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DEINSTITUTIONALIZATION OF THE
MENTALLY DISABLED IN OREGON

Region X, Seattle
Department of Health, Education, and
Welfare and other Federal agencies

*UNITED STATES
GENERAL ACCOUNTING OFFICE*

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ABBREVIATIONS

ADAMHA	Alcohol, Drug Abuse, and Mental Health Administration
CMHC	Community Mental Health Center
CSA	Community Services Administration
HEW	Department of Health, Education, and Welfare
HUD	Department of Housing and Urban Development
ICFs	Intermediate Care Facilities
MSA	Medical Services Administration
RSA	Rehabilitation Services Administration
SRS	Social and Rehabilitation Service
SSA	Social Security Administration
SSI	Supplemental Security Income
TMR	Trainable mentally retarded

CHAPTER 1

INTRODUCTION

There has been a major nationwide trend in recent years favoring treatment of mentally disabled ^{1/} individuals in communities rather than State institutions. This is widely referred to as "deinstitutionalization." Many factors brought about this shift, but the primary ones were the humanitarian concern about the poor conditions and limited treatment in State hospitals and the availability of new drugs which helped modify the extreme behavior of the mentally disabled and increased their receptivity to change. After the trend got underway, additional pressures and resources sustained and gave further impetus to it, notably: (1) increased funds provided by Federal, State, and local governments for community level services, (2) pressures by advocacy groups and other interest groups, and (3) court actions and Federal legislation calling for better treatment and increased access to needed services, such as education and vocational training.

Deinstitutionalization, if done correctly, means much more than simply moving people out of institutions. It is a concept calling for betterment of the individual. Ideally, successful deinstitutionalization occurs when a person changes from a dependent status in a State institution to an independent and meaningful life in the community. For some, such as the severely retarded with physical handicaps, this highest goal may be unreachable, but at least they may achieve a greater degree of independence and add more to their own life and to society than they can in State hospitals.

Moving mentally disabled people to the community level increases the potential for improving their lives, but it also increases the complexities of helping them. In the hospital, basically one organization is involved in meeting their daily needs (food, housing, etc.) and developmental needs (psychotherapy, habilitation training, education, etc.). In the community, many agencies are or can be involved for these same needs (see appendix III). Each agency has its own program purposes, eligibility requirements, range of services, and priorities on whom they prefer to serve. The mentally disabled person may need little or extensive amounts of help from one or more of the agencies and may be eligible under some programs but not others. Some services they need can be provided by many agencies, while other services are offered only by a few. Further, their needs change as they progress, or unfortunately, regress.

^{1/} The term "mentally disabled," as used in this report, refers to mentally ill and mentally retarded individuals.

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

BACKGROUND FOR OREGON

Prior to the 1960s, Oregon's State hospitals for the mentally disabled served as the primary public means for treating mental health problems. During the last 10 years, however, Oregon has moved from almost a total dependency on institutions for the mentally disabled toward the establishment of community programs. The availability of Federal funds, increasing concern about the quality of care in hospitals, availability of drugs to stabilize mental disorders, and the growing acceptance of community-based care and treatment for the mentally disabled provided the enticement for Oregon's deinstitutionalization efforts.

Reductions in the mentally ill hospital population started in 1959, while reductions in the hospitalized mentally retarded population started in 1968. The population at State mental hospitals reached a peak of over 5,000 persons in 1958 and since then, has been declining steadily (see appendix I). The average daily population for the three State mental hospitals has declined almost 75 percent from 5,065 in 1958 to 1,263 in 1974. Over 50 percent of this reduction took place between 1962 and 1967. These decreases occurred because of a reduction in the number of long-term and elderly patients and the use of drugs to stabilize mental disorders.

The reduction in the mentally retarded hospital population started slowly in 1968-69, picked up momentum in 1970 and continued through 1973-74 (see appendix II). The institutional population of the mentally retarded peaked at over 3,000 in 1967-68, and declined to about 2,200 during 1973-74. This was a statewide decline of about 27 percent in 6 years with 60 percent of the decline occurring in the 2 years 1972-73 through 1973-74. The reduction was achieved primarily by releasing the most capable residents and by expanding community services.

Many agencies have been involved in Oregon's deinstitutionalization effort. The Oregon Department of Human Resources is responsible for the main agencies that impact on the mentally ill and mentally retarded (see appendix III). Other agencies such as the Department of Education and the Department of Higher Education also impact on deinstitutionalization.

