciplinary basis,

—there was no indication that utilization review committees reviewed the necessity for admission and continued stay for each patient.

A subsequent study by the HEW Region I Special Initiatives Branch also disclosed that many skilled nursing facilities (SNF's) and ICF's in Massachusetts were substantially out of compliance with the Medicaid plan of care and utilization review requirements.

These findings are being contested by State officials and Medicaid service providers. The matter had not been resolved at the time of our review, although some corrective action had been initiated.

Discharge Planning and Follow-up

Federal regulations also require that the plan of care for Medicaid patients provide for continuing care and, when possible, discharge. The plan of care should specify what is being done to place patients in an alternate facility, if this is more suitable to their needs. Additionally, hospital discharge summaries should include specific instructions and recommendations to be followed in providing aftercare.

HEW regulations (45 CFR 208.1) require the State Medicaid agency to enter into written agreements with the State mental health agency which sets forth their respective responsibilities for Medicaid patients in mental hospitals. There are interagency agreements between the DMH and the Department of Public Welfare and between DMH and several other State agencies. The agreement between DMH and the Welfare Department, however, was generally not being followed. For example, the Department of Public Welfare was not reviewing discharge plans, and comprehensive discharge plans were not being prepared by DMH, although the agreement provided for both.

Federal regulations require on-site validation surveys be conducted to assure that the State Medicaid agency is complying with the outlined requirements and has an effective program of utilization review. HEW Region I had not monitored whether persons released from institutions had been properly placed in the community. For example, the Associate Regional Commissioner for MSA told us that HEW had not:

--Taken any official action regarding DI in Region I until the Committee was established.

--Evaluated the extent to which Medicaid discharge planning, follow-up and aftercare requirements are being met for Medicaid patients released from mental hospitals,

--Required States to submit annual progress reports showing actions taken to develop comprehensive alternatives to institutional care for the mentally ill, as required by Medicaid regulations,

--Directed its validation surveys of State Public Health activities towards evaluating whether persons are appropriately placed, have adequate plans of care and are receiving needed services. Rather, HEW efforts have been directed towards determining whether States have the mechanisms for carrying out these reviews. Also, State personnel who perform medical and professional reviews in nursing homes should have expertise in mental health or mental retardation.

Office of Long-Term Care
Standards Enforcement (OLTCSE)

According to its Director, OLTCSE has no direct responsibility for DI of the mentally disabled. He explained that OLTCSE indirectly affects State DI efforts by conducting quality assurance reviews which assess the quality of care being received by Medicare and Medicaid patients in Region I nursing homes. The purpose of these

reviews is to determine whether States are properly certifying nursing homes for the Medicare and Medicaid program.

A problem affecting the State's DI program was identified when several nursing homes were found by OLTCSE to be substantially out of compliance with Medicaid patient care and life safety code regulations. OLTCSE inspectors reported that substantial numbers of patients in these homes were former State Hospital mental patients placed there by DMH. According to the Director, one problem home was closed and the owner of three others agreed to sell the homes, but only after numerous investigations, hearings, and appeals were completed. During this process, the facilities continued to receive Medicaid payments and patients were not moved to other facilities. These homes were later decertified and are included in the 60 nursing homes that were decertified. (See Chapter 3.)

The Director said the reason for this problem is the failure of State Departments of Mental Health, Public Health, and Public Welfare to coordinate their activities in licensing and inspecting of nursing homes, and in assuring that mental patients are placed only in appropriate homes. He noted the following factors as contributing to this situation:

--failure of the Department of Public Health, which licenses and inspects nursing homes, to take prompt action and recommend that Medicaid payments be stopped in nursing homes that violate patient care standards,

--reluctance by the Department of Public Welfare to withhold Medicaid payment when nursing homes were found to be violating patient care and safety standards,

--failure by Department of Mental Health to assure that mental patients are appropriately placed in nursing homes,

--delays in the licensing procedures which permit nursing homes to begin doing business before they are licensed, and

--the time it takes to decertify a home due to the lengthy appeals process during which the nursing home continues to operate.

Social Services

At the Federal level, HEW administers the social services program which provides services to the mentally disabled. The method by which a State intends to conduct its social service program is set forth in a State plan that must be approved by HEW's Regional Commissioner, Social and Rehabilitation Service. This State Plan forms the basis for making Federal grants to the State.

HEW regulations implementing titles IVA and VI of the Social Security Act required that a plan be developed and maintained for each person receiving social services. The individual plans had to be reviewed at least annually to assure that they were being effectively implemented.

An HEW Regional Commissioner said lack of staff precluded monitoring to assure that the individual social service plans were being implemented. He stated that monitoring and evaluation of

State social services has been a problem because of (1) lack of staff, (2) lack of uniform standards for evaluating social services, and (3) ambiguous laws and regulations requiring subjective and often inconsistent interpretations. He said the social service aspects of DI could be improved at the Federal, State, and local levels, if:

--social services were more clearly defined,

--a system was designed that could accurately measure social service program effectiveness,

--uniform standards for evaluating social services could be developed.

Vocational Rehabilitation Services

Some patients discharged from mental hospitals and schools for the retarded are not being referred to the Massachusetts Rehabilitation Commission for vocational rehabilitation training (see p. 15). At the Fernald School for the Retarded, persons with an I.Q. below 50 are not referred to vocational rehabilitation for evaluation because local vocational rehabilitation counselors considered them untrainable. This may be contrary to the intent of the Rehabilitation Act of 1973 which requires that vocational rehabilitation programs give priority to the severely handicapped. The Act's emphasis on the severely handicapped is a clear mandate that while the program should be employment oriented, it should focus on those who most need its services.

Rehabilitation programs authorized under the Act are administered by the Rehabilitation Services Administration of the Office of Human Development. States wanting to participate in vocational rehabilitation programs must submit a State plan to HEW designating a single State agency to administer the programs. In Massachusetts, the Rehabilitation Commission is the State agency which provides services to the handicapped including the mentally disabled. The Federal financial participation ranges from 80 percent to 100 percent. In fiscal year 1973, the Massachusetts Rehabilitation Commission's total expenditures amounted to $15.9 million.

HEW program officials advised us that the State plan and reports are not reviewed in any depth because staffing limitations prevent extensive monitoring or comprehensive program review. The degree to which the severely disabled are being served by the Rehabilitation Commission had not been verified and no evaluation had been made of vocational rehabilitation programs as they relate to DI.

Barriers to DI identified by HEW Committee

The HEW DI Committee identified several barriers that are impeding DI efforts for the mentally disabled. Some of these were also identified by State and local officials and have been discussed in earlier chapters of this report--for example, the lack of emphasis placed on the "severely" disabled under the Rehabilitation Act of 1973; the lack of community residences; and community resistance and zoning laws that make it difficult to provide adequate community housing.

The Committee contacted HEW regional officials for their views on policies, laws and regulations which may impede DI efforts, but has not coordinated its activities with other Federal agencies such as DOL or HUD since this was not a committee objective. The Committee identified instances where HEW policy hinders DI, e.g., the duration of disability for eligibility under the SSI program. To counter these problems, the Committee recommended that the SSI definition of "disability" be liberalized; and that funds be made available to communities to establish housing and other needed support services for people released from institutions.

The Committee also attempted to establish liaison with States interested in obtaining HEW Region I assistance with their DI efforts. Five of the six New England Governors expressed interest. However, after the 1974 State elections, Massachusetts, Maine, and Connecticut changed administrations and, at the time of our review, the governors had not designated a liaison person for the DI Committee. The Committee has established liaison with representatives of Rhode Island and Vermont. The Committee report submitted to the Regional Director recommended legislative and policy changes to aid the DI process.

The Regional Director of HEW advised us that he has stressed the need for greater headquarters involvement in DI. He added that he recommended to HEW headquarters that DI be included as a priority in the fiscal year 1976 operational plan, but it was not included.

A Committee official stated that the Committee will not continue in operation through fiscal year 1976. However, a spin-off effort will focus on improving community-based services for three target populations--developmentally disabled/mentally retarded, emotionally ill, and the aged.

