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DEINSTITUTIONALIZATION OF THE
MENTALLY DISABLED IN MARYLAND

Region III, Philadelphia
Department of Health, Education, and
Welfare and other Federal agencies

*UNITED STATES
GENERAL ACCOUNTING OFFICE*

WASHINGTON REGIONAL OFFICE

JUL 7 1976

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UNITED STATES GENERAL ACCOUNTING OFFICE
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JUL 7 1976

Mr. Gorham L. Black, Jr.
Regional Director
Department of Health, Education
and Welfare, Regional Office III
Post Office Box 13716
Philadelphia, Pennsylvania 19101

Dear Mr. Black:

This report, prepared by our Washington Regional Office, discusses deinstitutionalization of the mentally disabled in Maryland and the related efforts of the regional activities of the Department of Health, Education, and Welfare and other Federal agencies. This report contains recommendations for

- establishing a deinstitutionalization focal point to assess and strengthen regional guidance and management as they affect deinstitutionalization,
- developing cooperative planning efforts with the Department of Housing and Urban Development, and
- obtaining the assistance of the Federal Regional Council.

Other recommendations are directed to:

- monitoring program requirements such as those for utilization control which affect deinstitutionalization,
- clarifying the followup responsibilities of State agencies for mentally disabled persons released from State institutions,
- assessing program activities serving or which could potentially serve the mentally disabled,
- clarifying the planning role of the developmental disabilities council in the States; and
- monitoring the effects of State vocational rehabilitation programs on deinstitutionalization.

We request that you advise us in care of the following address, of the action taken or planned in response to the recommendations, which are set forth on pages 63-65.

Mr. David P. Sorando, Regional Manager
U.S. General Accounting Office
Penn Park Building, Fifth Floor
803 West Broad Street
Falls Church, Virginia 22046

Copies of this report are being sent to the Department of Health, Education, and Welfare Comptroller and Audit Director; the Regional Administrator, Department of Housing and Urban Development; the Regional Director, Department of Labor; the Chairman, Mid-Atlantic Federal Regional Council, and State of Maryland officials.

In addition to the work in Maryland and in Region III, work was done in four additional States and their respective Federal regions. A report to the Congress is being prepared based on the combined results. Findings and recommendations, if any, related to the Departments of Labor and Housing and Urban Development will be included in the report to the Congress.

Sincerely yours,



Allen R. Voss
Regional Manager

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ABBREVIATIONS

ADAMHA	Alcohol, Drug Abuse, and Mental Health Administration
CMHC	community mental health centers
DD	developmental disability(ies)
DHMH	Maryland Department of Health and Mental Hygiene
DHR	Maryland Department of Human Resources
DOE	Maryland Department of Education
DOL	Department of Labor
GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
HUD	Department of Housing and Urban Development
MHA	Mental Hygiene Administration (Maryland)

MRA Mental Retardation Administration (Maryland)

PEPP Person Evaluation Profile Program of
 Efficiency, Relevance, and Accountability

PHS Public Health Service

SPS Social and Rehabilitation Service

SSA Social Security Administration

SSI Supplemental Security Income

CHAPTER 1

INTRODUCTION

Until the early 1960s, mentally disabled¹ persons were cared for predominantly in large public institutions. Frequently, the conditions in these institutions were deplorable and unacceptable but alternatives to institutionalization did not exist.

In the early 1960s, Federal and State Governments embarked on a broad new initiative to improve the care and treatment of the mentally disabled. This new approach involved establishing a series of programs to stimulate and support the development of a comprehensive array of community services as alternatives to institutional care, to enable mentally disabled persons to remain in or return to their communities, and to be as independent and self-supportive as possible.

Deinstitutionalization of the mentally disabled refers to the process of (1) preventing unnecessary admissions to institutions and (2) returning persons inappropriately institutionalized or those who have been rehabilitated to communities by developing appropriate community alternatives for their housing, treatment, training, education, and rehabilitation. It is recognized, however, that some mentally disabled persons do and will continue to need some type of institutional care and conditions in institutions should therefore be improved for those who need such care.

Mentally disabled persons generally need an array of services to overcome their handicaps and become less dependent or self-supportive, including diagnosis and evaluation, treatment, training, education, housing, employment, income support, social services, and followup. Alternatives to large public institutions include nursing homes, group homes, halfway houses, foster homes, apartment living, or return to one's own family and home.

¹Mentally disabled includes the mentally ill, mentally retarded, alcoholics, and drug abusers. Alcoholics and drug abusers were included in the review because they currently represent a large proportion of the patient load in mental hospitals. We did not, however, trace any alcoholics or drug abusers to the community.

MARYLAND'S STATE AND LOCAL AGENCIES
INVOLVED IN DEINSTITUTIONALIZATION

The Maryland Department of Health and Mental Hygiene (DHMH) was established July 1, 1969, as a new cabinet-level department consolidating and expanding the functions of the major State departments, boards, and commissions charged with providing or monitoring health, mental hygiene, juvenile, and related services to Maryland citizens

Mental Hygiene Administration

In fiscal years 1964 and 1965 the Maryland State Board of Health and Mental Hygiene, predecessor to DHMH received Federal grants totaling about \$109,000 to develop a comprehensive mental health plan. The Board established the Office of Mental Health Planning to develop the plan which was to provide, on a statewide basis, a framework for developing community-based comprehensive and adequate mental health services.

To implement the plan, the Maryland General Assembly enacted the Maryland Community Mental Health Services Act in 1966. This act established the Department of Mental Hygiene, now known as the Mental Hygiene Administration (MHA) which is responsible for treating and rehabilitating the mentally ill, as well as programs of prevention, casefinding, and early intervention for emotionally disturbed individuals.

Mental Retardation Administration

Traditionally, services for the mentally retarded in Maryland were provided through large State institutions, primarily Rosewood Center in Baltimore County. As early as 1960, however, a subcommittee of the Maryland State Planning Commission prepared a plan for an integrated statewide program for the retarded. Recommendations in this plan, together with suggestions made by a committee appointed by the Maryland State Board of Education in 1956 and a special Workshop on Residential Needs for the Retarded sponsored by the Department of Mental Hygiene in 1962, formed the basis for a regional approach to programming for the retarded. In 1965, Maryland published its first comprehensive plan for the retarded, prepared under title XVII of the Social Security Act, and the first Construction Plan for Mental Retardation Facilities.

On May 26, 1972, the Governor of Maryland signed into law the State's first comprehensive legislation for the mentally retarded. Such legislation conferred upon the Mental Retardation Administration (MRA) the position of administrative leadership and responsibility for the comprehensive planning and development of quality care and treatment for the mentally retarded.

Maryland State Planning and Advisory
Council on Developmental Disabilities

In June 1971, the Maryland State Planning and Advisory Council on Developmental Disabilities was established according to the provisions of the Federal Developmental Disabilities Services and Facilities Construction Act (42 U.S.C. 2670). The Council was moved in fiscal year 1974 from within the MRA to the Office of the Secretary of Health and Mental Hygiene.

The Council's overall goal is to promote and develop a comprehensive service delivery system for the State's developmentally disabled population. Its primary responsibility is to develop and implement an annual comprehensive State plan for meeting their needs. The 1976 State plan established the Federal deinstitutionalization goal as the State's main priority and included these objectives; involving Council resources in meeting Federal and professional certification standards for Maryland's six residential facilities for the developmentally disabled; expanding community-based residential programs; developing a system for securing the legal and human rights of the developmentally disabled; and developing a statewide data base.

In 1973, Maryland received a Federal grant of \$19,395 through the developmental disabilities (DD) program, to develop an institutional reform and deinstitutionalization plan for the mentally retarded.

Other State and local agencies

In addition to the MHA, the MRA, and the DD Council, other DHMH organizations provide or fund programs and/or services related to the needs of the mentally disabled. They are the Comprehensive Health Planning Agency, the Preventive Medicine Administration, the Administration for Services to the Chronically Ill and Aging, the Juvenile Services Administration, and the Assistant Secretary for Medical Care Programs. The Maryland Department of Human Resources (DHR)--designated as the Department of Employment and Social Services during our review--and the Maryland Department of Education (DOE) are the other two primary State agencies serving the mentally disabled. (See app. I.)

Maryland is divided into 23 counties and the city of Baltimore. At the local level the primary agencies involved in deinstitutionalization are the health departments, through their mental health division or clinic; departments of social services, and local education agencies.

PURPOSE AND
SCOPE OF REVIEW

Our overall objective was to determine the progress made and problems experienced by Maryland in implementing a deinstitutionalization program. Our assessment of the adequacy of actions taken by Federal agencies, to assist the States in their deinstitutionalization efforts, was done at the Federal Regional Council and the Departments of Health, Education, and Welfare (HEW), Housing and Urban Development (HUD), and Labor (DOL), Region III, Philadelphia, Pennsylvania. Our work in Maryland was done principally at DHMH, DHR and DOE headquarters in Baltimore City, Washington, Charles, and Anne Arundel counties. We also traced a small number of mentally disabled persons released from two State institutions, Crownsville Hospital Center for the mentally ill and Rosewood Center for the mentally retarded, to community providers of services. Our purpose was to determine

--whether these persons received the aftercare services recommended by the centers;

--the release planning, referral and followup procedures employed; and

--whether the release process addressed the comprehensive needs of these persons. (See app. II.)

Our review did not assess the quality of care received.

CHAPTER 2

PROGRESS AND PROBLEMS RELATING TO MARYLAND'S

DEINSTITUTIONALIZATION EFFORTS

Maryland has made progress in developing a comprehensive array of community services as alternatives to institutional care. Progress can be measured in terms of the number of mentally disabled served in the community versus those served in State institutions, expansion in community facilities and services, the passage of State laws which assisted the State's efforts, and special projects which affect deinstitutionalization.

Despite Maryland's progress, the State has encountered many problems which have hindered deinstitutionalization. Examples include increased total admissions to the State's psychiatric centers, lack of formal referral procedures to community providers of service, lack of appropriate community facilities, and inappropriate placements. The State and local factors hindering Maryland's deinstitutionalization efforts are discussed in chapter 3 while the impact of Federal programs is discussed in chapter 4

PROGRESS FOR THE MENTALLY ILL

Maryland's resident population in and first admissions to State psychiatric facilities had declined since fiscal year 1963. Mental Hygiene Administration statistics indicated the number of residents in State psychiatric facilities declined 38 percent from fiscal year 1963 to fiscal year 1974 from about 8,100 to 5,000 residents. Although State statistics showed first admissions increased from less than 4,200 in fiscal year 1963 to a peak of over 6,100 in fiscal year 1971, first admissions declined to approximately 3,800 in fiscal year 1974.

The median length of stay for those discharged from State psychiatric centers also declined. Although state-wide data was not available after fiscal year 1970, available data showed that the median length of stay was reduced from 5 months in fiscal year 1963 to 27 days in fiscal year 1970.

Maryland's geriatric evaluation services, community-based services directed to preventing institutionalization for persons 65 years and older, had a great effect on the number of aged persons institutionalized. In 1969, before the establishment of the evaluation services, 1,076 patients 65 and older were admitted to Maryland State mental hospitals. In 1974, only 606 aged persons were admitted.

Expansion in community facilities and services

MHA officials stated that growth in community facilities and services in recent years could be identified through the availability of community mental health center (CMHC) and mental health clinic services, data on persons served in the community versus the institutions; and increases in the amount, percent, and number of State grants made for community facilities and services. For example:

- Maryland had a network of 38 mental health facilities which consisted of 6 federally supported CMHCs¹ and 32 State supported mental health clinics.
- Available MHA data for September 1973 showed 1,125 admissions to State psychiatric hospitals as compared to 1,886 to the community programs.
- State funding for community mental health and alcoholism services increased from 15 percent (approximately \$9 million) of MHA's total budget in fiscal year 1973 to over 19 percent (almost \$15 million) for fiscal year 1976.
- An MHA official estimated the number of State grants for community facilities and services had increased from less than 10 in 1969 to approximately 130 in fiscal year 1975. The grant costs increased from about \$400,000 to over \$6 million during the period.

Plans to achieve a unified mental health delivery system

In July 1972 the new Commissioner of Mental Hygiene proposed:

- Dividing the four regional hospital centers into geographic units which would serve one or more counties or a portion of Baltimore City. Each unit would have full responsibility for its patients, related clinical decisions and program development.

¹Staffing grants only or construction and staffing grants; four other operational or planned clinics had Federal construction grants only.

--Unifying a hospital unit program with its corresponding community program. Maximum continuity of care would be provided by integrating the hospital unit staff with the mental health staff of the community it serves.

MHA officials said that organizing the hospital centers into geographic units has almost been completed. However, unifying the geographic units and the community programs into one local mental health system has been and will be gradual.

PROGRESS FOR THE MENTALLY RETARDED

The Rosewood Center is the primary public institution for the mentally retarded in Maryland. The institutional population at Rosewood has continually been reduced during the past few years from over 2,700 in fiscal year 1970 to approximately 2,100 in fiscal year 1974, Rosewood's population at April 1, 1975, was about 1,800. Further reductions are anticipated as regional residential centers and group homes are completed.

In 1971, the Secretary of the Department of Health and Mental Hygiene ordered that there be no new admissions to the Rosewood Center. In addition, he asked the courts to refer all court commitments to the Mental Retardation Administration. Although the order is not strictly applied, Rosewood's admission rate has been drastically reduced and admissions are limited to only the most severe cases. Before the 1971 order to restrict admissions, the institution averaged more than 275 admissions yearly. By 1974 annual admissions had declined to 98.

Expanding community facilities and services

In 1969, a Mental Retardation Facilities Construction Program was prepared based on the regionalization concept. The program called for completing five regional residential centers and an Inner City Mental Retardation Center, converting Rosewood to a regional residential center, and developing group home and day care facilities.

--By fiscal year 1975, Great Oaks and Holly, two of the five regional centers, had been completed. The Inner City Center is to be completed during fiscal year 1977. Of the remaining three regional centers one will be completed by fiscal year 1977, another by fiscal year 1979, and the third by fiscal year 1980.

--By May 1975, 3 small residential centers and 12 group homes, housing 202 residents, had been purchased, renovated, or constructed.

--Enrollment in day care programs increased from just over 100 retarded children in fiscal year 1963 to almost 2,500 children and adults in fiscal year 1975.

To achieve its legislative mandate, the MRA has established the general goal of developing a comprehensive, statewide community-based program for the mentally retarded. To accomplish this general goal, the MRA has established objectives to develop community services, achieve deinstitutionalization, and humanize institutional care for individuals for whom no other type of care is currently available.