The Department of Human Resources was formed in 1971 as an umbrella agency for most of the programs serving institutional populations. It includes the Mental Health, Public Welfare, Vocational Rehabilitation, Children's Services, Health, and Employment Divisions. The Mental Health Division is responsible for the care and treatment of the mentally disabled. The Division has broad responsibilities for administering the State's mental health program, including coordinating mental health activities at all governmental levels throughout the State and operating the State's five institutions for the mentally ill and mentally retarded. The Education Department is responsible for Special Education programs, while the Department of Higher Education is responsible for the Crippled Children's Programs.

Involvement of many agencies has been primarily at the local level, where employees provide services and assistance to mentally disabled individuals. The local agencies most involved have been community mental health clinics and local public welfare offices.

CHAPTER 2

STATE EFFORTS TO FURTHER DEINSTITUTIONALIZATION

The Oregon State government recognized during its early reduction of hospital populations that adequate community services and coordination between agencies were essential for successful deinstitutionalization. Several years passed before a series of actions were taken that clearly addressed these deinstitutionalization problems. Since 1972, the State passed legislation more specifically oriented towards former hospital patients and local treatment, assessed its deinstitutionalization efforts, increased its efforts to identify and develop needed community services, and improved its management and coordination.

COMPREHENSIVE PLANNING

Oregon has done some major comprehensive planning for deinstitutionalization of the mentally ill and the mentally retarded. Specific recommendations toward the development of community resources were made in plans issued during 1965. The plans, entitled "The Ultimate Goal, A Plan for Today" and "First Steps Toward Comprehensive Mental Retardation Services in Oregon," emphasized the need to develop a wide array of services and the need for coordination among agencies providing such support and services. The State has also recently assessed its deinstitutionalization efforts. In 1975, the Department of Human Resources completed two studies on deinstitutionalization and intends to use these studies for further planning.

The initial planning for deinstitutionalization and community care of the mentally ill began in 1963 when a Mental Health Planning Board was established to develop a comprehensive mental health plan. Some of the Board's recommendations concerning community services were that (1) development of comprehensive community mental health services should be the most important mental health goal, (2) psychiatric units in general hospitals should be encouraged and supported, (3) foster home care and halfway houses should be developed, and (4) privately operated community sheltered workshops should also be encouraged.

The Board also recognized the problem of coordination among agencies which can meet the needs of the mentally ill. It observed that before any meaningful collaboration among agencies could occur, each agency's responsibilities had to be clearly defined, similar or overlapping services had to be identified, specific areas in which particular agencies need to cooperate had to be identified, and sustained communication needed to be established.

Planning for the mentally retarded began in 1964 with 10 mental retardation planning committees involving some 300 citizens interested in and knowledgeable about mental retardation. The resulting plan described a wide array of services that the planners believed were needed by the mentally retarded, including foster care, group home living, sheltered workshops, job placement, and counseling services. Also emphasized in the plan was the need for coordination between the many agencies that provide these services.

In an effort to continue the planning for deinstitutionalization in Oregon, the Department of Human Resources assessed its deinstitutionalization efforts and completed a review of the available community support services in 1975. The Department's initial report (January 1975) stated that they are committed to continuing the movement of people from institutions into the community. The report noted, however, that the major deterrent to further deinstitutionalization is that only a few communities have a sound and adequate support system. The report further stated that without considerable effort and expenditure of funds, little can be accomplished for those remaining in the institution.

In response to these initial findings, the Department established a four person task force to examine basic community and residential services and how they relate to the former patient. The task force visited the five State institutions, community residential facilities, activity centers, workshops, and numerous other community services. The following conclusions were presented in the task force's May 1975 report:

- the current hospital population of both the mentally retarded and the mentally ill includes a higher percentage of "hard to place" people,
- placements out of the institutions are made to "what is available," and not necessarily what is needed,
- community placements for the mentally retarded are dependent on the availability of appropriate living facilities and day care, but day care resources (i.e., activity centers, workshops) are inadequately funded,
- community mental health clinics, given currently available resources, cannot meet the follow-up responsibilities for discharged persons, and
- several follow-up agencies have insufficient knowledge about the deinstitutionalized population.

COMPREHENSIVE COMMUNITY
MENTAL HEALTH LEGISLATION

Oregon had community mental health care legislation as early as 1962, but legislation specifically addressing the needs of former hospital patients was not passed until 1973. In 1962 legislation established the Mental Health Division to coordinate the State's mental health program, supervise the State's direct mental health services, and assist counties in establishing local mental health services. However, this early legislation did not require that aftercare be provided to released hospital patients and did not focus on services which could act as alternatives to hospitalization.