Agency Comments

In his reply to a draft of this report, the HEW Regional Director agreed with the status of DI efforts in Massachusetts and the need for better coordinated monitoring and more vigorous support efforts on HEW's part. He stated that the report will be helpful to HEW in further efforts to work with the States in support of DI efforts.

The Regional Director also advised us that in light of our findings, and other recent experiences of the Regional Office, he plans to conduct a full review of HEW efforts supporting DI and to determine what further steps are appropriate either within the Region or as recommendations for national policy changes.

He also stated that Public Law 94-63, enacted in July 1975, contains provisions which will have significant implications for future DI efforts by HEW and State Governments. (See Appendix VIII.)

DEPARTMENT OF LABOR (DOL)

One of the most critical problems in helping a person make the transition from an institution to the community is finding a suitable job. The lack of such opportunities for both persons re-

leased and those who could be released has been recognized by State and local officials.

To help with the problem, the President designated the Secretary of Labor as a member of the President's Committee on Mental Retardation. In an October 1974 statement on mental retardation, the President urged employers to use the U.S. Employment Service to the fullest extent possible to help find jobs for the retarded. Also, to enhance job prospects for the handicapped, including the mentally disabled, the Congress enacted Section 503 of the Rehabilitation Act of 1973.

Section 503 requires Federal contractors receiving contract awards of $2,500 or more to take affirmative action to hire the handicapped. DOL regulations implementing the Act require contractors and subcontractors with awards over $500,000 to file annual affirmative action reports. Region I DOL officials stated that the first reports were required March 31, 1976. Contractors with awards of less than $500,000 are still required to take affirmative action in hiring the mentally disabled and develop affirmative action plans, but are not required to file annual reports with the DOL.

The Region I official responsible for administering Section 503 told us that this program has not yet become fully operational. We were advised that 34 complaints had been received through December 1975 and were being investigated at the time of our review. Four of these pertained to the mentally disabled.

The regional office has been assisting contractors in developing their affirmative action plans. No compliance reviews had been undertaken and we were advised that no preference is given to the mentally disabled and all handicapped people are treated equally under the Act.

Officials from the Massachusetts Rehabilitation Commission and the Massachusetts Division of Employment Security (DES) told us that they had not taken action to implement Section 503. One problem identified was that the listing of Federal contractors included only those contractors with contract awards of $10,000 or more.

Agency Comments

In his reply to a draft of this report the DOL Regional Director stated that he had read the report and had not further comment to make until he receives the final report. (See Appendix IX,)

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)

HUD administers a variety of housing programs designed to enable persons with low and moderate incomes to live in decent, adequate housing. It also administers a community development program under which some community services can be provided to developmentally disabled individuals.

Overview of HUD Housing Programs

HUD programs include insuring private mortgages on community dwellings, providing loans for the construction or renovation of

buildings, rental assistance payments, and block grants for community development programs. The Housing and Community Development Act of 1974 includes provisions for community-based services such as social services, education, rehabilitation, health, recreation, and employment. In addition, some of HUD's programs include special provisions for the elderly and handicapped. Community-based housing that can be developed or used under HUD-administered programs include nursing homes, group homes, and cooperative apartments. We were advised that instructions implementing the Housing and Community Development Act of 1974 had only recently been received and had not been fully implemented.

The mentally disabled qualify for HUD-assisted programs on the same basis as other applicants. Until the enactment of the Housing and Community Development Act of 1974, which specifically included the developmentally disabled, HUD defined a handicapped person in terms of physical impairments only. In August 1971, the HUD General Counsel did render a decision to the State of Michigan's Housing Development Authority stating that mental retardation could be considered a handicapping condition for program eligibility purposes if it was caused by a physical impairment.

HUD's Role in Developing Housing for the Mentally Disabled

The need for HUD assistance in developing community-based housing for the mentally disabled has been recognized. The Secretary of HUD

was appointed to the President's Committee on Mental Retardation. In November 1971, the President, in announcing the launching of a national, coordinated effort to reduce the institutional population by one-third, directed HUD to assist in the development of special housing arrangements to facilitate independent living for the retarded in the community. In 1974, the President again stated that the Federal government, primarily through its housing agencies, will help retarded adults obtain suitable homes.

HUD Region I officials were apparently not aware of the August 1971 HUD General Counsel decision cited above or the Presidential directives that called on HUD to assist in developing community-based housing for the retarded. The Acting Regional Administrator told us that regulations and instructions for one of its rental assistance programs (Section 236 program) contain a definition of handicapped that was limited to a physical impairment. In addition, we were advised that because instructions from HUD headquarters had not been received, no specific actions had been taken to (a) carry out the Presidential directive, (b) give emphasis to the mentally disabled, and (c) take action to ensure that the mentally disabled applied for and received HUD-assisted housing. HUD officials explained that in general, housing programs include all handicapped people. In the absence of any central office directives or regulations to distinguish between the physically and mentally disabled,

regional program officials can't initiate efforts to specifically address the needs of the mentally disabled.

Housing Assistance Plans Place No Emphasis on the Mentally Disabled

One means available to HUD for evaluating the extent to which local housing authorities are considering the needs of the mentally disabled is to review the local housing assistance plan which is required by HUD for participation in the community development grant program. Under this program, local housing authorities must assess the housing assistance needs of lower income persons residing or expected to reside in the community and describe a program to assure that needed and appropriate health and social services are available. A HUD official advised us that housing assistance plans had been received and reviewed, but no emphasis was placed on the housing needs of the mentally disabled.

We visited two local housing authorities and found that the housing assistance plan did not address the needs of the mentally disabled. An official of one housing authority stated that they were planning to assist in the development of small residences for the mentally disabled on the grounds of a county hospital. However, this was dependent on the availability of funds and nothing definite had been undertaken.

A HUD regional official agreed that under current regulations its local housing representatives could play a more active role and

encourage housing program applicants to more specifically identify low-income target populations, such as the mentally disabled.

Agency Comments

In his reply to a draft of this report the HUD Regional Administrator stated that housing assistance plans were not the best method for identifying the housing needs of mentally disabled who meet the income criteria. He stated that the housing assistance plans do not specifically identify the mentally disabled as a target population and that using the plan for this purpose would probably require a directive from the central office.

He also advised that under the provisions of Office of Management and Budget Circular A-95, state and regional planning agencies are given the opportunity to review and comment on housing applications. In our opinion, placing the burden on state and local communities may not be enough to encourage local housing authorities to focus on the housing needs of the mentally disabled. (See Appendix X.)

CONCLUSIONS AND RECOMMENDATIONS

The conclusions in this report are based on data obtained in our review of deinstitutionalization activities in Massachusetts. Accordingly, we limited our recommendations to those which regional Federal officials can address under existing authority. Some of the matters discussed in this report will be included in a report to the Congress. Any recommendations relating to the Departments of Labor or Housing and Urban Development will be made in that report.

Health, Education, and Welfare

In view of the expressed preference of some Region I States to reduce their institutional population and treat more of the mentally disabled in the community, the Regional Director has taken a positive initial step by establishing the DI Committee.

As discussed in this and earlier chapters, however, we believe there are many other actions that can be taken within existing programs that will improve and coordinate the services available to the mentally disabled. We recommend that the Regional Director, HEW:

--Determine whether the social service needs of mentally disabled persons being released from institutions have been adequately assessed and, if not, make appropriate recommendations to the Secretary of HEW.

--Monitor State vocational rehabilitation programs to ensure that appropriate emphasis is given to persons with the most severe handicaps and that persons are not denied access to vocational rehabilitation services without an evaluation of their potential, as required by the Rehabilitation Act of 1973.

--Ensure State compliance with Medicaid discharge planning requirements for persons being released from mental hospitals and State schools for the retarded.

--Enforce HEW regulations requiring that independent professional reviews be done at least annually in Intermediate Care Facilities and assist the State in developing procedures for resolving differences of opinion on the findings and recommendations of independent review teams.

--Ensure that the State Developmental Disabilities program places appropriate emphasis on evaluating the efforts of State agencies that provide services to persons released from State schools. Also, assist the State Bureau of Developmental Disabilities in resolving the coordination problems among State agencies.