SPECIAL PROJECTS TO ASSIST DEINSTITUTIONALIZATION

Two special projects in Maryland have aided deinstitutionalization. One of these, at the Crownsville Hospital Center, is a 3-year federally funded Hospital Improvement Project grant entitled "Person Evaluation Profile Program of Efficiency, Relevance, and Accountability" (PEPP). The PEPP documents the details of evaluation, treatment, release planning, and followup for individual patients in some geographic units at the hospital center.

The other special project is the Special Services Information System which includes data for every child (20 years old or younger) who through professional diagnosis has been determined to be handicapped and in need of special services. The information system gives a profile of individually required services and identifies services needed and being provided by each agency and county.

LAWS AND REGULATIONS AFFECTING DEINSTITUTIONALIZATION

Beginning in fiscal year 1974 there was increased interest, legislation, and regulation in Maryland regarding the rights of the mentally disabled. Issues addressed by the State included involuntary admissions, patients' right to treatment, and education of the handicapped.

Regulations governing involuntary admission of the mentally disabled to facilities under the jurisdiction of and/or licensed by the Maryland Department of Health and Mental Hygiene have reduced the number of patients admitted to and increased releases from State hospital centers. During 1974, 1,893 mentally ill persons received involuntary

admission regulation hearings at the State's mental hospital centers. As a result, 720 (38 percent) were either not admitted to or were released from the institutions

Senate Bill 784, effective July 1, 1973, requires individualized treatment plans to assure patients' right to treatment. MHA developed a regulation specifying individual treatment plans for each patient and established staff-patient ratio criteria for the MHA's facilities according to the requirements expressed under patient-labor and patient-right legislation.

During fiscal year 1974 education of the handicapped became a priority issue in Maryland as the result of a Maryland Association for Retarded Citizens suit and a new education bylaw. The State now requires that public schools provide special and appropriate educational programming for all handicapped children.

READMISSIONS AND CONTINUED
INSTITUTIONALIZATION
OF THE MENTALLY ILL

Despite a decrease in first admissions, soaring readmissions caused total State psychiatric facility admissions to increase from about 7,300 in fiscal year 1963 to a peak of almost 17,000 in fiscal year 1972. In fiscal year 1974 admissions totaled about 12,500 or 172 percent of the fiscal year 1963 total. Readmissions climbed steadily from about 3,100 in fiscal year 1963 to almost 11,200 in fiscal year 1972 and decreased to about 8,700 (nearly triple the fiscal year 1973 figure) in fiscal year 1974.

In fiscal year 1973, the last year for which data is available, 41 percent of total admissions and 48 percent of readmissions were alcoholics. Those admitted with a primary diagnosis of drug addiction accounted for another 5 percent of total admissions.

Data supplied by DHMH indicated that the last medical reviews for Medicaid patients in State mental hospital centers recommended continued mental hospital placement for only 41 percent of the 1,392 patients reviewed. The Commissioner, MHA, estimated conservatively that 25 to 50 percent of the persons currently institutionalized could be treated in the community if funds specifically designated for mental health programs were available.

Data supplied by Crownsville concerning a representative geographic unit of the hospital indicated many persons remain institutionalized due to the lack of community services. From January 1, 1973, to December 31, 1974, the geographic unit had 837 total admissions, of which 598 (71 percent) were inappropriately institutionalized because of unavailable community alternatives. Crownsville estimated that as of January 1975, 85 (75 percent) of 114 patients in the same unit could be released if services such as day care, vocational training, transportation, employment, income assistance, and housing were available.

MENTALLY RETARDED
INAPPROPRIATELY PLACED

MRA's November 1974 survey indicated that 2,240 residents (80 percent of the total institutional population at Rosewood, Great Oaks, and three specialized centers) could be deinstitutionalized by fiscal year 1980. The survey showed that 316 were ready for immediate placement in the community, 797 could be placed if the specialized services relating to their individual needs were provided; and 1,127 were placeable in 2 to 5 years if appropriate prerelease training existed at the institutions. However, the MRA estimated that, due to fiscal and staff limitations, only 50 percent of the 2,240 residents will actually achieve community placement.

A Rosewood School official estimated that for the 1974 to 1975 school year one-third to one-half of the school's students (170 to 250 children) could function well in the community if school or residential placements were available. Since there is a lack of residential facilities for children who could be returned to a community school but not to their own home, Rosewood School has sought public school placement for children who remain Rosewood residents. Only a few children are placed each year.

Residents placed in "mini-institutions" and other facilities not suited to their needs

A major portion of the Great Oaks Regional Center's residents were transferred there from Rosewood because they were from the geographical area served by the center. Although the center provides these residents with better facilities, services, and programs, the former Rosewood residents were merely transferred to a mini-institution in that minimal community services were available. The transfer of Rosewood residents to Great Oaks, originally identified by the MRA as a deinstitutionalization effort, was later acknowledged as a means of accomplishing

institutional reform and not a means for achieving deinstitutionalization

In addition, the Director, MRA, stated that facilities identified as small residential centers would not be funded in the future by MRA because 4 existing centers housing a total of 130 persons were considered to be mini-institutions and provided little or no movement to the community for their residents. The Director also considered the only vocational rehabilitation quarterway house for the mentally retarded in Maryland to be merely a 70-bed extension of Rosewood.

Some Rosewood residents discharged from involuntary admission hearings or placed in the community, because no alternatives existed, were being placed in facilities which could not provide active treatment suitable to their needs. For example, our review identified at least 11 mentally retarded persons placed in a facility licensed for general intermediate care which was deemed an inappropriate setting due to the limited services offered.

The Director, MRA, identified two specialized State residential facilities which should or could be closed if community alternatives were available. One facility housing 99 profoundly or severely retarded children was to be closed during fiscal year 1975. Because no alternatives existed, the children were to be placed at Rosewood where the Director believed they would receive more appropriate services. The other facility contained 370 adults, who were moderately to profoundly retarded, ambulatory, and retained minimal self-care skills. According to the Director, all of the residents could be placed in the community if group homes for the more severely retarded were available.

Waiting lists for institutional and community facilities

Since Rosewood is technically closed to new admissions, no waiting list is maintained. Great Oaks, on the other hand, had a waiting list of about 40 individuals in March 1975. The list was increasing by approximately five a month.

The group homes and small residential facilities we visited were full. Some facilities had only small waiting lists since the turnover in residents was slow and there was no need for extensive lists. One group home operator had a list of 30 with a minimum 1-year waiting period.

The 150 bed intermediate care facility we visited maintained a small waiting list of 4 individuals

OTHER INDICATORS OF SERVICE NEEDS

The Special Services Information System identified about 7,100 handicapped children who were on waiting lists for available services as of March 15, 1975, while another 4,300 were inappropriately placed in other than recommended programs. These 11,400 children represented approximately 15 percent of the estimated 78,000 children diagnosed and determined to be handicapped. The number of mentally disabled children awaiting services or inappropriately placed as of March 1975 could not be determined. An earlier information system report had identified over 4,000 mentally retarded children on waiting lists and over 800 inappropriately placed.

The average waiting period for particular services varied greatly among agencies. The waiting period for educational services was 32 days while the waiting periods for MHA and MRA services were 464 days and over 2 years, respectively.

In fiscal year 1974 only 300 of an estimated 41,000 handicapped preschool age children had been identified and were receiving a special education program. The Maryland Department of Education projected that, in fiscal 1976, 30 percent (about 12,000 children) will be identified and/or included in a special education program.

In fiscal year 1974 approximately 3,000 severely handicapped children and youth in State institutions or in nonpublic facilities were not receiving adequate diagnosis, psychological evaluations, or needed services and were not being taught by fully certified teachers. For example, during fiscal year 1974 about 130 (22 percent) of Rosewood residents in need of special education were not being served.

In fiscal year 1975 only 20 out of an estimated 73 Rosewood residents were receiving the vocational education services they required. Many not receiving vocational education were inappropriately placed in a special education program at the institution.

CHAPTER 3

STATE AND LOCAL FACTORS

HINDERING DEINSTITUTIONALIZATION EFFORTS

Many of the problems identified in chapter 2 relate directly to the approach taken by Maryland in providing community-based services and facilities for the mentally disabled.

- Responsibility for and services provided to the mentally disabled were fragmented and unclear.
- Planning efforts, joint agency agreements, and cooperative arrangements did not adequately address the comprehensive needs of individuals being deinstitutionalized.
- A program for community-based facilities and services was only at the threshold of being developed and funded.
- Release planning and followup procedures to assure recommended aftercare services were received had not been implemented.

FRAGMENTATION OF RESPONSIBILITY AND SERVICES

Although responsibility within the Maryland Department of Health and Mental Hygiene for the mentally ill and retarded has been delegated to the Mental Hygiene Administration and the Mental Retardation Administration, other DHMH organizations and other State agencies control many resources and programs directed to fulfilling their needs. Neither the MHA nor the MRA has the staff and funds required to address the comprehensive needs of the mentally disabled.

The responsibilities of the other DHMH organizations providing programs and/or services related to the needs of the mentally disabled are:

- The Maryland Comprehensive Health Planning Agency is responsible for developing a coordinated statewide system of comprehensive health planning and for coordinating planning for resource use in the private and public sectors of the State's health industry.
- The Preventive Medicine Administration directs six major programs that provide technical and professional assistance, consultation, and some direct services, primarily to local health departments.

The Division of Crippled Children's Services, the Maternal and Child Health program, and the Child Group Day Care program provide services to the mentally disabled.

--The Administration for Services to the Chronically Ill and Aging provides inpatient services at five hospital centers through its treatment services components. Separate components provide adult disease control services and services to the aging

--The Juvenile Services Administration administers prevention, screening and evaluation, and habilitation services for delinquent and predelinquent children and operates community-based programs and institutions for their residential care.

Maryland's Department of Human Resources' Social Services Administration provides income maintenance and social services to eligible persons (based on earnings, age, disability, and children without support) The services include homemaker service, day care, foster homes, adoption services, protective services, and family planning which are provided by county departments of social services. DHR's Employment Security Administration is responsible for assisting the mentally disabled in finding employment and providing information to assure that Federal Government contractors take affirmative action to employ the handicapped.

The Division of Special Education in the Maryland Department of Education is responsible for the education needs of the mentally disabled outside the institutional setting (DHMH has this responsibility while an individual is residing in a State hospital center). Special education programs within the 23 county and Baltimore City school systems are operated by the local education agencies. DOE's Division of Vocational Rehabilitation provides services to mentally disabled persons directed toward restoring human resources so some type of gainful employment can be found. These services include evaluation, counseling, training, and other activity programs.

Roles and responsibilities for
deinstitutionalization not
clearly defined

Although several DHMH organizations and two other State agencies provide programs and/or services to the mentally disabled, their roles and responsibilities for deinstitutionalization had never been clearly defined. Responsibility for referrals to other agencies was not

established; retarded persons eligible for community services were not always served; and, in some instances, persons lived in unlicensed "foster care type" homes of less than four beds for which no State agency had responsibility.

Although DHMH operates foster care homes in which persons are placed directly from the institutions, county departments of social services are often used to find foster homes for persons being released. Provision of services to persons released from DHMH institutions or in DHMH foster care homes, however, is not recognized by the Social Services Administration as one of its responsibilities. For those persons placed by the DHMH, responsibility has never been established for referrals to the appropriate county department of social services, or for assuring that other types of general aftercare services, such as income and employment assistance, are provided.

Services in the community were not always provided for the retarded or those with multiple handicaps. For example, we were informed that although the Social Services Administration had several retarded children in foster care, when homes were scarce for normal children in need of foster care or when a retarded child presented problems, the Social Services Administration considered them the Mental Retardation Administration's responsibility. The Secretary, DHR, concurred that when limitations in funds and homes force a decision, priority must go to those neglected and dependent children for whom the Administration has guardianship and is mandated to serve.

DHMH and Social Services Administration officials stated that children and adults living in unlicensed foster care type homes of less than four beds are not supervised by either the administration or the DHMH. These homes are not required to meet foster care regulations, are not inspected by DHMH for sanitary conditions, and, since their availability and development are not known, do not receive adequate social services.

Coordinating and clarifying roles and responsibilities

Both the MHA and MRA had made limited progress in clarifying agencies' roles and responsibilities although some positive actions had been taken and other cooperative efforts were partially complete during our review. Among the positive actions were (1) MHA's contractual agreement with the Social Services Administration stating that the Administration would provide funds for the foster care placement of approximately 25 emotionally disturbed

children, (2) interagency reviews of fund allocations available to the Office of Aging and the DHR for community programs, including foster care and, (3) MHA and MRA representation on a statewide committee reviewing inequities in the foster care rates provided by various DHMH administrations and the DHR.

Proposed cooperative efforts during our review included.

- An MRA/Social Services Administration memorandum of understanding to clarify the financial and legal responsibility, including the provision of foster care, for institutionalized and deinstitutionalized children.
- A cooperative arrangement between Crownsville Hospital Center and the local education agency

PLANNING FOR DEINSTITUTIONALIZATION

In fiscal year 1975, DHMH prepared a 5-year Department Plan for fiscal years 1976 through 1980 to identify and offer alternatives for the key health service issues confronting the Department and the State. According to the plan, DHMH has adopted the long-term strategy of moving away from institutional care and developing other alternatives to residential care.

The deinstitutionalization priority, one of seven short-term priorities identified, is to be a continuing, three-part effort to insure that all those not absolutely requiring institutional care have access to adequate community-based care. Emphasis is on expanding community-based services, expanding evaluation and placement services, and reducing institutional populations.

MHA continuity of care planning inadequate

In 1969, the MHA implemented a plan for program development in its institutions and in various local communities. The objective of this plan was a network of accessible, coordinated mental health services. The MHA started to build this network in the local communities and develop liaison between these community programs, State mental hospital center programs, and other health resources. As discussed in chapter 2, a program was initiated in July 1972 to integrate hospital and community services into a unified mental health services system.

Despite the progress made, maximum continuity of care had not been assured because three of the four hospital centers had not integrated unit staff with mental health clinic staff in the county(ies) which the unit served. One hospital center, Crownsville, had not achieved a unified mental health delivery system because both hospital and county staff expressed reservations concerning the amount of travel involved, staff funding sources, and maintaining program autonomy.

The only region in the State that had integrated hospital and county staff was the Eastern Shore. This integration and coordination may have been assisted by the common boundaries established for the mental health Regional Director and the Eastern Shore Hospital Center's geographical region. The Regional Director was also the Superintendent of the hospital center and, as such, administered the hospital's State funds and may have influenced community mental health grant awards to county health departments and non-profit agencies within the mental health region. Although the superintendents of the other three State hospital centers were also regional directors, the counties served by their hospitals did not coincide with the geographical boundaries of the regions for which they were directors.