In 1973, Oregon formally adopted a comprehensive community mental health program for both the mentally ill and the mentally retarded. One element of the 1973 comprehensive program provided for the development of specific community services needed by the released hospital population. The program was initially presented in 1971 to the Oregon Legislature where it was favorably received, but further planning was directed. The additional planning was accomplished by the Mental Health Division in 1972. As a result, the comprehensive community mental health program became the central theme of the Division's 1973-75 biennium budget.

The Governor gave support for the new program. In his January 1973 presentation before the State Legislature, he said it was aimed at making appropriate help immediately available rather than waiting until hospitalization is required. He noted the program's goal was to provide an array of suitable treatment and service options in every community. The Governor said his legislative proposals were closely aligned with the basic goals of (1) improving programs designed for transition of clients into the community, (2) strengthening and developing community-based residential or institutional resources to serve as alternatives to centralized State institutions, and (3) strengthening and developing non-residential resources and programs to serve as alternatives or deterrents to institutionalization.

According to the Mental Health Division, the Legislature endorsed the program by approving the following:

- development of community alternatives to care and treatment in State hospitals for the mentally ill, mentally retarded, and those with problems of alcoholism and drug abuse.
- growth in community mental retardation, developmental disabilities, and alcohol and drug programs, which were integrated into the new Comprehensive Community Mental Health Program.

- strengthening of treatment staff in the State hospitals for the mentally ill and mentally retarded to allow for strong support of the total mental health program in its transition and the development of appropriate new roles.
- reorganization of the Mental Health Division central office staff to provide a structure for planned, orderly change and to assure program integration and quality.

The Division said that other legislation supplements the Comprehensive Program by (1) tightening involuntary admissions to State mental hospitals; (2) providing for day care, respite care, crisis intervention, and part-time care in Mental Health Division facilities; and (3) providing educational opportunities for the trainable mentally retarded.

EXPANSION OF COMMUNITY FACILITIES AND SERVICES

The availability of community facilities and services has been increased. Much of this is due to increased State funding. State funding for community-based programs for the mentally ill and mentally retarded has increased noticeably the last few years, especially since the comprehensive program was adopted. For example, the Mental Health Division has increased funding of community programs for the mentally disabled from \$5.2 million during the 1971-73 biennium to an estimated expenditure of \$8.5 million for the 1973-75 biennium. The Governor's budget recommendation for the 1975-77 biennium included over \$14 million for Mental Health Division community programs.

In response to increased funding, the community mental health programs have been serving an increasing number of persons. Mental health clinics increased the number served in fiscal year 1974 to 35,831 as compared to 22,632 in fiscal year 1971, for an increase of 13,199 persons served. During the same period, the number of mentally retarded served by community programs increased from 739 to 2,722. (See Appendixes IV and V).

In addition to increasing the availability of general mental health services in the community, the Mental Health Division has used some of the recent budget increases to develop specific community-based alternatives to hospitalization. Through the use of day treatment, local hospital treatment, group homes, and activity centers, progress has been made in reducing the use of State hospitals.

Specific alternatives
for the mentally ill

Day treatment and local hospital treatment have been identified by the Mental Health Division as priority service alternatives needing development. Day treatment and local hospital treatment were developed in several counties served by Oregon State Hospital. The Oregon legislature provided \$756,065 for the development of these services in 1973.

A Mental Health Division study showed that the seven counties receiving these services experienced a significant decline in admissions to Oregon State Hospital, while other counties in the same catchment area had a slight increase in admissions. The seven participating counties had a 16.8 percent reduction in admissions between 1973 (1,498 admissions) and 1974 (1,247 admissions).

The local hospitalization programs started in January 1974. A total of 493 community mental health patients received care in these inpatient programs. The Mental Health Division paid for the care of 214 of the patients during 1974, while the other patients had some other means of financing their care. The average length of hospitalization for the patients was 4.7 days.

The Mental Health Division is also attempting to develop residential care facilities for the mentally ill. The Division requested \$110,092 to develop four halfway houses in the 1975-77 biennium budget proposal. In addition, the Division proposed to initiate consultation and education programs for home operators in six counties. Only one county had such a program.

The State also has a federally funded project which places chronic patients in group home settings. The intent of the project is to train these people in the living and social skills necessary for them to maintain themselves as an independently functioning group. The project is being conducted at Eastern Oregon Hospital and Training Center and will run from July 1974 to June 1977.