--Consider the need for a mental health professional to evaluate the appropriateness of placement and services provided for the mentally disabled in intermediate care facilities. This could be evaluated when HEW conducts its validation survey of State utilization control programs.

--Work with State agencies to clarify the follow-up responsibilities of the Departments of Mental Health and Public Welfare for mentally disabled persons released from State institutions.

--Work with regional Labor and HUD officials, possibly through the Federal Regional Council, to coordinate Federal and State programs that can aid deinstitutionalization. For example, HEW could work with HUD to ensure that housing assistance plans adequately address the needs of lower income mentally disabled persons.

APPENDIXES

SUMMARY OF TRACING RESULTS

INTRODUCTION

The Massachusetts Department of Mental Health (DMH) operates 23 mental health facilities including 10 State mental hospitals and 6 State schools for the retarded which housed about 14,000 patients as of July 1, 1975. We selected a sample of patients who had been released from the Metropolitan State Hospital for the mentally ill and the Fernald School for the mentally retarded. These institutions were selected because of the large number of cases processed. DMH statistics showed that Metropolitan had closed the second highest number of cases among the State hospitals for the mentally ill and the Fernald School closed more cases than any other State school for the retarded.

We traced patients discharged from the two selected institutions to determine where they were discharged to, what services were prescribed when they were released and what services were actually received. Alcoholic and drug addicts were excluded from our sample.

DESTINATION OF PATIENTS RELEASED

The following table shows the destination of patients released from Metropolitan during July and August and from the Fernald School during July, August, and September 1974, adjusted for cases that were found to be duplicates, diagnosed as drug addicts or alcoholics and a case for which the record could not be located.

Released to:	Released From Metropolitan	Fernald	Total	Percent
Family, own residence	84	7	91	44
Nursing home	30	18	48	23
Hospital	25	-	25	12
Court	13	-	13	6
Family care (foster home)	5	2	7	3
Rooming house	6	-	6	3
Community residence	-	5	5	2
Residential school/home	4	-	4	2
Mental Health Center	3	-	3	2
Hotel	2	-	2	1
Half-way house	1	-	1	1
School for the retarded	1	-	1	1
	174	32	206	100

SAMPLE SELECTION

At Metropolitan and Fernald, 32 and 31 cases respectively, were selected for tracing. We found that generally, comprehensive discharge plans that identified the patient's total needs were not prepared. What a patient received was apparently determined by what was available, rather than what was needed. In twenty-one of the sixty-three cases traced, follow-up did not appear adequate.

The following schedule lists the principal State agency or organization to which the 63 patients were referred for follow-up:

	From Metropolitan	Fernald	Total
DMH			
CMHC's	18	4	22
Fernald School	-	14	14
Metropolitan State Hospital	8	-	8
Regional Office	-	2	2
DPW	6	9	15
Commission for the Blind	-	2	2
Totals	32	31	63

DISCHARGE PLANNING

We found that comprehensive discharge plans were not prepared for patients released from the Fernald School or Metropolitan. The Commissioner of DMH advised us that regulations which define total aftercare and follow-up responsibilities for serving the mentally ill are not available. Aftercare refers to the range of services required by patients discharged from institutions. Follow-up refers to the responsibility of qualified persons to assure that these services are being received.

Although comprehensive regulations are not available, there are three independent documents directed at aftercare and follow-up responsibilities. These are:

(1) An aftercare memo prepared by the Commissioner of DMH in September of 1974 and distributed to all DMH personnel.

(2) Standard contract between the discharging institution and the nursing home that accepts the patient.

(3) A joint agreement dated January 1966 between DMH and DPW. The most recent update to the agreement was in April 1973.

The aftercare memo states that no patient should be discharged from a State institution without an adequate aftercare plan; but does not identify what should be included in an aftercare plan or who is responsible to assure that the needs identified are provided. The memo makes no reference to the other two documents.

The standard contract between the DMH and the referral nursing home provides that DMH is responsible for the patient's aftercare during the first year. Metropolitan officials stated that during this period, hospital staff are required to evaluate the patient's progress quarterly and make appropriate notation in the patient's file. We were advised that after the one-year period, DPW social workers are responsible for follow-up.

The joint agreement between the Department of Public Welfare and DMH places the responsibility for mental patients discharged to the community with DMH. Under the agreement, DMH is responsible for developing a comprehensive social-medical-psychiatric plan for these patients. The agreement requires that discharge plans be approved by DMH central office before being reviewed and approved by Public Welfare. However, discharge plans were not approved by either agency's central office.

The agreement also requires that before the patient leaves the institution, the discharge plan should include the following: the type of residence to which he is being released, outpatient psychotherapy and psychiatric needs, the type of medication to be provided, as well as any social services--such as attendance at day hospitals, social centers or sheltered workshops. Under the agreement, the Department of Public Welfare is responsible for providing financial assistance to those who are eligible.

Despite the detailed data called for in this agreement, generally, the discharge plans at Metropolitan included only a brief history of the patient's stay in the hospital, the type of medication the patient had been given, and the place to which the patient was discharged. A few plans included more information such as the person responsible for follow-up, and the aftercare prescribed. Usually, discharge plans are prepared by the hospital staff, but occasionally, when a patient is discharged to a CMHC, the patient's needs are determined by the CMHC, rather than the hospital.

At the Fernald School, we also found that comprehensive discharge plans are not prepared. Usually, a letter is sent to the referral facility that includes a brief social and medical history of the patient, including the level of retardation. The aftercare plan is developed by the staff at the referral facility.

Metropolitan and Fernald officials agreed that comprehensive discharge plans are not prepared that identify all the service needs of the discharged patients. Metropolitan officials said that discharge plans usually identify only those needed services that are available and not the total support service needs of the patient. We were advised that at Metropolitan each hospital unit has its own method of preparing discharge plans and the extent of information included is not standardized. Fernald officials agreed that the failure to prepare detailed aftercare plans has been a

weakness in the past but the problem will be corrected.

TRACING RESULTS

Patients Referred to CMHC's

The 22 patients referred to CMHC's in the catchment areas serving Metropolitan and the Fernald School were generally receiving the prescribed aftercare services and follow-up visits. We were advised that there are no formal procedures for making referrals to CMHC's and most referral's were made informally by the social worker either by telephone or in person. A referral consists of a social worker contacting the CMHC and requesting that follow-up be provided a given patient upon release. Information concerning the patient is telephoned to the CMHC and usually includes the patient's social history, present medication, and treatment received at the hospital. Patients released to a CMHC are usually followed-up by a CMHC social worker.

Patients Placed In
Nursing Homes

We traced 24 patients placed in nursing homes--18 for Fernald and 6 from Metropolitan, and found that follow-up responsibility for patients discharged from both institutions is not well defined. Patients initially placed in a nursing home are considered to be on trial visit during the first year and follow-up responsibility is clear--

social workers from the institution are responsible. After the first year when the patient is officially discharged, it is not clear who will follow-up the patient. Each institution is discussed separately below.

Metropolitan State Hospital

During the first year, the six Metropolitan patients were followed-up but in some cases there were no follow-up summaries or progress notes in the patient's file and the records did not show the dates of visit by social workers. Nursing personnel at some homes said, however, that Metropolitan social workers were visiting the patients but could not recall how frequently. Although quarterly reevaluations are required under the agreement, they were not done.

Some Metropolitan social workers stated they continue visiting their patients indefinitely, while others stop after the first year. Nursing home officials said that Department of Public Welfare social workers also visit patients after the first year. Metropolitan social workers said they continue following some patients because they realize that Public Welfare social workers either don't follow-up after the first year or provide only superficial coverage due to their heavy caseload.

Case workers at Metropolitan advised us that they are not responsible for following-up patients released to nursing homes after the first year. They stated that follow-up responsibility rests with

the Department of Public Welfare since nursing home patients are frequently covered under the Medicaid program.

Fernald School

Of the 18 Fernald patients traced to nursing homes, 10 had been placed on trial visit and 8 had been discharged. While on trial visit, patients are followed-up by a Fernald social worker for one year. After this period, the patient is discharged and follow-up is discontinued.