The MHA had not met its objective of providing a network of accessible, coordinated community-based facilities and services because guidelines or procedures had not been issued to assist the counties in developing community resources and due to the lack of both Federal and State funds. Every county in Maryland, except those on the Eastern Shore, had proceeded to develop services independently of the others based on county mental health needs, size, officials, and funding.

MRA regionalization
plans not implemented

The first comprehensive plan for the mentally retarded and first Construction Plan for Mental Retardation Facilities prepared in 1965 addressed regionalization of programming, including deinstitutionalization. The regional approach was to provide a well-balanced array of needed services coordinated with one another and provided as close to a mentally retarded individual's home as possible. Although these plans were prepared in 1965, it was not until 1972 that a State law was enacted which separated retardation from mental hygiene and established the MRA.

In the 10 years that have elapsed since regionalization was proposed, original plans have been continually revised and only partially implemented. Maryland has never made a full commitment to any approach to regionalization evidenced by frequent turnover of administrators, continued centralization of staff resources, limited development of regional centers and group homes, and fiscal and staffing restrictions. The current MRA administrator has revised a previous approach to regionalization to conform to a "continuum of care" concept.¹

During our review the MRA was still a highly centralized organization exerting minimal impact on the planning and coordination of community-based services and programs. Until fiscal year 1976 communities were not required to prepare annual operating or construction plans. Since MRA reimbursed directly the private nonprofit organizations who provided community services, county and local officials were further removed from community service planning. According to the MRA, one of their chief handicaps in joint planning efforts was that they had no counterparts in local areas to relate to local departments of social services and local education agencies. The MRA 1976-80 plan provides that although policy formulation and management functions will be retained within the central office, MRA will decentralize its staff into the field to accomplish community organization, program monitoring, and evaluation and consultation.

With continual revisions in the regionalization approach, fiscal limitations, employment freezes, and staff ceilings, the facilities planned to support the regional deinstitutionalization concept had not fully developed. Only two of the planned five regional residential centers--originally identified as the programing centers for programs and service networks--had been completed.

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The selection, blending, and use in proper sequence and relationship of medical, educational, and social services required by a retarded person to minimize his disability at every point in his life span.

Partial implementation of a regional approach to deinstitutionalization had fostered a lack of coordination among the various agencies serving the retarded. As a result, many retarded persons were not receiving the full array of services they required. To identify gaps in community services and to locate community sponsors for operating needed services the MRA has established local planning to identify existing services, service gaps, and to develop priorities for services which will prevent institutionalization. In December 1975 the Maryland Department of State Planning reported that inventories of existing services had been completed in four of the six continuum of care areas which had been established throughout the State.

Objective data for
planning not available

One of the priorities identified in the DHMH 5-year Department Plan was to upgrade the quality and effectiveness of DHMH management, planning, information systems, program evaluation, and organizational relationships. However, the MHA and the MRA data which could assist in upgrading the quality and effectiveness of planning had not been developed

For example, the data required for projections and program evaluations was identified by the MHA in its 5-year plan and included admissions and readmissions or point of entry into the mental health system, discharges, length of stay, and expected needs at discharge for institutionalized patients. An MHA official stated, however, that data required to identify the needs of the mentally ill was not available and that budgetary priorities were not based on objective data. Because point of entry and other data was unavailable and since community programs were still inadequate, it was not known whether patients referred to community programs instead of being institutionalized were being admitted at a later date or whether these patients were receiving the services needed for rehabilitation

The Developmental Disability
Institutional Reform and
Deinstitutionalization Plan Grant

The objectives of this grant, awarded by HEW Regional Office III to the MRA in 1973, were to

1. Identify substandard aspects of the institutions' programs.

2. Identify resources in the facility and community for reducing the institutional population
3. Set timeframes and methodologies for reducing the institution population.
4. Aid in coordinating and incorporating the developmental disability and MRA State plans.

No plan was developed by MRA's grantee and the objectives of the grant were not met. Neither the substandard aspects of the institutions' programs nor the resources within the facilities and communities for reducing the institutional population were addressed, and no timeframes or methodologies were set. The deinstitutionalization philosophy included in a subsequent plan prepared by the MRA was accepted by the DD Council to aid in coordinating and incorporating their respective plans.

Deinstitutionalization not included in other DHMH administrations' and State agencies' plans

Although deinstitutionalization was a DHMH, MHA, and MRA planning priority, it was not necessarily a priority goal or included in the plans of the other DHMH Administrations and State agencies whose programs provide services to the mentally disabled. For example:

- Although the Maryland Comprehensive Health Planning Agency had included both mental health and mental retardation as health care issues in its July 1973 Comprehensive Health Plan, one official stated that the planning agency had never addressed the resources needed, conducted studies, or recommended or taken any actions to alleviate the mental health problems in the State.
- An official of the Division of Crippled Children's Services, Preventive Medicine Administration, stated that since the Administration does not operate any institutions, deinstitutionalization per se was not addressed in its 5-year plan. However, the Administration assists in determining the need for continued institutionalization through hospital utilization reviews.
- According to DOE officials, the Department had no policies, priorities, or plans which address deinstitutionalization. However, cooperative agreements existed to provide special education,

day care, and vocational rehabilitation. The department also has two projects directed to deinstitutionalization-- one focuses upon training personnel to work with severely and profoundly handicapped children in public school settings while the other serves retarded children from two residential centers in the Baltimore City public schools.

- An official of the Social Services Administration informed us that the Administration had neither established a deinstitutionalization plan nor prepared documentation regarding the social services role in the deinstitutionalization process. Emphasis on deinstitutionalization by DHMH has caused the Administration to direct more attention to the subject and several cooperative agreements have resulted. The official believed that existing social services objectives are consistent with the deinstitutionalization philosophy and many social services programs, such as day care, foster care, protective services, homemaker, and community home care assist in deinstitutionalization or preventing unnecessary institutionalization.
- The Employment Security Administration official responsible for services for the handicapped said that the Administration was aware of the State's deinstitutionalization effort only on an informal basis and had never planned for nor been contacted by MHA, MRA, or the DD Council. Since our review, the Executive Director, Employment Security Administration, has become a DD Council member and the Council is working with the Administration on updating the DD plan.

SHORTAGES OF COMMUNITY-BASED FACILITIES AND SERVICES

An important reason for the continued institutionalization of persons inappropriately placed in State hospital centers is the lack of community-based facilities and services. As discussed in chapter 2, Maryland has experienced problems in its deinstitutionalization efforts because every type of facility and service required for a unified mental health delivery system and a continuum of care program for the mentally retarded is either unavailable or insufficient in number. Based on our review in Maryland, the following facilities and services appeared to be of highest priority in implementing a State deinstitutionalization effort.

Facilities

Shortages existed in sheltered living facilities such as halfway houses, intermediate care facilities, small residential centers, foster care, nursing, and group homes for the mentally disabled in the State. In its fiscal year 1976 budget message the MHA stated that a program of sheltered living conditions was only at the threshold of being developed and funded. Because housing for both the mentally ill and the elderly was not available, the MHA identified community residential-care homes as its primary program need for fiscal year 1976.

The MRA identified the immediate need for the purchase and renovation or construction of a minimum of 155 group homes throughout the State by fiscal year 1982. Although the number of group home beds projected to be available by the end of fiscal year 1975 was 250, as of June 30, 1975, only 12 homes housing 88 individuals had been renovated or constructed.

Nursing homes and intermediate care facilities for older mentally retarded individuals who need medical attention and long-term care were not available. Existing nursing homes and general care facilities could not provide active treatment geared to the needs of the retarded while institutions certified as intermediate care facilities for the mentally retarded served persons of all ages and directed only limited resources toward the specific needs of the elderly.

Services

The most often identified shortages in community-based programs for the mentally disabled were day care; sheltered work facilities; transportation; community mental health center and mental health clinic services, especially for the mentally retarded; diagnostic, evaluation, and referral services; special education; 24-hour emergency services and partial hospitalization, temporary relief care; and employment. A discussion of needed mental health services and education follows.

Mental health services

Maryland had a network of 38 mental health facilities which consisted of 6 federally supported CMHCs¹ and

¹Staffing grants only or construction and staffing grants; four other operational or planned clinics had Federal construction grants only.

32 State supported mental health clinics. The six CMHCs and eight mental health clinics offered the five services--inpatient, outpatient, partial hospitalization, emergency, and consultation and education--considered essential by the National Institute of Mental Health. Of the remaining 24 mental health clinics, 7 offered 3 of the services considered essential while the remaining 17 offered only 2

In many of Maryland's counties services available to the mentally ill were limited because no CMHCs or mental health clinics offering the five essential services existed. For example, 15 counties had just 1 mental health clinic offering only 2 of the 5 services. In 1 of the 15 counties draft recommendations made by the Mental Health Advisory Committee in March 1975 indicated services were extremely lacking. As stated in the draft recommendations

- Services are provided by the mental health clinic only 4 hours a week
- Increasing present hours of service two-fold would provide only minimal service to about one-quarter of those estimated to need service.
- Part-time clinic operation, even substantially expanded, would force persons in immediate need of help to wait anywhere from a week to a month or more before they could be seen by a local mental health professional.

Where CMHCs or mental health clinics did exist, they appeared ill equipped to handle the needs of the mentally retarded. The majority of the local health departments, CMHCs, and clinics had no office, position, or focal point to coordinate, plan, or serve the mentally retarded. Responsibility for serving the retarded had never been defined as a responsibility of the CMHCs and the mental health clinics

Education

DOE's objective is for every county to implement by 1980 the Continuum of Education Services--a program designed to maintain handicapped children in regular classrooms. In fiscal year 1975, the continuum was operated in 31 of 937 elementary schools in 15 of 24 political subdivisions, and served approximately 6,200 children. The program was operating only in public day schools, even though the continuum design provides for its establishment in special public and nonpublic schools and in residential institutions. No program expansion is planned until a 2-year study is completed in fiscal year 1977.

Since there were few county programs for the severely or profoundly retarded, most of the mentally retarded children served by the counties were mildly or moderately retarded. Although some special schools existed, there were few or no programs in most counties for the mentally ill unless they could be contained in a regular class. According to county and institutional educators, the only alternatives for children excluded from the regular school system were the institutional schools or private facilities.

Funding for institutional care versus community programs

State funding for community programs had increased gradually for the mentally ill and greatly for the mentally retarded. (See app. III and IV.) By fiscal year 1976, however, State funding for community programs represented only about 19 and 20 percent of the MHA and MRA budgets, respectively.

The MHA originally believed a network of community-based mental health facilities and services could be accomplished with a gradual shift of funds and staff from the hospital to the community in an orderly manner and within available resources. However, the transition from long-term custodial care to intensive short-term care in the hospital centers, accompanied by an increase in readmissions, had resulted in increased institutional costs. As a result, the fiscal years 1974 and 1975 budgets had no increases for community program initiation or expansion, and the fiscal year 1976 budget request represented only 25 percent of the estimated need.

Despite growing emphasis on community programs, institutional costs still consumed about 80 percent of the MRA's fiscal year 1975 and fiscal year 1976 State budgets. Due to the increased costs of hospitalization, a potential reduction in the previously approved fiscal year 1976 State appropriation, and the expense associated with meeting new accreditation standards, MRA plans required increased Federal funding to supplement State support of its community facilities and services.

Low foster care rates hinder placement

Foster care maintenance for the mentally disabled in Maryland was financed by Supplemental Security Income (SSI), county, or institutional funding. Monthly payments to careholders ranged from \$91 in one county to \$180 for nonambulatory clients whose foster care was financed by

Rosewood. When foster care placements were made using SSI, up to \$136 of the monthly SSI payment was provided to the careholder.

Both MHA and MRA officials believed that existing financing was insufficient to maintain a mentally disabled individual in the community and to attract new careholders. MHA officials noted that due to the higher rates other agencies could pay for foster care, another State agency was placing children in foster homes originally developed by the MHA. While the highest monthly foster care rate for Maryland's mentally disabled was \$180, a study of foster home maintenance costs in another State showed the costs of maintaining a normal child to be as high as \$212 per month.

To assist in developing foster care homes the Social Services Administration authorized a higher special care rate for children transferred from group homes to specialized foster family care. The Administration believed that by moving children out of group homes receiving high rates of reimbursement, available funds could be extended to cover the higher special care rate and enable the purchase of supportive services.

INADEQUACIES IN RELEASE PLANNING AND FOLLOWUP

To reduce the number of mentally ill persons readmitted to State hospital centers, to assure that the comprehensive needs of both the mentally ill and mentally retarded are addressed before release, and to verify the receipt of recommended aftercare services, a structured program of release planning and followup is required that assigns responsibility and documents procedures. In Maryland we found opportunities for improvement in the release planning and followup for the mentally disabled.

Crownsville Hospital Center for the mentally ill

Crownsville provided a formal written response to our questions concerning release planning. The response stated that determination of a patient's readiness for discharge was generally made by a team including all disciplines involved in patient care and the patient himself. One specific objective of the release planning meetings held by the team was to assure that all necessary community agencies such as county health departments and out-patient clinics as well as proper family and concerned individuals were notified of a patient's pending release. Exceptions to this general

procedure occurred when a patient was discharged from an involuntary admissions hearing, or when a parent(s) demanded release against medical advice.

The Crownsville response further indicated that the comprehensive service needs of the patients were required to be identified on the release plan and were identified under the individualized treatment plan and on the discharge summary. If services were needed but were not available in the community, they would be identified on the release plan, at which time the hospital, day care center, or mental health clinic would continue to seek alternatives to the community deficiencies.

Since the State did not provide us access to actual patient records, we were unable to verify the accuracy of Crownsville statements concerning release planning and the identification of comprehensive service needs. However, during our tracing effort we found inconsistencies with the conditions described in the formal response.

Improvements in release
planning and referral procedures needed

Our tracing efforts and discussions with Crownsville officials showed that comprehensive needs of the patients were not identified during the release planning process; community providers of service, except for public health nurses, participated in the release planning process only on an irregular basis; and referral procedures to providers of service were weak.

The release plans for the patients we traced identified only primary health-related service needs, such as therapy and medication, and referral points, such as the clinics and day care. Responsibility for identifying comprehensive service needs then shifted to the community, usually to the local health department or mental health clinic. Officials confirmed that comprehensive service needs of patients were not identified during the release planning process.