Specific alternatives for
the mentally retarded

The Mental Health Division has taken specific steps to increase the services needed to keep the mentally retarded from remaining in a State hospital. The development and use of group homes, for example, has shown that many mentally retarded persons can return to the community. Activity centers have been expanded and classroom programs for the trainable mentally retarded (TMR) exist in most Oregon counties.

During the 1973-75 biennium, the Division increased the program capability of 7 existing group homes and helped establish 10 new ones. Seventy-two percent of the residents in these facilities had a history of institutionalization. The Mental Health Division only served 75 residents in community residential facilities in fiscal year 1972, while in fiscal year 1975, 172 persons were served.

Two unique group homes serving only the severely retarded were established during 1974 under a Federal grant. Twenty to 25 severely handicapped persons in State institutions were to be moved to the facilities. This project was Oregon's first attempt to deinstitutionalize the severely retarded. The superintendent of Fairview said the project has worked out well and that he is convinced that every retarded person can be deinstitutionalized.

To upgrade the level of care provided by group homes, standards were established in January 1975. One of these standards requires one training coordinator for each ten residents. The Mental Health Division, in its fiscal year 1975-77 budget request, stated that it supports this standard as the minimum necessary to ensure quality group care. The agency plans to provide grant-in-aid funds to allow 96 group home facilities to meet and maintain the new program standard during the 1975-77 biennium.

The Mental Health Division also provided funds to increase the availability of activity centers. Twenty activity centers were expanded and ten new ones were started by the agency during the 1973-75 biennium. The number of mentally retarded persons served by activity centers had jumped from 91 to 656 between fiscal years 1972 and 1975.

The Mental Health Division has the responsibility for developing TMR school programs in local school districts. In 1970, 466 retarded children attended TMR classes in 20 counties, while in 1975, 1,273 children were served in 33 of Oregon's 36 counties. Plans for the 1975-77 biennium call for serving 1,383 children, with special emphasis on developing TMR programs in remote areas. Also, to accommodate 110 institutionalized school age children in local school districts during the 1975-77 biennium, expansion of the TMR school program is planned.

Other agency efforts

Other State and local agencies have helped increase community services for the ex-hospital population. For example, the Public Welfare Division's Adult Services Section was providing an alternate care program for the mentally disabled during fiscal years 1973-74. Under the program, foster care, housing, homemaker and housekeeper services, chore services, and education and training are provided to

keep individuals out of State institutions. The Public Welfare Division indicated that in January 1974 it was providing alternate care for 61 individuals who otherwise would have been placed in a State institution. Almost one-half (27) of these people had been institutionalized prior to receiving alternate care services. The Adult Services Section also indicated that during 1974-75 approximately 450 mentally retarded persons were served in activity centers and some 175 mentally retarded persons from institutions were served by sheltered workshops under social service dollars. Also, social services were provided to more than 1,000 mentally disabled persons in adult foster and group homes.

To improve the quality of care, the Public Welfare Division has received funding to assist group homes meet minimum staffing and specific fire safety regulations, and two intermediate care facilities for the mentally retarded were certified.

The Vocational Rehabilitation Division was shifting emphasis to provide service for the mentally disabled in the community. For the mentally ill, closer working relationships were being developed with local mental health clinics, while programs for the mentally retarded were becoming more community based.

Local school districts were also expanding services to the mentally disabled. District officials in Multnomah, Washington, Marion, and Polk Counties said they were either providing their own special education programs for the trainable and educable mentally retarded and the emotionally disturbed, or had agreements whereby county intermediate school districts were providing the service. Several school districts were either in the process of expanding programs for the emotionally disturbed or were studying how to best serve this student population.

IMPROVED MANAGEMENT SYSTEM

Some improvements in State management which should benefit deinstitutionalization efforts have occurred in recent years. There is greater emphasis on coordination and service delivery problems and on the development of information needed by State program managers.

In 1971 the Department of Human Resources was established as an umbrella agency for many State agencies having human service programs. Most of the agencies serving the mentally disabled are now in the Department. The Department of Human Resources has committed itself to deinstitutionalization and is in a position to improve coordination between agencies. The Mental Health and Public Welfare Divisions have liaison staff at the State level, and liaison staff of the Public Welfare and the Vocational Rehabilitation Divisions have been assigned to State institutions.

In October 1974 the State Developmental Disabilities Council was elevated from the Health Division to the Department of Human Resources. At that time, the Department was designated as the State authority responsible for the development, supervision, and implementation of the Developmental Disabilities State Plan. This action should improve the council's ability to coordinate the broad array of services needed by the developmentally disabled.