The 10 patients placed on trial visit were being followed-up. A review of the patients' records showed that Fernald's policy of following-up nursing home patients on trial visit was being followed.

Of the remaining eight Fernald residents that were discharged to nursing homes, seven were referred to Public Welfare social workers and one to the DMH region staff for follow-up.

Four of the patients assigned to local public welfare offices were not assigned to social workers for follow-up. Three patients were assigned to social workers who advised us that they were not able to visit them regularly. Some social workers said their only responsibility was to assure that the patients' spending money was being properly accounted for. Others stated that they try to make sure that the patient is being properly cared for, but due to their extremely heavy caseloads the amount of time they can devote to this is very limited.

The patient referred to the DMH region staff was only assisted during the initial placement in the nursing home and then the case was closed.

Fernald social workers stated that after the first year they are not responsible for the patient. Fernald officials also share the viewpoint that the Department of Public Welfare is responsible for following-up nursing home placements after the first year.

Patients Placed in Community Residences

Four Fernald patients released to community residences on trial visit were to be followed-up by Fernald case workers. Two were placed into group homes and received daily supervision from the house parents. Fernald staff did not provide follow-up because of a verbal agreement with the house parents that they would immediately contact the case worker if problems developed. The remaining two patients were placed in a foster home. Although the Fernald staff kept in contact with the foster home, visits were not made regularly.

Fernald personnel said there is no follow-up policy for patients released to community residences or to their own homes. We were advised that follow-up responsibility will vary depending on the patient's needs.

Patients Referred to Metropolitan State Hospital for Follow-up

Eight Metropolitan patients were assigned to Metropolitan as outpatient cases for medication and supportive therapy. Three patients returned and received the prescribed service. The remaining five patients did not return and were not followed-up. Responsible officials said that they were not informed that the patients had been referred to their unit for service.

At Metropolitan, responsibility is not well defined among the various staff levels at the hospital. For example, conflicting responses were received from social workers, doctors, and nurses concerning patients required to return to the hospital for services. Some social workers said it was the responsibility of the doctor prescribing the medication to follow-up a given patient. The doctors believed that it was the responsibility of the nurse who administered the medication. The nurses advised us that they were not responsible for follow-up.

A Regional DMH official said that patients who return to the hospital for aftercare services make it difficult for the staff to reduce the patients dependence on the institution. Hospital officials said that the reason that patients return for medication, rather than go to a community facility, is that the hospital does not charge those who cannot afford to pay.

Patients Referred to the Massachusetts Commission for the Blind

Two patients that were discharged from Fernald and referred to the Massachusetts Commission for the Blind were not followed-up by either agency. Commission officials stated that they do not follow-up persons who are both blind and mentally retarded, but do provide services to the blind who are not otherwise handicapped and have a better chance of becoming gainfully employed.

The Commission and DMH were in the process of formulating an inter-agency agreement for providing services to blind, mentally retarded persons. At the time of our review, the agreement had not been finalized.

OTHER OBSERVATIONS

The following sections discuss several matters noted during our review at Metropolitan and the Fernald School.

Patients not being referred to the Massachusetts Rehabilitation Commission

Under an agreement with DMH, the Massachusetts Rehabilitation Commission is required to evaluate patients released from State institutions. Our tracing results showed that the Commission's procedures for screening and evaluation were inconsistent and not in accordance with the agreement. The agreement states that persons being released from state institutions should be screened to determine their vocational rehabilitation potential and that the Commission

shall accept as referrals for evaluation all persons recommended by the screening team. However, Metropolitan has not established a screening team; instead, caseworkers screen their patients before referring them for an evaluation by Commission personnel assigned to the hospital. As a result, some patients may not be receiving the vocational rehabilitation services offered by this agency.

There were sixteen patients[1/] that should have been referred for screening, but only five were actually referred. Caseworkers said that they considered eight to be inappropriate for referral to the Commission because of the patient's personal situations, e.g., a mother who could not work. The responsible caseworkers for the remaining three cases could not explain why the patients had not been referred. One said that the patient could have benefited from a Commission evaluation.

At Fernald, released patients are not routinely referred to the Commission. A local DMH official told us that only patients with an I.Q. of 50 or more (the minimum level where a resident is considered trainable or employable) are referred.

1/These patients were also referred to other agencies for follow-up and have been discussed in the appropriate sections.

Placement of Mentally
Retarded Patients in Metropolitan

In 1973 approximately 191 patients at Metropolitan were identified as mentally retarded. These patients should not be in a mental hospital, but were placed there because of overcrowded conditions in State schools for the mentally retarded.

The HEW Regional Director advised us that a far higher percentage of the current population of other State Hospitals in Massachusetts are mentally retarded, and that his staff has called this matter to the attention of the State several times.

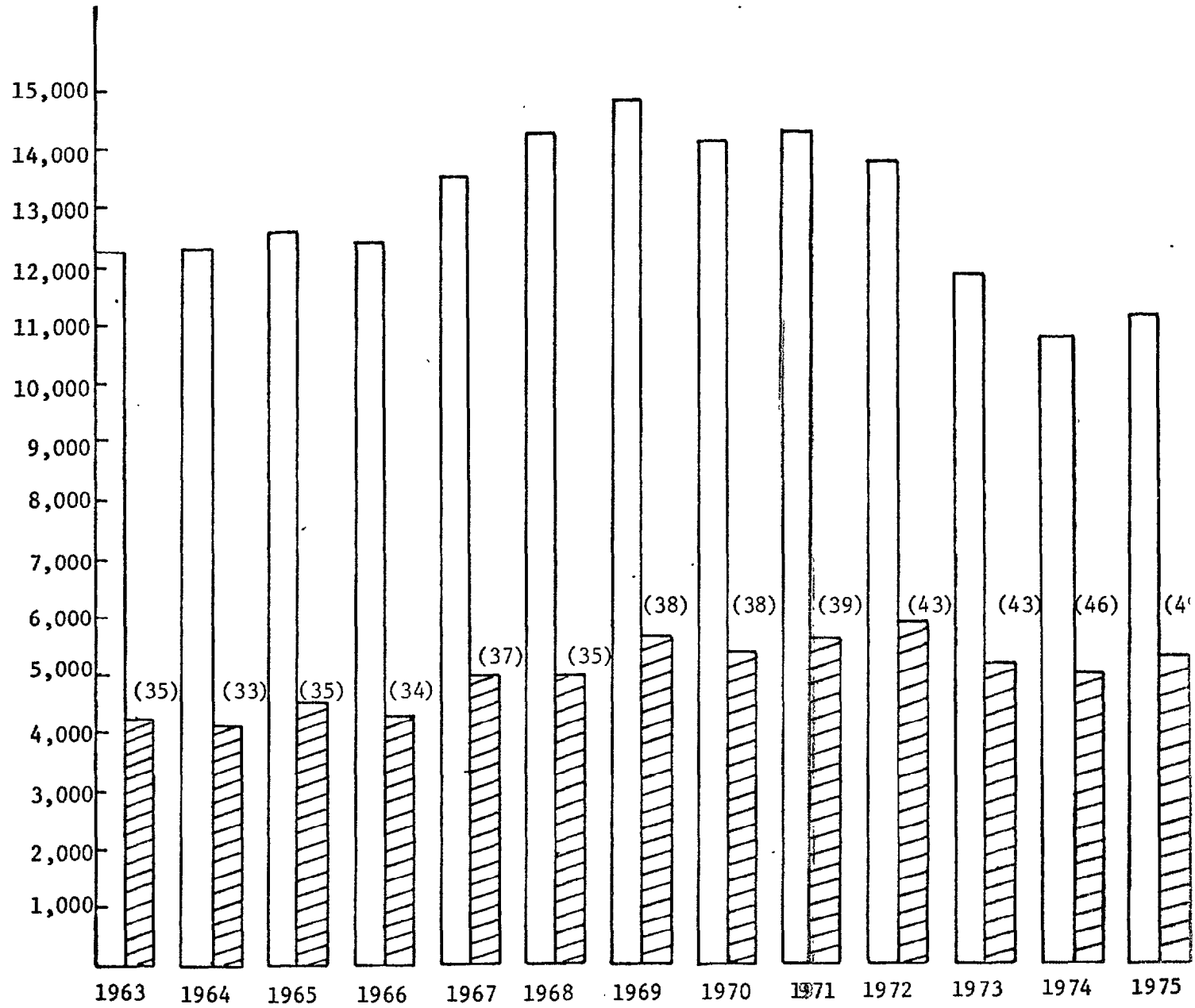
Officials at Metropolitan were aware that these patients should be in a school for the retarded and in May 1973 notified DMH headquarters. Hospital officials said that these patients should be transferred, but no action had been taken at the time of our review. Under the Medicaid program, schools for the retarded will qualify as intermediate care facilities and will be partially supported by Federal funds. The Secretary of Human Services advised that the State schools were provisionally certified for Title XIX reimbursement in March 1975 and that residents are now eligible and claims are being submitted. In order to be certified, however, the schools must fulfill plans of correction by March 1977. This process must be closely monitored to assure completion and acceptance of such plans.