We were also told that community providers of services only participated in release planning when hospital personnel felt they should be included and not on a regular basis. Only a public health nurse responsible for the county mental health outpatient clinic attended the regularly scheduled release planning meetings. Other community providers who attended on an irregular basis included social workers from the county's department of social services, probation officers, juvenile case workers, legal aides, alcoholic counselors, and representatives of the county's board of education.

Referral procedures, tested during our tracing efforts, were weak. Since no formal written referrals to community providers were made, referrals had to be noted by personnel from the accepting agency if they were in attendance at the patient's release planning meeting. If not in attendance, Crownsville personnel were supposed to make aftercare referrals by telephone.

As a result of lack of community participation in release planning and weak referral procedures, our tracing efforts showed that in many instances aftercare service providers had no knowledge of patients recommended to them by the institution. For example, of 47 patients recommended for mental health clinic aftercare services, only 8 went to the clinic as the result of a referral. The clinics had records on only 5 of the remaining 39 patients.

Since we were told that the comprehensive needs of patients were not identified during release planning, we tested the extent to which patients used social services after their release. For the 58 mentally ill patients traced, 22 had either applied for or were provided social services since July 1974. Social services had not been identified as a postinstitutionalization service need for any of the 22 patients. In fact, social services had been recommended for only 1 of the 58 patients we traced. A search through the county's social services records showed, however, that the department had not had any contact with this individual.

Aftercare and followup data
and procedures not available

Crownsville had limited data on the whereabouts of released persons. The only available data was for patients placed on foster care or those who were using the mental health clinic and day care center. No information was available for the patients directly discharged.

The MHA had not accumulated data showing whether persons released from the hospital centers received the aftercare services identified at the discharge or release planning meeting. DHMH officials stated that DHMH funds had been inadequate to assure and document followup after release. These officials stated that the hospital centers had not adequately planned or followed up on patients directly discharged. They believed the hospital centers and ultimately the MHA were at fault for failing to issue instructions or planning guidelines concerning aftercare services.

Inadequate followup
procedures at Crownsville

As a result of our tracing efforts, we found followup activities were limited at Crownsville. Crownsville's responsibility for followup, based on the type of release, was as follows:

Foster care release--Evaluative, supporting, and treatment for 1 year. However, followup services could be less than or more than 1 year depending on the patient's needs. When there were clinics or CMHCs in the zone of release, they were asked to accept the responsibility.

Convalescent leave release--Same as foster care except that if there were clinics or CMHCs in the zone of release, the patient was referred to them for followup.

Discharge--None. Generally referred patients to clinics or CMHCs in their zones. Evaluative, supporting, and treatment services were sometimes rendered. Patients discharged from Crownsville in fiscal year 1974 comprised 3,351 or 89 percent of the 3,771 individuals released.

Discharges included those as a result of involuntary admissions hearings or on demand by parent(s) which often afford little time for proper planning and referral before release. Patients discharged from hearings may be requested to accept hospitalization on a voluntary basis or were encouraged to accept outpatient treatment at a mental health clinic.

A Crownsville official indicated that for all types of releases their responsibility for patient followup ended once a referral had been made. It was then the responsibility of the individual or agency accepting the referral to perform followup activities.

Mental health clinic officials in the counties visited said they did followup action when a patient was referred or services were arranged for him. A clinic official informed us clinic followup responsibility began as soon as a patient referral was accepted although their followup effort was only to insure the individual kept his clinic appointments.

Rosewood Center for
the mentally retarded

When a resident was considered ready for release the Rosewood Social Service Department was responsible for conducting the release planning meetings. Representatives from

the institutional psychology department, the unit director from the resident's cottage, and on an as needed basis educational teachers, speech and hearing workers, vocational counselors, and others, were invited to attend. The resident and family, if any, were notified of the pending release and the appropriate community providers of services could be invited.

Recommendations concerning release and needed aftercare services were made and the release was planned. Although the procedure was informal, recommended aftercare services were documented and maintained. Exceptions to this general procedure occurred when a resident was discharged from an involuntary admissions hearing, on demand by parent(s), or from unauthorized leave status.

For residents released to public or private facilities, the Rosewood social workers arranged placement with the providers. When residents were released initially to a community provider of service, they were not discharged, and could be returned to Rosewood at the providers' discretion. If the residents and the provider were compatible, discharge from Rosewood usually occurred in 6 months to 1 year

For residents released to their families, foster care parents, or self-care, Rosewood social workers interacted with the residents in attempting to find appropriate placements and resources. These residents remained Rosewood's responsibility and institutional social workers were responsible for insuring that aftercare services were received.

Comprehensive needs not
identified at time of release

A Rosewood official and a county mental health clinic official said that the comprehensive needs of residents were not identified during the release planning process. Although the comprehensive needs of a resident were considered and discussed at the release planning meeting, unavailable facilities and services were not documented and the release plan addressed only those needs for which community alternatives were known to exist. Based on our suggestions, the Rosewood official responsible for release planning agreed to try implementing a release plan which identified a resident's comprehensive needs.

Aftercare and followup
data not available

Neither the MRA nor Rosewood had accumulated data showing whether residents released had received the recommended

aftercare services. Rosewood social workers were, however, aware of the aftercare services provided residents released to community providers of service. No data or information was available on the residents who were discharged

Followup procedures at Rosewood

While Rosewood maintained no followup responsibility for residents discharged from the institution, it did provide resident followup for other types of release.

For residents released to public or private facilities, Rosewood would assist in the resident's transition to the community for approximately 1 year and could readmit the individual if the placement proved inappropriate. The provider of service was responsible for aftercare services.

For residents released to their families or self-care, followup was maintained on a continual basis until discharge, which usually occurred in about 1 year. For foster care placements, Rosewood was responsible for medical and dental care and assisted the foster parents in using community resources. Followup was indefinite, as discharges to foster parents were rare.

During our tracing effort we found instances where these procedures were not followed. For example, for three residents placed on foster care in two nursing homes, their foster care status and Rosewood's corresponding responsibility for followup were not made known to the homes. Officials at both facilities were therefore reluctant to accept other mentally retarded residents.

Followup provided by other State agencies

Vocational counselors, county department of social services workers, and other State and county agency representatives participated in the release planning and followup. Minimum responsibility for followup was recognized by other agencies for providing aftercare services to the mentally disabled.

For example, vocational rehabilitation followup could be terminated 60 days after employment placement as long as both employee and employer expressed satisfaction. Local departments of social services officials stated they had no followup responsibility for persons released from institutions unless they were actively involved in a particular case. Their followup responsibility would begin once a released individual was referred to them or was receiving one of their services.

OTHER PROBLEMS HINDERING
DEINSTITUTIONALIZATION

The greatest single roadblock to deinstitutionalization may be community and parental attitudes toward the mentally disabled. Although Maryland was making strides toward deinstitutionalization and institutional reform, few programs were available to prepare families or the community to accept the return of formerly institutionalized persons. For example, once retarded children are institutionalized, families sometimes refused to accept them back into their homes. In these cases community placements must often be done without the family's cooperation and over their objections.

We were told that the Associations for Retarded Citizens were composed of the "vocal minority." The "silent majority," parents and guardians with mentally retarded children or relatives in institutions, consider deinstitutionalization to be a threat to their lifestyle and are therefore opposed to it. Some parents even refused to visit their children or respond to inquiries concerning them.

The problem of community and parental attitudes toward deinstitutionalization was even greater for the mentally ill. While mental retardation generates compassion in many, mental illness or the emotionally disturbed are generally repulsed by society. The public has been oriented to view mental illness as incurable, inherited, and a social stigma and believes that the mentally ill should be placed where society will neither be reminded of nor have to deal with them.

Negative community attitudes toward the mentally disabled were reflected in restrictive zoning and discrimination in employing the mentally disabled. Some county zoning ordinances prohibited sheltered living facilities such as group homes from being established or required the approval of neighborhood civic associations.

CHAPTER 4

IMPACT OF FEDERAL PROGRAMS

ON STATE AND LOCAL

DEINSTITUTIONALIZATION EFFORTS

Federal programs have been and are being used to assist in State deinstitutionalization efforts. State, local, and private agencies, supported in part with Federal funds, provide many of the community-based facilities and services for the mentally disabled. Third party payments received through programs such as Medicare and Medicaid are the major source of Federal reimbursement.

Federal requirements and certification standards impact on eligibility for, the quality of, and programing relating to community-based facilities and services. Federal regulations also impose management, monitoring, and evaluation requirements on State and local governments which affect deinstitutionalization.

In Maryland, two Federal programs directed to providing community-based alternatives to institutional care had not been fully effective nor met goals and objectives related to deinstitutionalization. Although the requirements of several Federal programs affect release planning, followup, and after-care, we found that these requirements were not always met and that Maryland could improve its implementation of these programs and more clearly define responsibilities. In some instances, Maryland could assist deinstitutionalization through improvements in meeting utilization, independent medical, and professional review requirements. Other opportunities exist for Maryland to use Federal program resources to assist deinstitutionalization through developing alternatives to institutional care and improving cooperation and coordination in implementing Federal programs.

FEDERAL FINANCIAL INVOLVEMENT IN MARYLAND

As discussed in chapter 1, initial planning for deinstitutionalization in Maryland was prompted and financially supported primarily by the Federal Government. In addition, the Federal Government has supported the construction and staffing of community-based facilities, a variety of services provided to the mentally disabled in both institutions and communities, and special efforts and projects directed to deinstitutionalization.

Maryland uses a variety of federally supported programs to support the costs of providing care and services to the

mentally disabled. Although precise information on the total amount of Federal funds used for this purpose was not available, some data was obtained. Appendix V shows the fiscal year 1974 Federal funds that were identified as being obligated or expended for the mentally disabled.

FRAGMENTATION, COMPLEXITY, AND
MULTIPLICITY OF FEDERAL PROGRAMS

Maryland's Mental Hygiene Administration and Mental Retardation Administration did not have all of the funds needed to place and support mentally disabled persons in the community, and therefore, had to rely on other State agencies and programs to provide funding and services.

Fragmentation found at the State and local levels was attributed, in part, to the fragmentation of the Federal programs assisting deinstitutionalization. Since none of the Federal programs address the comprehensive needs of deinstitutionalization and available funds were limited, Maryland used a variety of federally funded programs. Federally supported agencies, including the Social Services Administration, the Employment Security Administration, the Division of Special Education, the Division of Vocational Education, and the Division of Crippled Children's Services, provided a variety of programs and services to mentally disabled adults and children who met eligibility requirements and not as a part of a planned, systematic strategy to accomplish deinstitutionalization. Each of these agencies and programs had goals and objectives, eligibility requirements, and restrictions and limitations, some of which affected the State's deinstitutionalization efforts.

The Secretary of the Maryland Department of Human Resources, in his comments on our draft, discussed some reasons for program fragmentation, gaps in service, and minimal cooperation between the various agencies. In part, he commented

"Maryland's programs serving the mentally disabled are organized by their functional areas in accordance with the various statutes mandating the services to be given and the population to be served. State funding is based upon and usually limited to these mandated services and the identified population. Federal agencies support this specialized approach with separate regulations, funding formulas, and philosophical approaches which establish barriers toward comprehensive programs and interagency cooperation. Only if more resources are made available and there is more flexibility to co-mingle funds, will it be possible to resolve these problems."

The Medicaid agency, however, disagreed that various federally supported agencies lack cohesive planning and described Maryland's geriatric evaluation services as a planned, systematic strategy to accomplish an alternative method of care for the mentally disabled. In support of our views, the Maryland Department of State Planning in December 1975 reported as a problem the lack of coordination between agencies on developing their deinstitutionalization policies. Further, an MHA official acknowledged that geriatric evaluation services are directed only to the aged and would have no effect on the mentally retarded.

Using Developmental Disabilities and
Community Mental Health Centers programs
for deinstitutionalization

The two principal federally supported programs which focused on deinstitutionalization in Maryland were the Developmental Disabilities (DD) and Community Mental Health Centers (CMHC) programs. Both of these programs were directed to providing community-based alternatives to institutional care and at coordinating and stimulating deinstitutionalization efforts. Although both programs had assisted in developing community alternatives to institutionalization, neither had been fully effective, met envisioned goals and objectives, nor been able to resolve the underlying problems relating to deinstitutionalization.

More effective use of
DD program possible

Among other purposes, the DD program was established for the retarded and those with related disabilities to (1) identify needs and develop comprehensive plans to meet these needs, (2) stimulate and coordinate other agencies to take specific actions to provide services, and (3) fill gaps in services and facilities. Deinstitutionalization is a major goal of the DD program.

Maryland's DD program had identified the services provided to the developmentally disabled through programs and facilities in the State, had identified services and programs needed but not available, and had awarded grants to State agencies which proposed to fill the gaps in services or programs. The DD program also planned to develop a state-wide system to identify all handicapped persons in the State and services available to them. We found, however, that the Maryland DD program had not been effective

--in developing a comprehensive multiagency action plan for filling identified gaps in services,

- in clearly defining the roles and responsibilities of other State agencies for deinstitutionalization, and
- in stimulating other agencies to adopt specific goals, objectives, or priorities for deinstitutionalization.

Opportunities for improvements
in the DD Council's planning process

The purpose for developing a DD State Plan is to bring together all concerned State agencies, both public and private, to study and determine immediate and future needs for the developmentally disabled. The fiscal year 1975 and 1976 Maryland State Plans for Developmental Disabilities identified services provided to the developmentally disabled through programs and facilities in Maryland and service gaps and problem areas uncovered in the Council's review of existing services. The gaps in service were identified by the Council or by the individual Council members for their respective agencies.

The identified gaps in services, however, required resources which far exceeded the DD and MRA funds available and were in areas other than "mental retardation services" such as community-based residential facilities, income support, medical assistance, sheltered work facilities, social services, special education, and child health services for which other agencies had primary responsibility or funding. This situation therefore placed great importance on the need for comprehensive planning, multiagency participation, and coordination.

Our discussions with responsible officials and review of the fiscal year 1975 and 1976 plans indicated that there were opportunities for improving the planning process for the developmentally disabled. The DD planning process had proceeded slowly, had not identified all gaps in services or programs, and had not formulated a plan for filling gaps or for establishing responsibilities for providing the services and programs not available. Some agencies responsible for programs and services affecting the developmentally disabled were neither addressed in the DD plan nor represented on the DD Council. The Medicaid agency, one of nine specific programs required by Federal guidelines to be considered in preparing the plan, and the Department of Economic and Community Development responsible for housing, were not identified in the fiscal year 1975 and 1976 plans or represented on the Council.