The Director of the Department of Human Resources wrote us in November 1975 that the Department had established a Facilities Committee which includes not only representatives of the several Divisions, but also staff from the State Fire Marshal's Office, Department of Education, private agencies and consumer groups. He said this Committee is examining policy, defining roles, identifying unmet client needs and the resources which can be utilized or developed to meet those needs; is becoming an increasingly effective force in coordination and planning; and is impacting on deinstitutionalization.

The Mental Health Division was reorganized in 1973 to provide better focus on the integration of community and State hospital programs. Three regions were established corresponding to the catchment areas of the three State mental hospitals. The Regional Directors are responsible for all mental health services provided under the Division's programs. Their concerns include the coordination of services and continuity of care between State hospitals and local community programs, implementation of programs developed by the Division's program offices, and communication to the Division of the needs of local areas and the results of local planning. The Division has also established three program offices for mental and emotional disturbances, mental retardation and developmental disabilities, and alcohol and drug programs. The Directors of these offices are responsible for planning, program and resource development, standard setting, and monitoring and evaluating all mental health programs in the State.

The Mental Health Division is developing an information system which should improve its ability to manage the State mental health system. Data on patient characteristics and client movement is being collected. Expansions of the information system currently underway or planned are intended to help Division management analyze the State mental health system's capabilities and the cost of providing treatment to individual clients.

The Department of Human Resources is also responding to the need for better information. In 1975 it established an inter-divisional task force to catalog and describe the various community support systems that are currently in operation in Oregon. Also, this task force is to

prepare a manual describing several proven techniques which could be used by the various divisions and communities to establish a community support system responsive to that individual community's need.

CHAPTER 3

MENTALLY DISABLED NOT RECEIVING NEEDED COMMUNITY SERVICES

Although there has been a substantial reduction in Oregon's hospital population, a significant number of persons are still being served by State hospitals. In 1974, over 7,000 persons were served by the State's three mental hospitals, and over 2,000 mentally retarded persons remained hospitalized. Many of these persons could have been served in the community. The communities, however, do not have the needed services. According to the Director of the Department of Human Resources, the reduction in the State hospital population has outpaced the ability of communities to meet the needs of the mentally disabled. Consequently, many persons released from State hospitals are not receiving adequate community services. For some individuals, this has meant return to a State hospital for care and treatment.

MANY MENTALLY RETARDED REMAIN IN THE STATE HOSPITALS

A large number of mentally retarded persons remain in State hospitals and others are admitted to State hospitals because there are not enough community resources to enable them to be deinstitutionalized. An Arthur Young & Company study at two State mental retardation hospitals concluded that in May 1974, 63 percent of the population could be placed in the community if additional community facilities and services were available. For Columbia Park Hospital and Training Center, the study showed that (1) if sheltered care facilities, nursing, and foster homes existed in greater numbers, an estimated 150 of the 330 clients could be placed; and (2) if improvements were to occur in specific areas, such as foster and group home provider training, activity center staff ratios, and transportation, an estimated additional 100 could be placed. For Fairview Hospital and Training Center, the study projected that 223 individuals could be placed within 1 year with an additional 714 being placed after a 1-year period, if additional community services were available. The superintendent of Fairview Hospital told us that many persons now in the institution are in a "holding pattern" waiting for the development of community living facilities. The estimated average length of stay at Fairview was 10 years.

The director of the Diagnosis and Evaluation Center, which authorizes admissions to institutions for the mentally retarded, said that philosophically all placements made to institutions are inappropriate and

made only because there are not enough suitable community resources. In the Arthur Young report, the director said that the 38 admissions in 1972-73 were approved mainly because services were lacking in the communities.

UNNECESSARY ADMISSIONS AND
READMISSIONS OF THE MENTALLY ILL

Without adequate community care and treatment resources, many mentally ill persons are being admitted and readmitted to State hospitals for care and treatment. The Mental Health Division and State hospital officials share the belief that many admissions and readmissions could be avoided if adequate community programs were available. For example, officials at Dammasch said that about 25 percent of the persons admitted could have been intercepted and treated in the community and that many of the long-term patients could be placed in the community if appropriate facilities and services were available.

State mental hospitals admitted about 6,000 clients for treatment and released 6,269 clients during FY 1973. Of those admitted in 1973, nearly 60 percent had been treated at least once previously. In 1974, Dammasch had 3,017 admissions, and of those admissions, 1,519 or about 50 percent were readmissions. Dammasch's clinical director told us that the average Dammasch patient has been admitted to an institution two or three times.