Patient Refusal of Follow-up and Aftercare

Several of the patients released in July-September 1974 refused aftercare treatment or follow-up. Officials at Metropolitan stated that although patients refusing aftercare and follow-up is a persistent problem, patients have a right to refuse such services. To require them to receive anything that they do not want is a violation of the patient's civil rights.

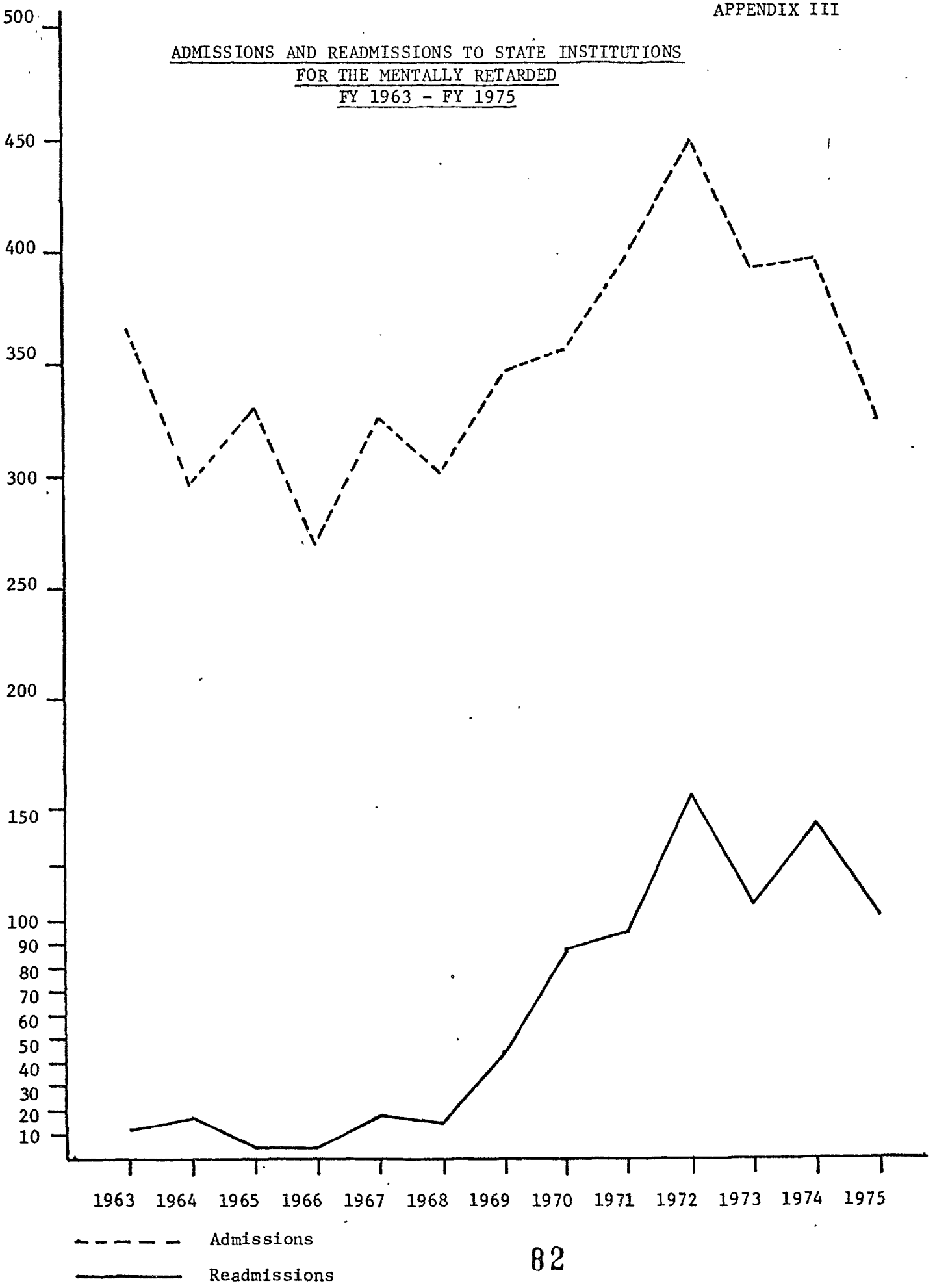
Only one patient released from Fernald refused aftercare and follow-up. Fernald officials stated that nothing could be done for this patient if he did not want the services offered.

ADMISSIONS AND READMISSIONS TO STATE INSTITUTIONS
FOR THE MENTALLY ILL
FY 1963 - FY 1975

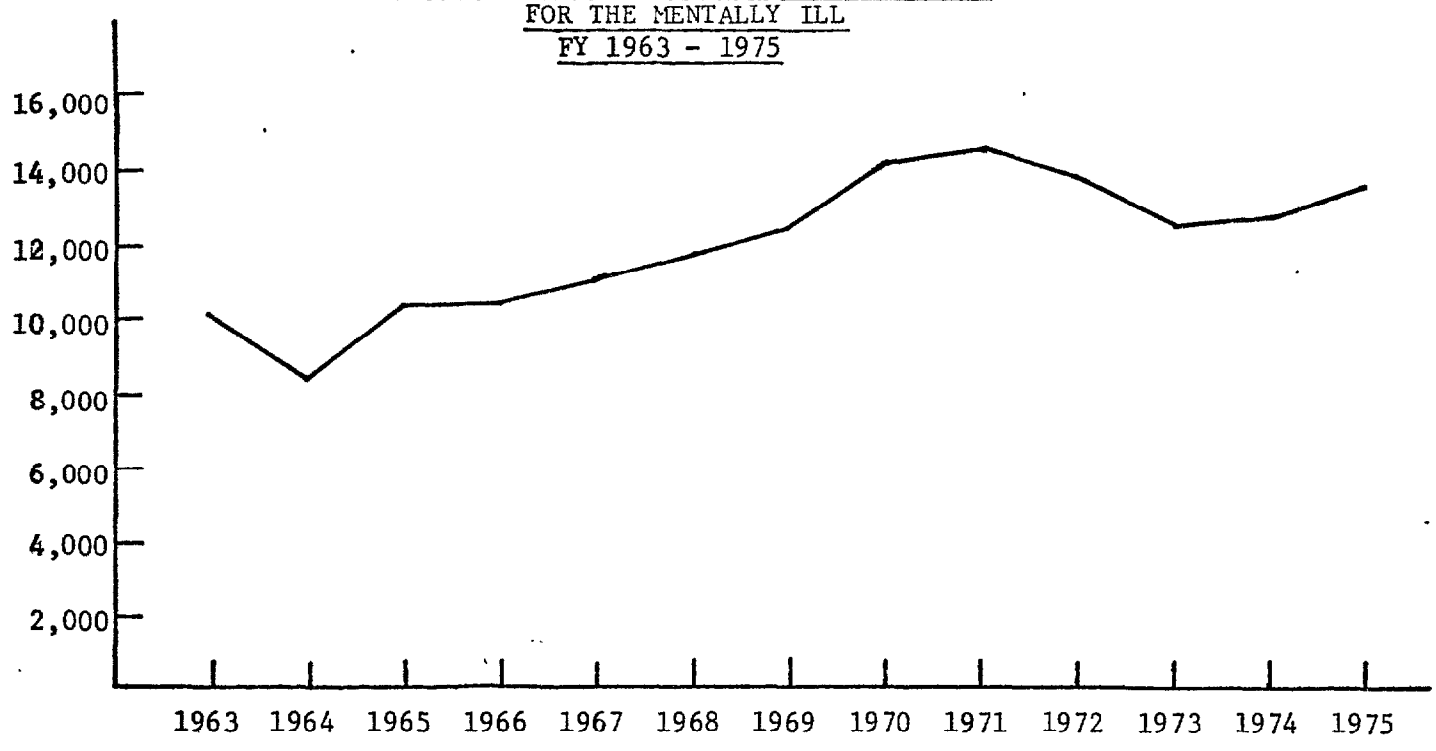


NOTE: Figures in ( ) indicate percentage of admissions that are readmissions.