The fiscal year 1974 Maryland plan established goals, objectives, priorities, and methods for developing new programs and for improving or expanding existing facilities and services. The 1975 and 1976 plans provided estimates of the number of developmentally disabled in the State without establishing an objective data base from which to work. Recognizing that the objective data required to identify service needs was not available, the Council plans to direct a portion of its resources in fiscal year 1976 to developing a statewide information and referral system which will identify all handicapped persons in the State and the services available to them.

The fiscal year 1975 and 1976 plans did not identify all gaps in services because (1) service gaps for the State organizations providing planning and housing were not included; (2) the Council experienced difficulties in acquiring necessary data, agency personnel reluctance, and were under a time constraint when the plans were being developed; and (3) local or county officials' involvement was minimal.

The plans did not include gaps in services identified by the organization responsible for State planning, even though this department had recognized deinstitutionalization as a statewide problem area and had initiated a study to identify the administrative procedures, gaps in community facilities and services, and social attitudes which negatively affected the State's deinstitutionalization efforts.

The plans did not include steps for filling the identified service gaps and had not established responsibilities for providing the services not available. Responsibilities were not addressed in the DD plans or in the planning documents of the health agencies identified as providing programs or services related to the needs of the developmentally disabled. For example, although the plans stated that there are not enough group living facilities for mentally retarded adults, they did not identify the State Medicaid and housing agencies as ones which could participate in the support of such facilities.

After our review, the Maryland DD Council was selected to participate in a federally sponsored planning design test. According to the Council, the data gathered during this planning process should enable them to have accurate data available and will specifically identify and clearly define the roles and responsibilities for other State agencies for deinstitutionalization.

Comments received from State officials indicated that differences of opinion exist within the State concerning the

DD Council's planning role. For example, the Secretary of the Maryland Department of Health and Mental Hygiene, said that the DD Council is not the planning body within the State for the developmentally disabled but is only for advising and assisting in planning. On the other hand, the Council describes its role as providing a central focus for planning and coordinating services and, as previously mentioned, is participating in a planning design test. The Council's bylaws, consistent with Federal regulations, provide that the general functions of the Council are to plan and evaluate programs in the State for the developmentally disabled, and to advise the Governor on matters pertaining to administering the DD program and State programs for the developmentally disabled.

The DD Council's effect on other State agencies has been limited

By using its funds as seed money, the Council intended to encourage the other State agencies to use their funds and to seek additional funds to augment the resources needed to carry out and develop services. As a result of Council action, some specific actions were taken to benefit deinstitutionalization and, according to the Council's executive director, agencies appeared to be making attempts to address the disabled within their own funding constraints and budgetary limitations and were working together to meet identified gaps in services. We found, however, that the Council had limited success in influencing the State agencies who controlled the resources and programs directed to the needs of the developmentally disabled because the Council had neither the authority nor the funds to require their coordination and cooperation. Further, the Council was slow in using its funds to generate additional Federal, State, and local funding.

Since the need for facilities and services far exceeded the DD and MRA funds available, the DD Council served as a broker to secure services for the developmentally disabled from the other State agencies who control the resources and programs directed to such generic needs as residential facilities and income support. The broker function included directing the other State agencies in how to qualify for funding from various Federal agencies such as those supporting social services, transportation, and employment and training. The Council found that the progress made and problems encountered in obtaining coordination and cooperation related to the priority given to deinstitutionalization by the State agencies and the funds they were willing to allocate.

We contacted State agencies responsible for mental retardation, crippled children's services, education, vocational rehabilitation, social and employment services, and comprehensive

health planning to determine what actions they had taken as a result of the DD Council's influence. Three of the agencies had taken no action or were not aware of actions taken as a result of requests by the Council, one agency had not been contacted concerning an identified problem for which it had responsibility, one agency thought coordination was needed at the operating rather than the agency level, and the director of one agency thought that the Council had not met its mandate because it awarded numerous grants of small amounts (an average of \$19,000 per grant in fiscal year 1975) rather than awarding fewer yet larger grants of a more continuing nature.

At the local level, we contacted community development, housing, and human resources officials in one Maryland county to determine what influence the DD Council has had on their planning for the developmentally disabled. Despite identified shortages of community residential facilities, officials said that the DD Council had not contacted the county regarding deinstitutionalization and the related housing needs of the mentally retarded; the county had included only the elderly and minorities, and not the mentally disabled, in its Housing Assistance Plan required by HUD; and the county's full-time position for planning and coordinating special services for the handicapped had been eliminated from the county budget.

Analysis of the Council's progress in awarding DD grants indicated that the Council was slow in generating additional funding. For fiscal year 1972 through fiscal 1975, the Council had awarded 55 grants totaling over \$1 million to 35 different organizations serving the State's developmentally disabled population. However, only 28 grants were awarded for fiscal years 1972 through 1974 and the remaining 27 grants were awarded in fiscal year 1975. In addition, the major portion of the nearly \$557,000 contributed by grantees during fiscal years 1972 through 1975 was not contributed until fiscal year 1975.

Screening and aftercare provided by CMHC's

MHA had no data on the extent to which the federally funded CMHC's in Maryland had screened persons before their admission to State mental hospital centers or provided after-care or followup services to patients released from the centers. Nor did it have data showing whether released persons received the aftercare services identified as needed when they left the centers.

A report on unification efforts involving a federally funded CMHC in Maryland indicated several persons were

needlessly being referred to a State hospital center because they were not being screened or evaluated by the CMHC before their admission. In addition, MHA officials said closer coordination should be required between State hospital centers and CMHC's because (1) many CMHC's had not made diagnoses before referring persons to the centers, (2) individuals may be screened at the State hospital centers without the CMHC's ever becoming involved, and (3) persons released from the centers may not be referred back to CMHC's for followup and aftercare services. The Community Mental Health Centers Amendments of 1975, enacted July 29, 1975, require closer coordination between CMHC's and the State hospital centers.

Problems relating to
Federal funding for CMHC's

Maryland officials cited several problems with the Federal funding of CMHC's which they believe have adversely affected the program.

- Federal cutbacks in program funds earmarked for CMHC's in favor of relying on third party payments, such as Medicaid, Medicare, and insurance, will have an adverse effect on the continuity of care available to mentally ill persons because collections from third party payers may not necessarily be reinvested in mental health care.
- Methods for continued funding for CMHC's as Federal support declines and ends had not been established and may prove to be a difficult problem to overcome unless third party payments increase in the future.
- In fiscal year 1975, only three federally supported CMHC's and three State funded mental health clinics had separate agreements for outpatient services reimbursement under Medicaid. The remaining three federally supported CMHC's and 29 State-funded mental health clinics could be reimbursed for outpatient services if they were considered a component of the county health department and eligible for funds under formula grants. However, no data was available to identify eligible CMHC's or clinics.
- The Federal Government's imposition of requirements on federally funded CMHC's to provide special services for alcoholics and drug addicts without the additional funds needed had reduced the CMHC program's overall effectiveness.

MORE ACCOUNTABILITY
FOR RELEASE PLANNING,
AFTERCARE, AND FOLLOWUP NEEDED

In chapter 3, we noted problems in Maryland with release planning, followup, and aftercare and that responsibilities for these were not always clearly defined. Although the requirements of several federally supported programs address these problems, we found that these requirements were not always met, that intended results were not always being achieved, and that operational improvements could be made in Maryland's implementation of federally supported programs to improve release planning, followup, and aftercare and to more clearly define responsibilities.

Medicaid, Medicare, and social services are examples of the federally supported programs used by Maryland to assist in caring for the mentally disabled which contain requirements affecting release planning, followup, and aftercare. Some of the applicable requirements are discussed in the following paragraphs.

Federal regulations require that post-institutionalization plans be prepared which include provision for appropriate services, protective supervision, and followup for persons in institutions who are supported by Medicaid or Medicare. Service plans and followup were also required for those persons for whom federally supported social services were used to help in the deinstitutionalization process.

In addition, Federal regulations for the Medicaid and social services programs require that the agencies administering these programs develop and implement cooperative arrangements or agreements to insure coordination among the federally supported programs. For example, for persons 65 or older being released from mental hospitals who were covered under Medicaid, State Medicaid agencies are required to have in effect written agreements with the State mental health authority clearly setting forth the responsibilities of the two agencies, including arrangements for joint planning, developing alternate methods of care, and providing post-hospital followup by hospital or mental health agency staff.

In Maryland, only informal cooperative arrangements existed between the Medicaid agency and other State agencies serving the mentally disabled. The arrangements did not address followup for persons who were receiving services outside Medicaid benefits.

State Medicaid officials commented that it had not been thought necessary for written agreements to be effected since

both the State Medicaid agency and MHA are in the same department. HEW Region III concurred initially that informal cooperative arrangements are normal under these circumstances. HEW later concurred that the ineffectiveness, not the informality, of cooperative arrangements was the basis for the point being made. For example, the State Medicaid agency is not responsible for followup, nor does it have the staff to do so. The MHA, however, had not monitored or evaluated followup activities for mentally disabled persons released from institutions.

Although Federal regulations require that post-institutionalization plans include provisions for appropriate services needed after release, our review indicated that, as discussed in chapter 3, the comprehensive needs of patients were not identified during the discharge planning process and that identified needs were not always made known to community providers of service. For the mentally retarded residents we traced to the community, only those needs were addressed for which community services were known to exist. For the mentally ill patients we traced, no formal written referrals were made to community providers of service and the receipt of needed services could not be assured.

In arranging for foster care, social services regulations required a State to (1) assure placement in approved settings suitable to the needs of the person, (2) assure that persons will receive proper care in such placement, and (3) determine the continued appropriateness of such placements, at least annually.

Maryland officials stated Federal social services funds were not being used by public institutions to provide discharge

planning or to help persons return to communities during our review.¹ Such funds were used, however, when county departments of social services assisted in helping persons to return to communities from institutions at the institution's request. The most frequent type of assistance provided by the county social services departments was making arrangements for foster care placements.

As noted in chapter 3, many persons returned to the community and placed under foster care arrangements received Supplemental Security Income. With certain exceptions, SSI regulations do not require that recipients have a treatment plan or be provided with needed services. However, mentally disabled persons who were recipients, applicants, or potential recipients of financial assistance, such as SSI, were also eligible for social services assistance. Therefore, Federal requirements regarding the appropriateness of facilities or services applicable under these circumstances were those under the social services programs, especially requirements pertaining to individual service plans and the appropriateness of foster care arrangements.

In Maryland, two separate foster care systems existed, one administered by institutional social service workers and the other by county departments of social services. Since officials said Maryland was claiming Federal reimbursement only for the county-provided services, Federal requirements

¹In 1973, Maryland submitted a claim to HEW for nearly \$8 million in Federal reimbursement for "social services" provided to the mentally disabled under a purchase of service arrangement between DHMH and DHR. Services for which Maryland claimed Federal reimbursement included inpatient services in State mental hospitals and public institutions for the retarded, services in CMHC's, day care services for the mentally ill and mentally retarded, and foster care services for the retarded. Claims for inpatient mental hospital services included medical and surgical services provided. HEW disallowed these claims for a number of reasons, including its contentions that (1) eligibility was determined on a geographical, not an individual basis, (2) services for which reimbursement was claimed were not covered under the State plan or properly executed purchase of service agreements, and (3) some costs, such as medical and surgical costs, were not allowable as social service costs as claimed. Maryland disagreed with HEW's position, and the issue had not been resolved as of the time we completed our fieldwork.

under the social services programs would apply only to the county departments.

As discussed in chapter 3, however, responsibilities of the institutional and county social services systems had not been clearly defined or understood, there was a lack of cooperation and communication between the county departments and the DHMH-operated institutional departments, and no procedures existed for referral of persons placed in foster care to the appropriate county department. Consequently, there was no assurance that persons placed into foster care by the institutional staff were receiving appropriate services or that the foster care arrangements continued to be appropriate.

INAPPROPRIATE PLACEMENT

As noted in chapter 2, many mentally disabled persons remained in institutions who didn't necessarily need that level of care or had been placed into inappropriate settings or those which did not provide needed services. Our observations on the effect of federally supported programs on these conditions are discussed in the following sections.

Improvements in meeting utilization,¹ independent medical and professional review requirements could assist deinstitutionalization

The Federal Government has recognized the problem of inappropriate institutional and nursing home placements and has imposed several Medicaid requirements on the States. The Federal mechanism established to eliminate inappropriate placements, to identify the need for additional services, and to explore alternate placement is the utilization control process. Federal legislation requires that the States

¹HEW Regional Office III agreed with our statements concerning Maryland's utilization control process. However, utilization review has become an HEW priority and the Regional Office had evaluated Maryland's utilization review plan and has developed a corrective action program. A review of the program and the actions taken by Maryland through November 1975 showed that the deficiencies we identified had been addressed and that Maryland is on schedule for the corrective action plan.

implement a program to control the utilization of services in mental hospitals, skilled nursing facilities, and intermediate care facilities, including institutions for the mentally retarded. Medicaid reimbursements may be decreased by one-third in States where an effective program to control the use of services does not exist.

Of the three types of reviews required, utilization reviews are required in all of the types of facilities cited above. Independent medical reviews are required in mental hospitals and skilled nursing facilities while independent professional reviews are required in intermediate care facilities, including institutions for the retarded.

In addition, for intermediate care facilities, the State Medicaid agency is required to (1) evaluate the availability of community resources, (2) document unavailability if this is the case, and (3) initiate plans for active exploration of alternatives if it is determined that services are required by a person whose needs might be met through the use of alternatives that are currently unavailable.

In Maryland, the medical evaluation of the need for admission and the feasibility of alternative care was being done for persons 65 years and older for whom institutionalization in a mental hospital center had been proposed in only 19 of Maryland's 24 political subdivisions. Medicaid officials said the five counties in which medical evaluations are not being done are small, rural counties in which only 5 to 10 percent of the State's population resides. Efforts are being made to expand these services statewide.

Other areas for improvement identified in Maryland's utilization review procedures were:

--The utilization review procedures included the use of a utilization review checklist for each patient which addressed the necessity for and desirability of admission and continued stay as well as the feasibility of using alternatives. However, if the admission or continued stay resulted from unavailable alternatives, the services that were needed were not specified on the checklist.

--The State Medicaid agency had delegated responsibility for evaluating the various utilization review programs at the mental hospitals and Rosewood to another DHMH agency. The other agency is responsible for the State licensing process and for Medicaid and Medicare certification in State mental and retardation facilities.