RELEASE WITHOUT ADEQUATE
COMMUNITY SUPPORT

Because of the shortage of community resources to serve former hospital patients, many people were released to the community without adequate support. There is a lack of day programs, activity centers, and sheltered workshops. Consequently, some of the mentally disabled have been placed in situations inappropriate to their needs and are existing in the community without any programs to help them participate in community life.

Mentally retarded

Many mentally retarded persons have been placed in nursing homes that do not provide adequate support. A study covering fiscal years 1970-74 showed that about 250 retarded persons had been placed in nursing homes. The study apparently was done in response to a request from the Oregon Legislature. The Mental Health Division was planning to investigate whether these individuals were obtaining appropriate services. Many State and local officials believed that many mentally retarded persons have been inappropriately placed into nursing homes.

A Department of Health, Education, and Welfare (HEW) Audit Agency report released in January 1975 said that 10 of 33 retarded patients they reviewed had to be returned to State institutions or transferred to other facilities because the nursing homes could not provide proper care or services. In addition, the report said that, as a result of these improper placements, there were discipline problems with the retarded patients and disruption of the well-being of the nursing homes' other patients.

The following are some additional examples where mentally retarded persons have not received adequate support:

- A county service coordinator told us she had identified about 25 mentally retarded persons transferred from institutions to nursing homes, where they were receiving only custodial care, even though about one-third of them were capable of participating in some kind of program.
- A Health Division official said in June 1974 that his staff had found four mentally retarded males in a nursing home living in a daylight basement, where their only recreation was a record player. They apparently were not participating in any other activities or training.
- The nursing home ombudsman told us that she found two mentally retarded boys who had been released to a nursing home where they were receiving no support, were half naked, and were generally not being cared for.

Mentally ill

Released mentally ill persons are also faced with a lack of community support. Communities have only a few mental health programs which can provide support to the former hospital patient. As a result, many former patients are in the community without opportunities to participate in community life. For example, one doctor at Dammasch told us that the most common complaint among readmitted patients is that there was nobody to relate to and nothing for them to do. A county mental health worker who did a study on former mental hospital patients told us that they spend a lot of time wandering around town with nothing to do and that community mental health clinics were not attempting to improve the quality of the person's life.

In addition, an April 1973 study on former Dammasch patients stated that they had unmet needs which included: (1) the need for structured living situations, jobs, and daily routines; (2) the need

to overcome loneliness by providing friends, better family relationships, and social activities; and (3) the need to enhance mobility through assistance with transportation and money problems and provisions of access to community clinics.

The living environment of some former hospital patients also did not provide much support to supplement what was available in the community. For example, a Department of Human Resources Task Force on deinstitutionalization reported in 1975 that a typical day for a mentally ill person in a nursing home or home for the aged was sleeping, eating, watching television, smoking cigarettes, sitting in clusters in the largest room, and looking out the window. There was no evidence of an organized or developed plan to meet the person's needs.

During our review, we visited five residential care facilities. Operators of four facilities told us that they had no organized activities. For example, at one board and room home, we were told that watching television, listening to the radio, and reading were the only activities.

CHAPTER 4

INCREASED EMPHASIS ON DEINSTITUTIONALIZATION NEEDED

Oregon has made progress in its deinstitutionalization efforts, but problems still exist. There are still many persons receiving treatment in State hospitals, even though they could be treated in the community. In addition, some persons released from State hospitals are without adequate community support. There are two main elements, community services and leadership, needing the State's attention to improve deinstitutionalization.

The most obvious barrier is the shortage of community facilities and services. Better community support systems are needed as deinstitutionalization progresses because the remaining population in the institutions tends to consist of those patients who need the greatest amount of services to be released to communities. Few communities in Oregon have the array of services and facilities needed to support the mentally disabled. Because of the lack of adequate community support systems, unnecessary use of State hospitals is occurring, and communities offer little in the way of alternatives for the mentally disabled.

Leadership is essential to emphasize and integrate the State's deinstitutionalization effort. The involvement and independence of the many agencies providing services must be unified into a single effort to meet the needs of the mentally disabled. These other agencies only serve the mentally disabled as part of a larger population eligible for services. Increased leadership is needed at both the State and local level. Some agencies lack an emphasis or an awareness about the needs of the mentally disabled, and without the emphasis and focus, the community support system is fragmented and uncoordinated. The release planning and followup systems reflect this need for more leadership in the State's deinstitutionalization effort.

HIGHER PRIORITY NEEDED FOR DEVELOPING COMMUNITY FACILITIES AND SERVICES

Funds administered by the Mental Health Division have a significant impact on the improvement of community-based facilities and services in Oregon. However, programs for improving community services for the mentally ill and mentally retarded still represent a small percentage of the State mental health budget. Also, few communities provide the needed range of services, and as a result significant gaps exist in the facilities and services needed to support former hospital patients.