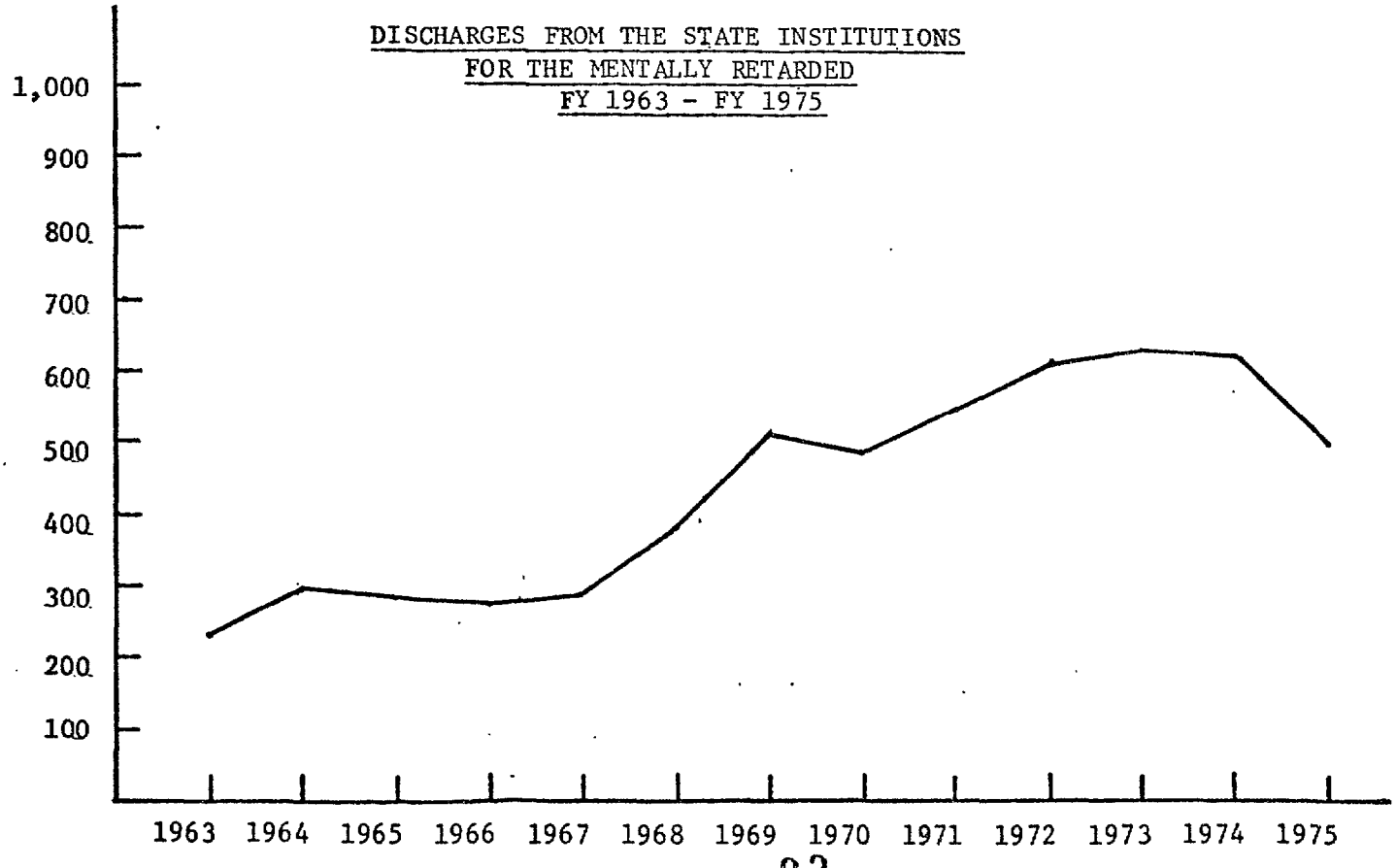
ADMISSIONS AND READMISSIONS TO STATE INSTITUTIONS
FOR THE MENTALLY RETARDED
FY 1963 - FY 1975



DISCHARGES FROM THE STATE INSTITUTIONS
FOR THE MENTALLY ILL
FY 1963 - 1975



DISCHARGES FROM THE STATE INSTITUTIONS
FOR THE MENTALLY RETARDED
FY 1963 - FY 1975



LISTING OF AGENCIES INCLUDED IN THIS REPORT AND A BRIEF DESCRIPTION OF THEIR RESPONSIBILITIES AS THEY RELATE TO DEINSTITUTIONALIZATION

State Agencies	Responsibilities include:
EOAF - Executive Office for Administration and Finance	Administering and controlling the financial policies and programs of Massachusetts.
BDD - Bureau of Developmental Disabilities	Administering the Developmental Disabilities (DD) program as outlined in the State DD plan; coordinating interagency planning for persons who are developmentally disabled which includes the mentally retarded, but not the mentally ill; filling gaps in service by providing grant funds to public and private agencies for programs that meet the objectives in the DD plan.
EOHS - Executive Office of Human Services	Coordinating activities for state human service agencies, many of which administer Federal programs that provide planning funds and services to the mentally disabled.
DPH - Department of Public Health	Inspecting, certifying and licensing health care facilities in the state. Also, DPH administers the Maternal and Child Health, and the Crippled Children's programs which provide services to persons with certain physical handicaps, some of whom may be retarded.
DPW - Department of Public Welfare	Administering the Medicaid program under Title XIX of the Social Security Act, which provides medical and public assistance to the State's needy, including the qualified mentally disabled. DPW is the State social services agency and funds services to the mentally disabled under Titles IVA, IVB, and VI of the Social Security Act (now Title XX).
MCB - Massachusetts Commission for the Blind	Providing vocational and other support services to the State's blind citizens.

LISTING OF AGENCIES (continued)

State Agencies	Responsibilities include:
DMH - Department of Mental Health	Administering state mental hospitals and schools for the retarded; preparing comprehensive discharge plans that provide for all patients needs including medical, social, psychiatric and vocational services. DMH is also responsible for establishing a comprehensive program of community based mental health and retardation services for the mentally ill and retarded in Massachusetts.
MRC - Massachusetts Rehabilitation Commission	Administering the State's vocational rehabilitation program. MRC evaluates physically and mentally disabled persons to determine if they can become employable by receiving vocational rehabilitation services.
DCA - Department of Community Affairs	Overseeing public housing in Massachusetts. DCA has established a Bureau of Housing for the Handicapped (BHH) and has issued guidelines to local housing authorities and other sponsors for the development of housing for the handicapped.
DES - The Division of Employment Security	Helping the mentally disabled find jobs, and assigning counselors to case conference committees at DMH facilities.
DOE - Department of Education	Administering the State Special Education Law (Chapter 766).