Neither agency had taken any actions to explore the use of community alternatives for those persons inappropriately placed. The Medicaid agency had taken no action because community alternatives were known to be unavailable. The other agency initiated enforcement action only when the level of care was determined to be less than acceptable and not when patients were inappropriately placed in institutions

--An independent professional review done at Rosewood from April through August 1975 identified that utilization reviews had not been done for 944 out of 986 patients receiving Medicaid reimbursement.

Independent reviews

Independent medical and professional reviews at the State mental hospitals and Rosewood were identifying persons who did not need that level of care or were not receiving needed services. For example, the most recent independent medical reviews at the State's mental hospitals showed that 59 percent of the patients no longer were in need of psychiatric hospitalization. Also, the most recent independent professional review at Rosewood showed that of 986 residents, 500 were not receiving needed social services, and 645 did not have an individual plan of care. The review team recommended alternative placement for 184 residents (19 percent), some to other State facilities and some to foster homes or nursing care facilities.

The most recent independent professional review at one intermediate care facility where many of the residents were former patients in mental hospitals or institutions for the retarded recommended change in level of care for 30 residents out of 134 reviewed. In addition, the independent professional review team found that the residents of this facility were not receiving needed social and psychiatric services.

We noted that independent review teams did not (1) address the feasibility of using community alternatives for persons inappropriately placed, (2) cite the unavailability of specific community alternatives as reasons for admission or continued stay, or (3) address the adequacy or appropriateness of discharge plans. If recommendations for discharge were made, the Medicaid agency did not followup on the disposition of the recommendations. Many persons identified as inappropriately placed could not be transferred to a more appropriate setting because of the lack of suitable alternatives.

Although several persons had been transferred from State institutions to skilled nursing and intermediate care facilities, independent review teams did not include a mental health or retardation professional to evaluate the appropriateness of the services being rendered by these facilities to meet the special needs of the mentally disabled.

We were told that independent reviews have not been conducted at five of the six State facilities certified in fiscal year 1975 as intermediate care facilities for the mentally retarded.

Officials said that since Maryland's Medicaid agency is in DHMH, and not DHR, Maryland has never been able to implement the social services support required to adequately evaluate the extent to which persons are inappropriately institutionalized or institutionalized because no alternatives exist. The Medicaid agency has not incorporated these issues into its independent medical or professional reviews because budgetary constraints have prohibited it from purchasing services under contract from the Department of Human Resources.

Potential violations of Medicaid restrictions

We visited a facility which was licensed under Medicaid for 150 intermediate care beds. Although not specifically designated as an intermediate care facility for the mentally ill or mentally retarded, a review of patient records indicated that 60 percent of the patients were diagnosed as mentally ill and another 7 percent as mentally retarded. Approximately 81 percent of these residents were former patients of State hospital centers for the mentally ill or retarded or had received inpatient psychiatric treatment in a general hospital. The patients ranged in age from the early 20's to 90 years of age.

According to Medicaid regulations, Federal financial participation under Medicaid is not available for any individual under 65 years of age who is a patient in an institution for mental diseases, except for those persons under 22 in psychiatric hospitals. A facility which primarily cares for the mentally ill would be deemed to be an institution for mental diseases under Medicaid regulations. The facility we visited had 59 mentally ill persons under 65, some of whom may, therefore, not be entitled to Medicaid benefits.

The Medicaid agency commented that this observation reflects a lack of understanding of the admission process to a "non-mental institution" because formerly institutionalized patients are not discriminated against by denying them the right to physical ailments which may necessitate intermediate or skilled nursing care. However, recent Federal guidance states that the character rather than the licensure status of the institution is relevant in determining availability of Federal financial participation. Specifically, institutions "primarily" managing patients with behavior or functional disorders and which are used largely as an alternative care facility for mental hospitals are considered to be "institutions for mental diseases."

Medicaid regulations require that intermediate care facilities only accept those persons whose needs it can meet, either directly or in cooperation with other providers of care. Eleven mentally retarded persons appear to be inappropriately placed into this general intermediate care facility because services were not available to meet their needs. These placements may therefore violate Medicaid regulations and could jeopardize the facility's certification.

OTHER CONDITIONS RELATED TO FEDERAL PROGRAMS

In addition to the need for more accountability for release planning, aftercare, and followup, and the problem of inappropriate placement, opportunities exist for Maryland to use Federal program resources to enhance their deinstitutionalization efforts. For example, developing alternatives to institutional care through Medicaid funding, and improving cooperation and coordination in implementing Federal programs could increase the effectiveness of the use of Federal funds. Some problems we identified, however, relate to Federal requirements or State budget restrictions which may impede the State's efforts to maximize use of Federal resources.

State expenditures will be required for Maryland to retain certification under Federal programs for its major institutions for the mentally disabled. The MHA requested \$3 million for fiscal year 1976 for three regional hospital centers to meet newly developed higher standards by the Joint Commission on Accreditation of Hospitals and HEW's raised standards and tightened compliance procedures for certification under Medicare and Medicaid. Estimates of Federal funds which could be lost if the three hospitals were decertified ranged from \$6.2 to \$20 million. For the State to obtain accreditation for its six regional residential centers

for the mentally retarded between 1977 and 1981, it is estimated that over \$9 million would be needed for operating expenses and over \$25 million would be needed for construction.

The following sections discuss the effect of Medicaid, social services, Supplemental Security Income, vocational rehabilitation, Department of Labor regulations, and housing and urban development programs on Maryland's deinstitutionalization efforts.

Coverage of the mentally disabled under Maryland's Medicaid program

Some aspects of Maryland's Medicaid program do tend to discourage institutionalization of the mentally disabled and encourage their greater reliance on outpatient and community care. Despite some efforts to discourage institutionalization, however, Maryland's Medicaid agency has imposed restrictions on services available to persons who are mentally disabled and does not make maximum use of some optional services which would have assisted in the State's deinstitutionalization efforts.

Day care

States can currently fund day care under Medicaid in mental health clinics provided the services are given by or under a physician's supervision. Maryland's Medicaid program did not include day care services directed specifically to the mentally disabled and only covered day care services for the aged at one location. According to the Medicaid agency and MHA officials, Maryland's Medicaid program did not cover day care services because State matching funds were not available. The MHA officials believed, however, that the development of a statewide system of health-related day care programs was a necessity if the State's deinstitutionalization efforts were to be successful.

Small intermediate care facilities

Intermediate care facilities for the mentally ill were limited to two State hospital centers. No private facilities were engaged in the total concept of intermediate care for the mentally ill, although some patients were placed in general skilled nursing and intermediate care facilities directly from the mental hospital centers. However, comprehensive data on the extent of these placements or the services received by these persons was not available.

Many community-based general intermediate care facilities of more than 4, but less than 20 beds, had been developed in Maryland. However, because of the stringency of the new intermediate care facilities standards published by the Department of Health, Education, and Welfare in January 1974 many of these facilities have been forced out of existence and the few that remain may, according to the State, soon disappear because of the additional expenditures required to meet the new requirements and the limitations on reimbursement rates the State imposes.

Similarly, small community-based intermediate care facilities of 15 beds or less for the retarded that are provided for in HEW's January 1974 regulations have generally not been developed in Maryland even though Federal Medicaid funds will cover part of the costs of such facilities. The Superintendent of one of Maryland's regional centers for the retarded said he believed the requirements for these small intermediate care facilities were too medically oriented and too stringent and would not provide a normal living environment.

Comprehensive mental health program

States providing inpatient mental hospital care to persons 65 or older under Medicaid must have agreements among agencies for (1) the development and implementation of a comprehensive mental health program for all age groups and (2) joint planning for this purpose. Such States are also required to submit annual progress reports to HEW. In Maryland, cooperative arrangements had not been developed and annual progress reports were not being submitted to HEW.

The Medicaid agency commented that formal agreements have not been necessary because of the communication routes available. The agency indicated that MHA would be approached about the possibility of submitting annual reports to HEW. In discussion with MHA, we found they were unaware of the views of the Medicaid agency concerning the matters discussed in this report.

Supplemental Security Income (SSI) and social services

In Maryland, foster care placements of mentally disabled persons were frequently made using SSI payments for income maintenance. Persons receiving SSI support are eligible for social services under the Social Security Act which in Maryland are provided primarily by the county departments of social services.

Although Maryland's social services program provides a variety of services to the mentally disabled who meet eligibility requirements, the State had no data on the number of mentally retarded or ill persons served or the portion of the budget they represented. Due to the lack of State matching funds, Maryland did not expend all available Federal funds for social services under the Social Security Act in either fiscal year 1973 or 1974. Since no data was available on the mentally disabled served, social services officials were unable to assess the effect of the restricted spending on the State's deinstitutionalization efforts.

An important objective of the SSI program is to improve systems of information, referral, and followup in the States. The intent is that States will be able to concentrate on social and rehabilitative services rather than cash assistance. Maryland officials, in coordination with a Social Security Administration (SSA) representative, developed a referral form and related procedures to be used within the State for making social services referrals. We found, however, that many of the SSA branch offices were not using the formalized referral forms required for SSI recipients and that those making referrals were not doing appropriate followup. Baltimore City's social services department had not received instructions concerning the referral procedures and was not returning the forms as required to the SSA branch office.

During our review we identified the following additional problems with the SSI program which hindered placing or maintaining low income mentally disabled persons in the community:

- Both social services and mental health officials said the lack of a provision within the SSI program for extra payments to meet emergency needs represented a gap in service.
- Delayed SSI disability determinations and lengthy periods required to receive initial SSI checks have caused some patients to remain institutionalized and others to return to the institution when SSI payments were not received. Although Maryland had been assured by SSA that under their prerelease procedures the SSI waiting period would not exceed 30 days, months were sometimes required for initial SSI payments to be received.

--Support and maintenance reimbursements made by Maryland to nonprofit residential facilities, such as group homes for the retarded, were treated as unearned income for group home residents making them ineligible for SSI. Public Law 93-484 excludes as unearned income the value of support and maintenance furnished by nonprofit, nonmedical institutions and private, nonprofit sources, but deems as income to the individual the value of support and maintenance provided by a governmental source.

Vocational rehabilitation

The Rehabilitation Act of 1973, which requires vocational rehabilitation agencies to serve first those with the most severe handicaps, has had minimal impact on serving the severely retarded in Maryland. This occurred because the scale of retardation for the provision of vocational rehabilitation services in Maryland is one standard deviation higher than the scale recognized by the American Association for Mental Deficiency. Using Maryland's scale, a service gap existed for the severely retarded with IQ's ranging between 25 and 39, who should be served first according to the intent of the act.

For example, in fiscal year 1974, 330 Rosewood residents classified as severely retarded by the Association were prohibited from receiving vocational rehabilitation services because Maryland's Division of Vocational Rehabilitation classified them as profoundly retarded. A Maryland official said Federal guidelines allow the States to establish the definition of retardation for determining eligibility for vocational rehabilitation services and that most States interpret the Federal guidelines using the same scale that Maryland uses.

Wage requirement having detrimental effect

The requirement that wages be paid to institutional workers (29 C.F.R. Part 529) under the Fair Labor Standards Act is having a detrimental effect on the Division of Vocational Rehabilitation's institutional programs. Most of the Division's vocational training programs involve work experience such as custodial and food service training which would require that payments to clients be made unless the training programs are changed to use only an academic approach. The Division's programs are being curtailed to include only 1 hour of supervised instruction a day

A Maryland official stated that unless vocational rehabilitation training programs were exempt from the wage and hour regulations approximately 1,600 to 2,000 persons classified as severely disabled will not obtain adequate vocational training. Maryland would not be able to meet the goals set by the Congress in the Rehabilitation Act of 1973 unless their institutional vocational rehabilitation programs continued to involve work experience. Further, if payment of wages is required, some training programs would terminate because no funds are available.

Department of Labor Region III commented that the regulations provide enough flexibility "to preclude any serious economic impact on the regulated institutions." For example, any institution can establish an evaluation and training program under which commensurate pay is required, but such pay could be as little as 5¢ per hour. Authorization for payment of subminimum wages to patient workers in institutions is also available under provisions for group minimum wage, individual exception, and work activities center. Four Maryland centers for the mentally disabled have already obtained authorization to pay subminimum wages, and, in one instance, the center is authorized to pay subminimum wages under the four types of certificates which are available.

Employment

Section 503 of the Rehabilitation Act of 1973 (29 U.S.C. 793) requires every Federal Government contractor with a contract over \$2,500 for the procurement of personal property and nonpersonal services, including construction, to take affirmative action to employ the handicapped. Maryland's Employment Security Administration had not assisted in enforcing section 503 because mandatory job listing data was required only for veterans for contracts exceeding \$10,000, and because veterans receive first employment priority.

Potential HUD funding

We were told that in Maryland HUD funds have never been used for constructing group homes for the retarded and no programs exist for the mentally ill who cannot live independently. Initiative for programs directed to the mentally disabled would have to come from the appropriate State Agency (MHA or MRA), communities, or interested groups.

Because housing for the mentally ill and the elderly in Maryland is not available, the MHA identified community residential-care homes as its primary program need for fiscal year 1976. Maryland considered a housing concept implemented in Ohio where a certain portion of available federally assisted housing units were allocated for community facilities to serve deinstitutionalized patients. Maryland officials considered the concept to be unworkable, however, and it was not implemented.

CHAPTER 5
MORE EMPHASIS ON
DEINSTITUTIONALIZATION BY
REGION III AGENCIES NEEDED

Even though presidential and congressional concerns have been expressed about reducing institutional populations, Region III agencies had not developed a comprehensive, systematic, and clearly defined plan to assist Region III States in their deinstitutionalization efforts. Region III agencies had not made concerted efforts to focus their resources or coordinate their efforts to accomplish the deinstitutionalization goal.

Two HFW programs (Community Mental Health Centers and Developmental Disabilities) administered by Region III directly address deinstitutionalization. These programs have helped, but they had not been totally effective, had not had the effect that they were expected to have, and did not have all the resources or coverage needed to achieve their goal.

It appears that Region III agencies have approached deinstitutionalization by relying on the myriad of social, welfare, and other programs that affect general population target groups (the poor, the aged, children, or the disabled) to address and accomplish this goal individually, without any central guidance, management, coordination, or focus on deinstitutionalization.