Shortages of community services
for the mentally ill

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

Community mental health clinics have only recently been given the responsibility for meeting the needs of former hospital patients. Previous legislation made community clinics responsible only for mental health counseling services to community agencies, public education in mental health, and basic testing, diagnostic and referral services. Aftercare for former hospital patients was only an optional service. The 1973 comprehensive legislation required community mental health clinics to provide aftercare to former hospital patients. However, access to programs still is a problem for the former hospital patient. Community mental health clinics served 30,441 persons in fiscal year 1973 compared to 26,665 served in 1972. Although more persons were served in clinics, only about 700 of the 6,269 patients released from the three State mental hospitals went into community programs in fiscal year 1973.

Almost one-half of the communities were reported as unable to place a patient in a local treatment program after evaluation without a long waiting period. For example, a Mental Health Division review in 1974 of Multnomah County's program showed that intake at two of the county's four clinics was closed and a third clinic had a 4 to 6 week waiting list. This county sends over 1,800 persons to Dammasch each year, with many of these being readmissions. Clinics have been providing limited services to the former hospital population, and have primarily been providing only medication services to this population.

Few communities have the range of services needed to prevent State hospitalization. Only 5 of Oregon's 30 county mental health programs offered a complete range of alternatives to State hospitalization. The Mental Health Division has identified day treatment and local hospital treatment as the highest priority service alternatives that need to be developed. But, they believe, for these services to be effective, communities must also offer residential care and emergency services. Less than half of the counties offer these services. The following is a breakdown of the number of county mental health programs offering these particular alternative services.

	<u>Number of programs offering service</u>
Day or night treatment	15
Emergency services	13
Community residential care	12
Local in-patient treatment	11

Shortage of community services
for the mentally retarded

The major barrier preventing further deinstitutionalization of the mentally retarded is the lack of community resources to support former hospital patients. Residential care, such as group homes, foster care, and specialized care facilities such as nursing homes, as well as services that supplement the residential care, are needed. These supplemental services include training, employment, education, and transportation.

The need for residential care has prevented many mentally retarded persons from leaving State hospitals (see page 13). In a study done for Oregon on deinstitutionalization, Arthur Young & Company concluded that:

- given certain community developments, the average daily population in Oregon's facilities can be significantly lowered, and
- the community developments required to accommodate those residents now placeable must be extensive and varied with major emphasis to be placed on group homes and nursing homes with tie-ins to other community services (e.g., activity centers).

The Mental Health Division budget summary factbook for the 1975-77 biennium gives some insight into the size of the gaps in services supplementing residential care. For example, it stated that activity centers in fiscal year 1975 served only 656 of the estimated 4,283 needing this service. The related budget request said that approximately 50 percent of existing activity centers had a waiting list of retarded persons already living in the community. The factbook stated that 1,273 children were served by classroom for the trainable mentally retarded compared to 3,458 estimated as needing this training. Although these figures include the needs of the total mentally retarded population, they show that the institution population faces tremendous competition for these services.

State and local officials, advocates for the mentally retarded, and social service personnel we interviewed agreed that there is a shortage

of school programs, activity centers, workshops, and employment opportunities. For example, the Polk County community service coordinator said in January 1975 that they had only one activity center (which was usually full), no sheltered workshops, and very few employment opportunities. In Marion County, a welfare liaison worker told us there was a critical need for some sheltered workshops in the Salem area, as evidenced by their having to bus a retarded individual about 40 miles to a workshop in a nearby county. In Washington County, better sheltered workshops and an activity center have been identified as the two most needed services by the local developmental disabilities council.

Lack of transportation services and recreational activities were identified as special problems in two counties we visited. In Polk County, inadequate public transportation was cited as a significant problem by a welfare caseworker and the community service coordinator. In Washington County, the President of the Washington County Association for Retarded Citizens said that public transportation was terrible and that more services were needed.

Increased funding needed for
community facilities and services

Oregon's five State hospitals for the mentally disabled continue to account for most of the Mental Health Division's budget. About 80 percent of the mental health expenditures went to State hospitals in the 1971-73 biennium, according to the following table derived from Division reports.