2 of 2

LISTING OF AGENCIES (continued)

Federal Agencies	Responsibilities include:
HUD - Department of Housing and Urban Development	Administering housing programs designed to enable low and moderate income persons to live in decent, adequate housing. Some HUD programs include special provisions for the handicapped. The Secretary of HUD is a member of the President's Committee on Mental Retardation.
DOL - Department of Labor	Administering Section 503 of the Rehabilitation Act of 1973. This section requires contractors and subcontractors with awards over $500,000 to file annual affirmative action reports with DOL. The Secretary of Labor is a member of the President's Committee on Mental Retardation.
HEW - Department of Health, Education, and Welfare	Providing financial support under various State programs that serve the mentally disabled, including the vocational rehabilitation, social services and Medicaid programs. Under these programs there are provisions for Federal monitoring of State activities.
SRS - Social and Rehabilitation Service	Providing direction and control of all SRS programs and resources. SRS also approves the method by which a state intends to conduct its social service program.
SSI - Bureau of Supplemental Security Income	Administering the SSI program, which is designed to establish uniform eligibility requirements to replace the varying standards that previously existed under the public assistance programs for the aged, blind and disabled.
RSA - Rehabilitation Services Administration	Administering programs authorized under the Rehabilitation Act of 1973.
MSA - Medical Services Administration	Administering the state's Medicaid program. Also MSA analyzes state plans for medical service programs.

LISTING OF AGENCIES (continued)

Federal Agencies	Responsibilities include:
SIB - Special Initiatives Branch	Monitoring State's quality control systems to assure adherence to Federal Medicare/Medicaid regulations. Also SIB is responsible for monitoring utilization reviews to assure adherence to Federal Medicaid regulations.
OLTCSE - Office of Long Term Care Standards Enforcement	Conducting quality assurance reviews to assess the care being received by Medicare/ Medicaid patients in nursing homes and institutions for the retarded.

The Commonwealth of Massachusetts
Executive Office for
Administration and Finance
State House, Boston 02133

March 22, 1976

Mr. Louis Lucas
Assistant Regional Manager
United States General Accounting
Office
Regional Office, Room 1903
John F. Kennedy Federal Building
Government Center
Boston, MA 02203

Dear Mr. Lucas:

I have reviewed the issues prepared by the Office of Federal State Resources for a negotiation meeting held with Thomas J. McGrane, Supervising Auditor, and Kenneth Croke of your office on February 18, 1976. Dr. Fraser has advised me that your office found the General and Specific Comments helpful in the interests of accurate reporting, and significant changes were made with respect to these issues at a follow-up meeting on March 2nd.

Sincerely,

John R. Buckley
Secretary

JRB:jv

The Commonwealth of Massachusetts
Executive Office of Human Services
Room 109 State House
Boston, Massachusetts 02133
Area Code (617) 727-7600

JERALD L. STEVENS
Secretary

April 5, 1976

Louis Lucas
Assistant Regional Manager
United States General
Accounting Office
Room 1903
J.F.K. Federal Building
Government Center
Boston, MA 02203

Dear Mr. Lucas:

The Executive Office of Human Services has received responses from four agencies regarding the content of the GAO "Draft Report to the Congress of the United States: Summary of Deinstitutionalization Efforts in Massachusetts and in Region I Federal Agencies: Code 10210." Although methodology was questioned by the Department of Mental Health (in particular the generalization of conclusions to the entire state from observations made in one region), the data contained in the report is in general considered accurate and the recommendations sound.

In particular, the following conclusions delineated in the report were cited as accurate and worth highlighting:

1. Many people are inappropriately admitted to institutions because of lack of community services.

2. Many people remain in institutions who do not need such care in large part because of lack of community placements and suitable housing in the community.

3. Many people have been released without adequate services and without comprehensive discharge plans.

4. Coordination among the various state agencies serving the mentally disabled needs to be improved.

5. Former patients and retarded persons have been discharged to nursing homes which in certain cases are probably substandard from a psycho-social standpoint.

6. Many patients are not being deinstitutionalized to lower level care facilities as recommended by periodic medical reviews, in certain cases due to lack of community alternatives.

7. There is a lack of an overall Department of Mental Health information system to assist in evaluation of aftercare services provided to patients.

8. The state is missing Federal reimbursements for which it is eligible.

9. The quality of health services in our institutions is sub-standard in many respects.

10. Coordination among state agencies needs to be improved to bring about an integrated aftercare approach to the client.

11. The Department of Mental Health/Mass. Rehabilitation Commission which calls for every discharged patient to be evaluated by Mass. Rehabilitation Commission is only partially implemented.

12. The absence of adequate community mental health standards, as well as the absence of a full-fledged monitoring system have contributed to maintaining the status quo delineated in the Report.

Certain recommendations were also cited as particularly sound:

1. The development of a tracking system for deinstitutionalized patients.

2. A change in the MRC policy manual which presently considers persons with I.Q. below 50 as untrainable and therefore ineligible for services.

3. Development of DMH regulations on after care and follow-up.

I would like to point out that certain steps are being taken to address the issues outlined in the GAO report. Detailed work plans and timetables for task completion will be developed by lead agencies in each problem area and progress will be closely monitored by my staff. These activities should be highlighted in the GAO report as the Commonwealth's response to the problems discussed in the report:

1. Title XIX evaluations and client plans including comprehensive discharge plans have been developed on each resident of every state school.

2. Responsibility for the aftercare of each client discharged from the institution will be clearly assigned to the DMH Area Director, thereby insuring that one person can be held responsible for the clients' progress. Each Area Director will likewise be assigned responsibility for a geographic unit at the State Hospital, thereby insuring continuity of care between the institution and the community.

3. Standards for community services are being developed by the Department of Mental Health which will focus on the aftercare problems experienced by clients discharged from institutions.

4. A system of monitoring the quality of care provided to these clients is being developed. This effort will draw upon the expertise of professionals as well as citizens.

5. The Department of Mental Health is developing a Management Information System that will facilitate the monitoring of services to clients as well as generate management information to ensure that scarce resources are used effectively.

6. The health services provided at DMH institutions are being reviewed with the expectation that glaring deficiencies will be rapidly corrected. A contractual strategy involving the resources of Boston's major teaching institutions is being employed to achieve this goal.

7. The Department of Mental Health is currently working to remove some of the fiscal limitations on the development of community services which have partially been responsible for the inadequacy of the aftercare services stressed in the Report:

a. Selected state hospitals are being consolidated with Public Health hospitals in order to reduce the amount of resources spent on bricks and mortar. Subject to the Legislature's approval, the savings generated from this program of consolidation as well as the additional revenue generated are scheduled to be redeployed for the development of community services.

b. A working document is being developed which advocates a change in the Medicaid retention formula in order to permit community mental health clinics to retain 100% of their Medicaid collections.

8. Mass. Commission for the Blind is working with the Department of Mental Health to develop cooperative approaches to the deinstitutionalization of blind persons. The posture of Massachusetts Commission for the Blind during the beginning efforts of deinstitutionalization of blind-retarded persons was to deny all services except Financial and Medical Assistance.

Rehabilitation efforts were viewed as DMH's responsibility exclusively and in fact, there were officially acknowledged to be only 50 retarded-blind persons in institutions. Currently, MCB estimates there are approximately 500-600 blind persons in DMH facilities and views the deinstitutionalization process for these people as a cooperative effort between DMH and MCB. Though planning and programming are in the early stages, non-parallel service systems are being developed for formalization in an interagency agreement.

[See GAO note.]

I hope these comments will be useful. Should you have any questions, please do not hesitate to contact Charles Stover at 727-8036.

Sincerely,

Jerald L. Stevens
Secretary

JLS:jg
cc: Commissioner Robert L. Okin, M.D.
Director Elton Klibanoff, Esq.
Commissioner Alexander E. Sharp, II
Commissioner Marie A. Matava

GAO Note: The deleted comments relate to matters discussed in our draft report but omitted from or modified in this final report.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
REGION I
JOHN F. KENNEDY FEDERAL BUILDING
GOVERNMENT CENTER
BOSTON, MASSACHUSETTS 02203

OFFICE OF
THE REGIONAL DIRECTOR

6 FEB 1976

Mr. Louis Lucas
Assistant Regional Manager
General Accounting Office
Room 1903
John F. Kennedy Federal Building
Boston, Massachusetts 02203

Dear Mr. Lucas:

Enclosed is our response to your draft report "Summary of Deinstitutionalization Efforts in Massachusetts and Region I Federal Agencies."