FEDERAL REGIONAL COUNCIL

Although the Federal Regional Council mission includes coordinating direct Federal program assistance to State and local governments, and deinstitutionalization efforts are assisted by various Federal programs, the Mid-Atlantic (Region III) Federal Regional Council had not addressed deinstitutionalization. Reasons for not addressing deinstitutionalization included (1) the lack of headquarters instructions regarding deinstitutionalization from the Department of Health, Education, and Welfare, the Office of Management and Budget; or the Under Secretaries Group; (2) no mandated objective specifically directing the Council to address deinstitutionalization; and (3) the belief that deinstitutionalization is predominately an HEW concern. We were told that headquarters instructions tend to focus Council activity on more general intergovernmental management and planning concerns than the topic of deinstitutionalization. In contrast, the Department of Housing and Urban Development has suggested that to increase its responsiveness to the needs of the elderly and

handicapped, HUD may best enlist the aid of other Federal agencies through Federal Regional Council activities.

HEW

HEW Region III had not developed a comprehensive, coordinated, consistent, or systematic approach to deinstitutionalization and, with a few exceptions, had not devoted much effort to implement the national deinstitutionalization goal. Agency-wide plans, goals, or objectives to accomplish deinstitutionalization had not been formulated or established. Further, guidance or instructions identifying specific steps to be taken by and roles and responsibilities of component agencies had not been issued.

We interviewed or obtained written responses from HEW Region III officials concerning the emphasis, coordination, monitoring, evaluation, and enforcement directed to deinstitutionalization. Our inquiries were made to officials representing the Office of the Regional Director, the Office for Human Development, the Public Health Service (PHS), the Social and Rehabilitation Service (SRS), Social Security Administration, and the Office of Education.

Emphasis

HEW Region III officials said they had not established objectives, instructions, or priorities for deinstitutionalization. Regional agencies were not emphasizing deinstitutionalization because they had not received directives or objectives from HEW headquarters to do so. According to regional officials, deinstitutionalization had not been established as a priority issue within HEW.

The HEW Regional Director had no offices within his immediate jurisdiction with direct operational responsibility for administering programs for deinstitutionalization. He had not proposed a specific deinstitutionalization Operational Planning System Objective for Regional III until late fiscal year 1975, and as of April 1975, PHS headquarters had not made a decision on the proposed objective.

The Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Branch had established no additional objectives for deinstitutionalization beyond those in existing mental health programs. Officials expressed concern that inadequate resources (e.g., CMHC funding and regional staffing) existed to fulfill present guidelines by HEW headquarters without adding new plans to assist the States with their deinstitutionalization efforts. In fact, successive reorganizations within PHS Region III had resulted in the provision of only limited

technical assistance and cooperation to Maryland's Mental Hygiene Administration.

For the most part, activities specifically addressing deinstitutionalization had been undertaken only by the ADAMHA Branch and the DD program. Other regional agencies had generally not undertaken deinstitutionalization activities, and those undertaken had been limited to research and demonstration or other special projects

All program activities of the ADAMHA Branch were directed to moving people out of institutions or preventing institutionalization. In addition to administering the CMHC staffing and construction program, and other mental health programs, the Branch administered a State program development project in one Region III State. This project is a cooperative Federal-State mechanism to assist States in strengthening their alcohol, drug abuse, and mental health programs.

According to a Region III official, all DD services and resources have been directed to the deinstitutionalization goal. For example, in February 1975, the DD program sponsored a training program during which participating Region III States discussed their projects and studies directed to achieving deinstitutionalization. Despite the DD program's emphasis on deinstitutionalization, Region III had not developed a formal policy statement on deinstitutionalization setting forth goals, responsibilities, resource commitments, and accountability.

Limited efforts by other regional agencies included the implementation of prerelease procedures for potential Supplemental Security Income recipients in public institutions and an SRS research and demonstration project. The research project was to establish a procedure for transferring residents of institutions for the mentally ill, retarded, and the juvenile offender to the community.

Coordination

Only minimal coordinating efforts for deinstitutionalization had taken place in Region III. In accord with actions taken at headquarters, most regional coordinating efforts had been directed to the aging. In contrast, no working agreements, implementing guidelines or cooperative planning efforts had been formalized at Region III to address deinstitutionalization. Coordinating mechanisms intended to focus on the handicapped, including the mentally disabled, had little effect on coordinating or influencing other agencies to focus on the deinstitutionalization goal.

DD had taken little action to coordinate or influence other agencies to focus on deinstitutionalization. For example, a regional official said vocational rehabilitation personnel had taken no specific action as a result of requests from the regional DD specialist. We were also told limited working relationships exist with HUD and Department of Labor at the regional level.

Although PHS personnel had worked with other regional agencies, not much coordination was done to benefit deinstitutionalization. They had difficulty gaining the cooperation of other agencies to expand reimbursement to CMHC's.

Each regional office was directed to designate a person to represent the Office for Handicapped Individuals in the region. This person was to be the focal point for the handicapped. The Region III representative had not, however, directed or coordinated regional activities for deinstitutionalization, or even the handicapped, because he had not been instructed or provided guidance clearly setting forth his authority and responsibility.

Monitoring, evaluation, and enforcement

As discussed in chapter 4, several Federal programs contain requirements which, if implemented, could assist in the deinstitutionalization process. For example, utilization control was established to eliminate inappropriate placements, to identify the need for additional services and to explore alternate placement. Other Federal requirements exist for the development of (1) cooperative agreements among State agencies, (2) community alternatives and community care mental health programs, and (3) postinstitutionalization plans which include provision for appropriate services and followup. As previously discussed, programs administered by PHS Region III as well as the DD program devote all of their resources to deinstitutionalization. Other programs administered by regional agencies which serve general population groups, such as the poor, the aged, or the disabled, also affect the deinstitutionalization process.

HEW Region III had done little or no monitoring or evaluation of the requirements affecting deinstitutionalization and inappropriate placement, and comprehensive systematic data on the whereabouts of released persons was not available. We were told that regional personnel had not evaluated State compliance with Medicaid requirements directed at using community alternatives and had not required compliance with requirements to develop cooperative agreements and comprehensive community care programs. In some instances, no action

had been taken to enforce regulations affecting deinstitutionalization, or officials were unaware of existing requirements. Regional agencies had not monitored their programs' effect on deinstitutionalization or the effect of revised program direction or procedures.

Neither PHS nor the DD program at Region III had information on the reduction of institutional populations, the whereabouts, or the quality of care being received by released persons. Due to staff limitations, PHS was unable to make the site visits necessary for providing Federal advice or monitoring to States in the implementation of their mental health programs.

Region III officials said they did a validation survey in 1974 to determine whether utilization controls were being implemented but that no special emphasis was given to the mentally disabled. At least one institution for the mentally disabled, however, was surveyed in each Region III State. They said that independent reviews have only determined whether an individual was receiving the appropriate level of care and have not addressed the feasibility of using community alternatives. They said, however, that if inappropriate placements were identified, independent review teams may have made referrals to appropriate State or local agencies.

Neither Medicaid, the Office of Long Term Care Standards Enforcement, nor a special SRS review group at Region III had evaluated discharge planning at State institutions for the mentally disabled. Medicaid officials said they had not evaluated discharge planning nor determined whether utilization and independent reviews were made of such planning because HEW headquarters had not directed the region to do so. Medicaid officials also said they had not evaluated followup and aftercare provisions for persons released from mental hospitals (persons 65 or over or under 21) or institutions for the retarded.

Regional Medicaid officials had taken no action to enforce the requirements of an instruction (p. 47) which limits the transfers of mentally retarded persons to facilities which cannot adequately care for them. The DD representative was not aware of the instruction and was not aware of placement problems in Region III States.

Regional Medicaid officials were not aware of the Medicaid regulation prohibiting placement of mentally ill persons under 65 in facilities other than mental hospitals considered institutions for mental diseases and therefore were not monitoring or enforcing this requirement. As discussed in chapter 4 (p. 46), it appears that mentally ill persons under 65 in one

Maryland facility may not be entitled to Medicaid benefits

Regional SSI officials had not monitored the implementation of prerelease procedures for potential SSI recipients in public institutions. SSI officials had no information concerning SSI recipients discharged from institutions and no data to indicate to what extent mentally disabled persons had taken advantage of prerelease procedures. Further, they had no information on the number or percentage of mentally disabled persons refused services by vocational rehabilitation and no data to identify the effect of SSI on deinstitutionalization.

Regional vocational rehabilitation personnel had not evaluated the impact on deinstitutionalization of emphasizing the severely disabled. Reported data summarizing the number of severely disabled clients in caseloads of State vocational rehabilitation agencies, first and second quarters of fiscal year 1975, included no separate data for mentally disabled clients. Impressive gains cited by rehabilitation agencies regarding the increase in the number and percentage of rehabilitations classified as mentally ill have only recently been analyzed to reveal that the increase occurred primarily in a category which included less severe handicaps, no rehabilitative gains had been made for nearly a decade in those categories of the mentally ill classified as severely handicapped.

Regional social services personnel had not monitored or evaluated the effect of social services on deinstitutionalization. Factors contributing to lack of monitoring were: (1) no guidelines were established by headquarters for evaluating services provided to enable persons to remain in or return to their homes or communities, (2) minimal reporting was required (reporting of services related to deinstitutionalization was required in only one instance), and (3) annual State plans had not been required making it difficult to evaluate a State's efforts toward deinstitutionalization.

Conditions appearing inconsistent
with deinstitutionalization

Regional agencies identified HEW program conditions which appeared to be inconsistent with the deinstitutionalization goal:

- Lack of a clear reimbursement policy within HEW regarding ADAMHA projects provided a barrier to community mental health projects. HEW has encouraged Federal health programs to maximize receipt of third-party payments (Medicaid, Medicare, and

social services programs administered by SRS and SSA yield a substantial percentage of these funds). At the same time, SRS and SSA have had the goal to control program costs. Due to HEW policies designed to minimize financial outlays, ADAMHA projects were encountering difficulties in obtaining reimbursements in some States. For example, some State Medicaid agencies refused to reimburse ADAMHA projects, difficulties existed in gaining both Medicaid and Medicare certification for free-standing CMHC's; and some private insurance carriers were beginning to follow Medicaid's example by limiting reimbursement for services provided by ADAMHA.

--Region III identified obstacles to cooperative support of programs for older poor Americans in the legislation for title XX of the Social Security Act (a continuation and adaptation of federally supported social services programs under titles IV and VI) and titles III and VII of the Older Americans Act. For example, the Older Americans Act prohibits individual eligibility determination while title XX mandates individual eligibility determination. Other obstacles included disincentives to pooling of resources and to the most efficient method of administering resources at the State and local level.

Positive agency actions

As discussed in chapter 4, HEW Region III evaluated Maryland's utilization review plan and has developed a corrective action program. A review of the program and the actions taken by Maryland through November 1975 showed that the deficiencies we identified had been addressed and that Maryland is on schedule for the corrective action plan.

HEW Region III has developed a proposal to evaluate Pennsylvania's domiciliary care pilot program. If approved, the project should provide feedback on methods of improving the personal care of clients and model legislative regulations which other States may adopt in their development of licensing requirements.

HUD

The President's November 1971 statement on mental retardation directed HUD to assist in developing special housing arrangements to facilitate independent living arrangements for retarded persons in the community. In October 1974, the President stated that primarily through its housing agencies, the Federal Government will help retarded adults

obtain suitable homes.

HUD Region III specialists for the elderly and handicapped said they had not taken action to implement this directive because they had not received headquarters instructions to do so. In HUD Region III, proposals for housing for the mentally retarded had not been solicited, nor had procedures been established to assure that the mentally disabled were identified for inclusion in HUD programs. No guidelines had been provided to area offices, and no publicity efforts had been organized. Officials said HUD funds had never been used for constructing group homes in Region III. Since there were no State housing efforts directed to deinstitutionalization, HUD Region III had not monitored or evaluated the effect of its programs on the deinstitutionalization process.

Although two of the three Region III specialists for the elderly and handicapped had attended a seminar which identified the President's 1971 statement on mental retardation, they said no instructions to implement the statement were ever received. One specialist stated that all special efforts since 1972 had been directed toward the elderly.

HUD Region III had not undertaken joint efforts with other agencies to assist in deinstitutionalization. One HUD specialist for the elderly and handicapped was unaware of possible relationships between HUD area offices and federally funded CMHC's and said he had no dealings with HEW concerning the provision of housing for the mentally disabled. Although HUD had entered into agreements with other agencies for aggressive action to assist the elderly, and, in some cases, the handicapped, no agreements were directed specifically to the mentally disabled.

One official said although Section 232 of the United States Housing Act authorizes mortgage insurance for skilled nursing homes and intermediate care facilities, HUD has no statutory authority to provide additional financial assistance such as interest reduction payments, low interest mortgages, or rent supplements. Supplemental financial assistance and the supervision and services required in skilled nursing facilities and intermediate care facilities must be provided by other Federal or State agencies because HUD is neither equipped nor authorized to develop, manage, or provide services in such specialized residences. According to the regional official, the coordination between HUD and the other Federal agencies required to adequately implement such a joint program does not exist.

To qualify for funding under the Housing and Community Development Act of 1974, community public housing agencies are required to submit a plan including an assessment of community housing needs for lower-income persons including the handicapped. HUD Region III officials stated that housing for the mentally disabled is not a required category in developing plans and HUD guidelines do not identify the mentally disabled as a segment of the total group of lower-income persons in the community whose needs must be considered. The plans submitted to date by community public housing agencies had assessed only the needs of the physically handicapped and had not addressed the needs of the mentally disabled. The regional specialists stressed that responsibility lies with the States and units of local government to take initiative in developing plans and programs for the mentally disabled.

HUD Region III officials believed that two additional considerations exist in supplying housing to the mentally disabled

--HUD officials stated that even if the special needs of the mentally disabled were addressed, HUD is not committed to funding all of the housing needs identified in the housing plans. They believed the criteria used to evaluate applications would seriously limit participation of the mentally disabled in HUD supported programs. HUD officials believed that the most effective, local means of assuring housing for deinstitutionalized mentally disabled persons is to include local housing authorities as part of the referral system with specific, carefully selected units set aside for deinstitutionalization.

--Although HUD has programs for the physically handicapped who require special architectural features to assist them in living independently, HUD cannot fund supportive social services. The HUD officials believed that the mentally disabled who frequently need supportive services were not as suitable for conventional HUD assisted housing as the physically handicapped who could usually live independently with the removal of architectural barriers.

The HUD Region III officials believed that without a more substantive mandate from the Congress, the President, or the Office of Management and Budget setting forth

specific steps to be taken and revisions in enabling legislation allocating specific resources for the mentally disabled, no HUD-assisted housing programs will be available to assist in deinstitutionalization.

Findings related to HUD will be included in a separate report to the Congress and any recommendations will be directed to the Secretary, HUD.