On the whole, I agree with your conclusions about the status of DI efforts in Massachusetts and the need for better coordinated monitoring and more vigorous support efforts on HEW's part. The report will be helpful to us in further efforts to work with the States in support of DI efforts.

[See GAO Note]

We appreciate the opportunity to review the draft report. If we can be of further assistance, please let me know.

Sincerely,

Warren McTague
Robert Fulton
Regional Director

Enclosure

HEW - Region I

Comments on Draft GAO Report on
Deinstitutionalization Efforts in Massachusetts
and by Region I Federal Agencies

We have very carefully reviewed the draft report "Summary of Deinstitutionalization Efforts in Massachusetts and in Region I Federal Agencies." Our response is divided into two parts. First, we have some general comments on the report and in the second part specific sections of the report are discussed in more detail.

General Comments

The GAO very accurately point out a key problem which seriously hampers effective implementation of deinstitutionalization. This is the lack of cooperation among the State agencies involved. There must be stronger inter-agency cooperation than has been the case in Massachusetts thus far. We in HEW are trying in a variety of ways to assist the Executive Office of Human Services in strengthing such coordination.

Even more emphasis could have been given to the inhibitions to DI posed by the restrictions placed on fiscal and personnel flexibility by the State legislature. State agencies have very little flexibility to mount any additional effort on DI. Retraining, replacing, and deploying permanent State employees in the institutions is extremely difficult. Transferring funds is impossible without legislative approval. Moreover, there is a dearth of planning, management, and evaluation capacity at the State level. All of these constraints coupled with the fiscal crisis are major factors that should be emphasized in any review of DI activities in the Commonwealth.

[See GAO Note]

The Community Health Services Act, (PL 94-63) enacted in July 1975, contains provisions which have significant implications for future DI efforts by HEW and State Governments. Public Law 94-63 requires:

1) A State plan for DI that relates not only to patients released from mental hospitals but to retraining of staff in these facilities.

2) A comprehensive plan for mental health services in each catchment area of the State that includes programs for institutionalized patients.

3) That each CMHC assume responsibility for:

(a) Participating with the courts and other agencies referring persons for admission to State mental hospitals; and developing alternative placements whenever possible.

(b) Providing appropriate follow-up and aftercare services for patients being discharged from State mental facilities.

(c) Providing residential services (half-way houses, cooperative apartments, etc.) for patients in transition from State hospitals to community living.

[See GAO Note]

Specific Comments on selected portions of Draft GAO Report

[See GAO Note]

Chapter 3

Pages 16 and 17.

Relationships between the Massachusetts Rehabilitation Commission and the Regional Office of HEW and other State agencies were reviewed by an evaluation team established by the Regional Director in late 1975. A draft report on that review has recently been provided to MRC for comment. Also, a review of the program performance of MRC will be conducted in February and March, 1976 by a team composed of Region I Rehabilitation Services Administration and Social Security Administration representatives. This review will include a particularly careful examination of MRC's work with the severly handicapped (SSA/VR programs), in light of the policy reflected in the Vocational Rehabilitation Act of 1973.

Page 25.

The lack of an adequate management information system has been cited as the highest priority of the new Commissioner of the Department of Mental Health. We concur that the need for a comprehensive evaluation system as cited in this report is badly needed.

Chapter 4

Page 27.

All of the conditions cited have also been verified in our site visits and contacts with State mental health facilities, State hospitals and Community Mental Health Centers. It might be important to note that the first three conditions have been influenced adversely by the Commonwealth's line-item budgetary mechanisms, the lack of flexibility to transfer funds from State hospitals to community programs and the reluctance on the part of the General Court to agree with this mechanism, and the fiscal crisis in the Commonwealth.

Pages 30-31.

Medcaid reimbursement for mental health services may be further restricted since this report was written because of the State's current financial crisis which has resulted in Medicaid cutbacks. Further, there is no mention of the tremendous difficulties and delays in getting mental health centers and clinics certified for outpatient and partial hospitalization services. This is a complicated process that involves several State agencies including the Rate Setting Commission. Unfortunately, other third-party reimbursement mechanisms follow the pattern established by Medicaid and further restrict the number of dollars available for community mental health services.

[See GAO Note]

Chapter 5

In light of the GAO findings, and other recent experiences of the Regional Office, the Regional Director plans to conduct a full review of Regional Office efforts in support of DI and to determine what further steps are appropriate either within the Region or as recommendations for national policy changes. This review will be completed and emsuing actions initiated by April 15, 1976.

[See GAO Note]

Appendix I

Page 13.

While this report deals only with Metropolitan State Hospital, it might note that far higher percentages of the current populations of other State hospitals in Massachusetts are mentally retarded. This is a matter that has been called to the attention of the Department of Mental Health several times by staff of PHS. If the adult retarded in mental hospitals were transferred to a distinct part, and if the ICF and Skilled Nursing Home patients were similarly placed in separate administrative units, the number of patients in any State mental hospital requiring only definitive psychiatric care would be infinitesimally small. Massachusetts no longer has any large State mental hospitals. It does have a large amount of real estate with a number of buildings - many unoccupied - that house persons with a variety of conditions with mental illness as the reason for continued hospitalization rapidly becoming a minority issue as compared to gerontology, mental retardation, and socially inadequate syndromes.

GAO Note: (1) The deleted comments relate to matters discussed in our draft report, but omitted from or modified in this final report.

(2) Page references in this Appendix refer to our draft report and do not necessarily agree with the page number in this final report.

U. S. DEPARTMENT OF LABOR
Office of the Secretary

Office of the Regional Director
Region I

John F. Kennedy Federal Building
Boston, Massachusetts 02203
617 223-5430

February 26, 1976

Mr. Louis Lucas
Assistant Regional Manager
Regional Office
U.S. General Accounting Office
1903 John F. Kennedy Federal Building
Government Center
Boston, Massachusetts 02203

Dear Mr. Lucas:

We have read with interest your draft report on deinstitutionalization in Region I.

According to the report, findings involving the Massachusetts Division of Employment Security have been discussed with them. Also, the requirements of Section 503 of the Rehabilitation Act of 1973 have been discussed with our Employment Standards Administration and their comments are in your report.

There are no further comments that I wish to make until we receive the final report.

Sincerely,

Gerald P. Reidy
Regional Director

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT
JOHN F. KENNEDY FEDERAL BUILDING
BOSTON, MASSACHUSETTS 02203

REGION I

JAN 1 3 1976

IN REPLY REFER TO:
1C

Mr. Louis Lucas
Assistant Regional Manager
U. S. General Accounting Office
1903 John F. Kennedy Federal Building
Boston, Massachusetts 02203

Dear Mr. Lucas:

Thank you for the opportunity to comment on your draft report, "Summary of Deinstitutionalization Efforts in Massachusetts and in Region I Federal Agencies," which you sent me January 6. Members of my staff who have read it feel that it is a very clear and comprehensive statement.

[See GAO Note]

I have two comments. First, as a technical matter, the special focus of the provisions of the Housing and Community Development Act of 1974 relating to housing needs is on lower-income persons. [See Section 104(a)(4)(A), 42 USC 5304, 88 Stat. 638.] Consequently, the implementing regulations [24 CFR 570.303(c)(2)] and the application form HUD-7015.9 limit the required assessment by localities of housing needs of the handicapped to those who are of lower income.

Second, the housing needs aspect of housing assistance plans submitted to HUD by applicants for CDBG funds will be reviewed by the Department's field staff during the processing of applications. To facilitate this review, a major opportunity is presented to the state and to regional planning agencies which, under the provisions of OMB Circular A-95 [and reiterated in the regulations for the CDBG Program], are provided an opportunity to review and comment on the applications [of which housing assistance plans are a part] submitted by communities to HUD. The "A-95 process," therefore, is a major vehicle through which interested state agencies may bring to the attention of applicant jurisdictions the housing assistance needs of any identifiable segment of the lower-income community, such as handicapped/mentally disabled persons.

Sincerely,

Maurice E. Frye, Jr.
Regional Administrator

GAO Note: The deleted comments relate to matters discussed in our draft report but omitted from or modified in this final report.