DOL

As discussed in chapter 4, section 503 of the Rehabilitation Act of 1973 (29 U.S.C. 793) requires government contractors whose contracts exceed \$2,500 for the procurement of personal property and nonpersonal services to take affirmative action to employ and advance qualified handicapped individuals. The DOL regional official responsible for implementing section 503 said full implementation of this section had generally been delayed. He said no contract monitoring under the law has been done for any handicapped group, and nothing specific had been done for the mentally disabled. Emphasis has been placed on dealing with individual complaints and informing Federal contractors and advocacy groups of their obligations and rights under the law.

Findings related to DOL will be included in a separate report to the Congress and any recommendations will be directed to the Secretary, DOL.

RECOMMENDATIONS TO THE REGIONAL DIRECTOR, HEW

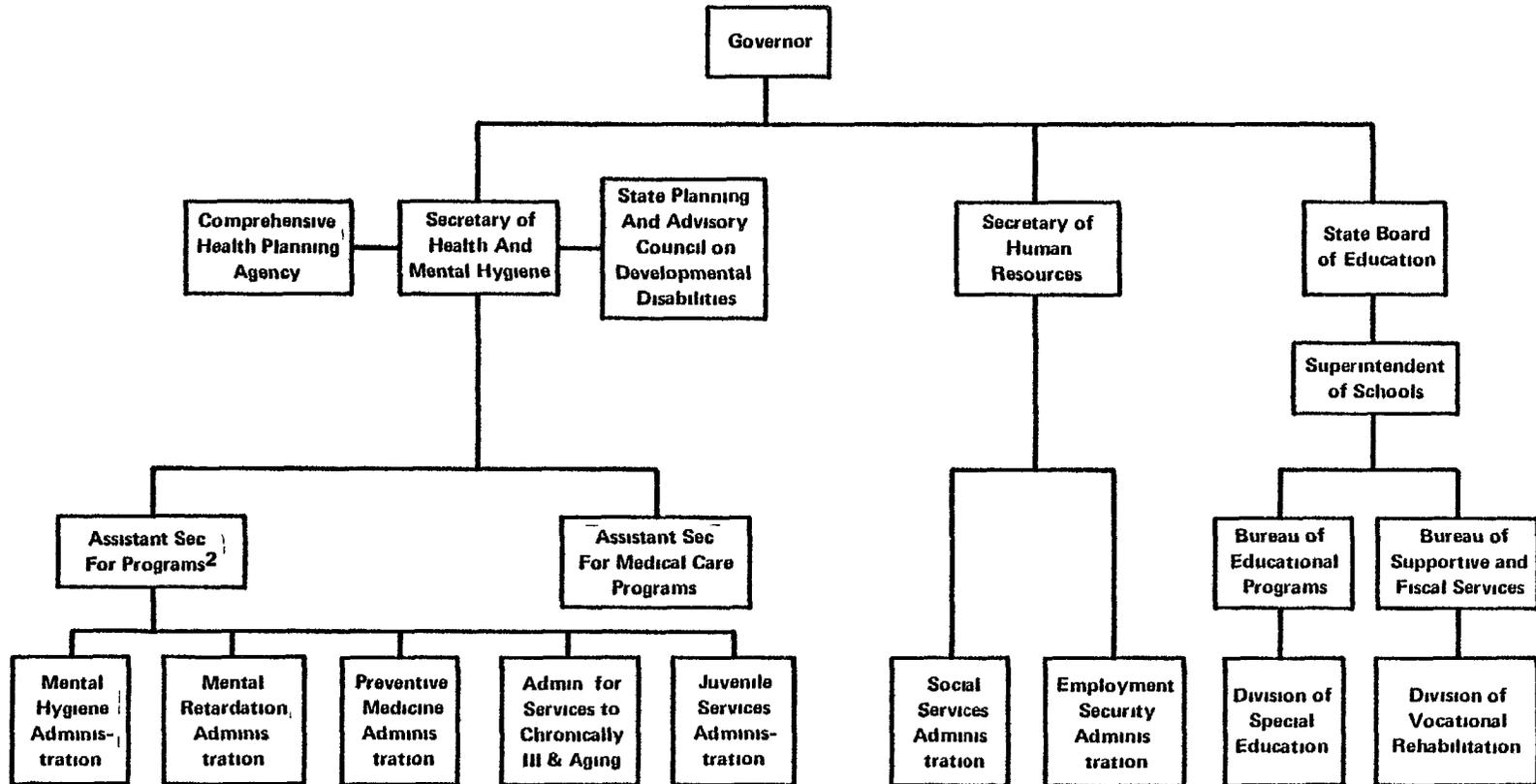
Our review in HEW Region III was directed to assessing, within the framework of current Federal programs, the adequacy of actions taken by regional HEW agencies to assist the States in their deinstitutionalization efforts. As discussed, we believe that HEW Region III has not provided central guidance or management to the States to assist them with deinstitutionalization.

In view of the Federal legislative intent to assist in deinstitutionalization (e.g., CMHC, DD, and social services programs under title XX of the Social Security Act), the extent of Federal social and welfare programs serving general population groups which may include those who are mentally disabled, and the expressed preference of some Region III States to reduce their institutional populations, we believe that actions can be taken within existing programs to provide improved direction and coordination to the States in providing services to the mentally disabled. We recommend that the Regional Director, HEW:

- Establish within the regional office a focal point to assess and strengthen regional policy, strategy, and operational guidance as they affect deinstitutionalization.
- In the absence of specific initiative from the Office of Management and Budget or the Under Secretaries Group, request that the Mid-Atlantic Federal Regional Council assist in coordinating Federal program assistance for deinstitutionalization provided to State and local governments.
- Assess the Federal, State, and local program activities serving or which could potentially serve the mentally disabled and make recommendations for needed change to HEW headquarters.
- Develop cooperative planning efforts with HUD Region III to use for the mentally disabled the resources available under the Housing and Community Development Act of 1974.
- Assist State agencies to clarify and coordinate the followup responsibilities of mental health departments and social services departments for mentally disabled persons released from State institutions. (See p. 14.)
- Monitor the requirements of programs which affect deinstitutionalization, specifically, (1) utilization control requirements established to eliminate inappropriate placements, identify the need for additional services, and to explore alternate placement; and (2) requirements for the development of cooperative agreements, community alternatives and community mental health programs, and postinstitutionalization plans including provision for appropriate services and followup.
- Monitor the use in SSA branch offices of the formalized referral forms required for SSI recipients and the followup being performed. (See p. 50.)
- Clarify the planning role of the DD Council in States, such as Maryland, where differences of opinion exist concerning the responsibilities of the State's mental retardation agency and the federally established Council. (See p. 36.)

--Monitor State vocational rehabilitation programs to assure that the severely mentally disabled are being served and to assure that vocational rehabilitation programs are assisting deinstitutionalization

MARYLAND'S PRIMARY STATE AGENCIES INVOLVED IN DEINSTITUTIONALIZATION¹



66

¹ Chart does not represent complete departmental structure but only shows the State organizations primarily involved in deinstitutionalization

² Subsequent to our review a DHMH reorganization distributed the responsibilities of the Assistant Secretary of Programs among an Assistant Secretary for Mental Health and Addictions (Mental Hygiene Drug Abuse Alcoholism) an Assistant Secretary for Health (Preventive Medicine Aged and Chronically III and two additional administrations) and an Assistant Secretary for Special Programs (Juvenile Services Mental Retardation and a new Developmental Disabilities Administration)

SCOPE OF TRACING
MENTALLY DISABLED PATIENTS FROM
CROWNSVILLE HOSPITAL AND ROSEWOOD
CENTERS TO COMMUNITY PROVIDERS
OF SERVICE

PURPOSE AND RESULTS

To determine the release planning, referral, and followup procedures employed when individuals were released from Crownsville Hospital and Rosewood Centers to community providers of service and whether recommended aftercare was provided. The results of our tracing effort are incorporated in the body of the report

QUALIFICATIONS ON RESULTS

- Quality of care and appropriateness of prescribed services were not included as a review objective.
- Individuals whose primary diagnosis were alcoholism or drug abuse and the elderly were excluded from the tracing sample.
- Individuals were traced primarily to Baltimore City and three counties--one urban and two rural.

EXTENT OF COMMUNITY CONTACTS

During our tracing efforts, we made contacts with various local officials and community providers of services. These contacts included the county health officers and public health nurses; department of social services directors, special education officials; officials of nursing and group homes, halfway houses, and facilities certified for intermediate and domiciliary care; and local advocacy groups.

CROWNSVILLE HOSPITAL CENTER

Crownsville Hospital Center, one of four regional mental hospital centers in Maryland, was selected for tracing mentally ill individuals because:

- It served both urban and rural counties as well as a portion of Baltimore City.
- Patient census as of June 1974 was about 800 compared to 400, 1,500, and 1,900 for the other three centers.

--Admissions during fiscal year 1974 totaled approximately 3,800 compared to 800, 3,000 and 4,000

--The staff/patient ratio for fiscal year 1975 was about 1.25/1 compared to .75/1, .85/1, and 1.50/1.

--A Federally-funded Hospital improvement Project grant--PEPP (see p. 8)--documents the details of evaluation, treatment, release planning, and followup for each individual patient in some of the hospital units.

Access to patient records was not provided by Maryland. The State attorney general's office approved access only to the patient's name, location to which he was released, to whom he was referred, and the services needed. Since access to patient records was denied, we were unable to determine for the patients traced the reason for admission and/or readmission, diagnosis, and Federal assistance provided after release from the institution.

Scope of tracing

Patients at Crownsville are released from five geographical and four specialized units. The Anne Arundel County Unit, which serves an urban population, was selected for our tracing because it uses the PEPP and Crownsville officials believed it to be representative of most geographic units in the hospital. We selected additional patients from a Tri-county unit which serves three rural counties geographically removed from Crownsville. A limited sample of 17 adolescents (15 from Anne Arundel and 2 from one of the rural counties) released during the 1973-74 school year was also selected to determine whether they were readmitted to their respective school systems after release.

The tracing sample consisted of the sample of 17 adolescents and all patients, 109 in total, released from both the Anne Arundel and Tri-county units during the 2-month period of July and August 1974. Since the tri-county unit was not included in the PEPP system, we relied on Crownsville employees to obtain aftercare information from patient records

Based on the PEPP data and discussions with Crownsville personnel, the original tracing sample was reduced from 126 patients to 75 because some patients were released with no recommended aftercare facility and/or service, some were released to counties not selected for tracing, or for other reasons.

ROSEWOOD CENTER

Rosewood Center is the primary public institution for the mentally retarded in Maryland. Rosewood's residency was about 1,800 as of April 1, 1975, compared to planned residencies ranging from 71 to 470 for the 6 other State residential facilities for the retarded. In fiscal year 1975, funding for Rosewood comprised 48.2 percent of MRA's operating budget.

Initial tracing information was obtained from the individual resident medical records and discharge summaries. Followup information was obtained through Rosewood social workers and community providers of service. This information was obtained primarily through interviews and was not otherwise verified.

Scope of tracing

During the first quarter of fiscal year 1975, 89 residents were either discharged or placed in the community by Rosewood. From this sample we selected 50 individuals to trace--22 released to Maryland community providers of service and 28 from other types of releases (self care, foster care, elopement, and to families).

We traced the 22 residents released to community providers of service to the facility referred. Residents released to families, self care, and foster care parents and those who eloped were traced through information provided by Rosewood social workers.

MENTAL HYGIENE ADMINISTRATION BUDGET
STATE FUNDS ONLY

	<u>1973</u>	<u>Percent</u>	<u>1974</u>	<u>Percent</u>	<u>1975</u>	<u>Percent</u>	<u>1976</u>	<u>Percent</u>
	(000 omitted)							
<u>Program</u>								
Headquarters	\$ 1,347	2	\$ 876	1	\$ 1,040	1	\$ 1,095	1
Institutional Programs	50,396	83	53,960	83	56,898	82	60,567	80
Community Mental Health and Alcoholism Services	<u>9,139</u>	<u>15</u>	<u>10,225</u>	<u>16</u>	<u>11,604</u>	<u>17</u>	<u>14,857</u>	<u>19</u>
TOTAL	<u>\$60,882</u>	<u>100</u>	<u>\$65,061</u>	<u>100</u>	<u>\$69,542</u>	<u>100</u>	<u>\$76,519</u>	<u>100</u>

MENTAL RETARDATION ADMINISTRATION BUDGET
STATE AND LOCAL FUNDS ONLY

<u>Program</u>	<u>Fiscal Years</u>					
	<u>1970</u>	<u>Percent</u>	<u>1975</u>	<u>Percent</u>	<u>1976</u>	<u>Percent</u>
	(000 omitted)					
Headquarters	\$ -0-	-0-	\$ 256	1	\$ 351	1
Institutional Programs	14,729	100	29,216	80	32,473	79
Community Services	<u>-0-</u>	<u>-0-</u>	<u>6,793</u>	<u>19</u>	<u>8,073</u>	<u>20</u>
TOTAL	<u>\$14,729</u>	<u>100</u>	<u>\$36,265</u>	<u>100</u>	<u>\$40,897</u>	<u>100</u>

FEDERAL FUNDING FOR THE MENTALLY DISABLED IN MARYLAND

<u>Federal program</u>	<u>FY 1974 funds</u> (000 omitted)	<u>Remarks</u>
Medicaid	\$ 8,413	These funds were expended in support of institutionalized mentally disabled persons Information on Medicaid reimbursements for clinic services directed to the mentally disabled was not available
Medicare	2,905	Expended in support of mentally disabled
Social service contract	2,043	Mentally retarded adult and child day care programs Other social services programs provided a variety of services to mentally disabled adults and children, but no data was available on the number served or the portion of the budget represented
Community Mental Health Centers	1,627	Expended to provide community-based mental health services
Public Health Service Act (Section 314(d))	237	Expended to provide community-based services Partial support of geriatric evaluation services
Developmental disabilities	333	Expended to provide community-based services
Education	875	Expended in support of institutionalized mentally disabled
Vocational rehabilitations	5,156	An estimate derived by multiplying the number of mentally disabled persons rehabilitated (3,622) by the average cost per rehabilitation (\$1,736) by the percent of Federal funds provided (82%) The vocational rehabilitation program rehabilitated 1,744 institutionalized patients while the remaining 1,878 were rehabilitated through general and educational programs based in the community
Crippled Children's Services	182	Represents estimated funds expended for the mentally retarded A similar estimate for the mentally ill was not available, although officials stated that funds expended on the mentally ill were negligible
Supplemental Security Income	^a -	Payments of up to \$146 00 per month for a single person were a major source of income for foster care placements
Total	<u>\$21,771</u>	

^a
Figures unavailable