Mental Health Division
1971-73 Expenditures

	<u>Amount</u>	<u>Percent</u>
Hospital services	\$57,077,632	80
Contract services (includes grant-in-aid to local programs)	5,963,941	8
Non hospital services	4,921,704	7
Other	<u>3,280,118</u>	<u>5</u>
Total	<u>\$71,243,395</u>	<u>100</u>

Mental health expenditures in the 1973-75 biennium and the Governor's budget recommendation for the 1975-77 biennium have placed more emphasis on the development of community facilities and services, but hospital expenditures are still expected to represent almost 70 percent of the direct mental health service costs during the 1975-77 biennium.

Less State funding than was anticipated for community-based programs for the mentally ill apparently has put pressure on already financially troubled county budgets. According to the Mental Health Division, many counties are in a fiscal crisis because of the ever-increasing demand for mental health services and a high rate of inflation. Under the comprehensive community mental health program the Mental Health Division can provide up to a 50 percent match in grant-in-aid money to local mental health programs. The State support was limited, however, to a 6 percent increase which the Mental Health Division indicated in its fiscal year 1975-77 budget request did not keep up with inflation. The budget request said that rather than providing a match of 50 percent in fiscal year 1973, the State averaged a match of only 42 percent. The State Department of Human Resources reported in January 1975 that the State match had declined further to 40 percent, thus hampering the counties' ability to develop mental health programs.

According to the Mental Health Division, inadequate State funding, coupled with county fiscal problems, has forced local community mental health programs into a critical situation. The Division reported that community programs were losing staff and a number of county commissioners were considering withdrawing their funds completely, forcing the State to take over the community mental health programs. Accordingly, the Division requested increased funding for county grant-in-aid programs in the 1975-77 biennium.

The Division also said that inadequate funding of the new involuntary commitment law (SB 510) had an adverse impact on services provided by community mental health programs. The State only allocated \$225,000 for counties to carry out their responsibilities under this law; as a result, county resources have been used for these purposes at the expense of the basic mental health programs. Washington County's plan for fiscal year 1975, for example, stated that all new funds had been allocated to the implementation of the law, focusing on prepetition interviews and pre-commitment hearing investigations, which the county recognized could help to reduce admissions to State hospitals. However, the county noted that no new funds from the State were available to significantly add to alternatives to State hospitalization. Multnomah County reported that the lack of adequate State funding for the law had caused the county to reduce services to less severely disturbed clients in order to provide screening and aftercare services.

The Mental Health Division said the budgetary crisis at the county level has also resulted in the reduced use of public health nurses in mental health programs, even though nurses had contributed significantly to the delivery of services for those released from State hospitals and those allegedly mentally ill for whom commitment has been requested. For example, an official of the Multnomah County Public Health Office said that in fiscal year 1973, nurses in the emotional and mental section made 5,700 home visits, seeing 1,529 individuals--a 44 percent increase in the number of home visits and a 50 percent increase in the number of people seen--and that during the same period, the County Nursing Division experienced a 62 percent increase in group visits which consist of visits to group homes for therapy. The County's Public Health Officer told us in February 1975, however, that because of budget cuts the Division's emotional and mental section and the follow-up service it provided had been eliminated. Another official said the budget cuts will also affect the assistance the county public health nurses had been giving the county mental health clinics by giving medication shots and providing for followup at the local clinics.

NEED FOR MORE EFFECTIVE
LEADERSHIP AND COORDINATION

Oregon does not have a comprehensive deinstitutionalization plan addressing the various State and local agency responsibilities and roles for implementing deinstitutionalization. Responsibility for providing leadership to coordinate and integrate services to the mentally disabled has been assigned to the Mental Health Division. However, the Division must depend upon a number of agencies, primarily those in the Department of Human Resources, to support deinstitutionalization. The effectiveness of the Division's leadership and the cooperation of other agencies needs to be increased.

The Mental Health Division is the only State agency solely responsible for the mentally disabled. By law, one of the Division's functions is to direct, promote, correlate, and coordinate all the activities and direct services for the mentally disabled. Early State planning recognized that the mental health agency needed to collaborate with other agencies so that mental health expertise could be used. These other agencies provide services to the mentally disabled, but the mentally disabled only represent a portion of the group served by the agencies. For example, Employment Division officials indicated they were aware of the Mental Health Division's attempts to move the mentally disabled into the community. But, they noted that this group represented only a small portion of their client population.

The Mental Health Division has not been totally successful in working with other agencies to identify the deinstitutionalization

responsibilities and roles of the other agencies. Mental Health Division officials agreed that other agencies' responsibilities and roles are not clearly defined. Officials in the Public Welfare, Employment, Children's Services, and Crippled Children's Divisions and in the Department of Education indicated they can serve or have served people who have been released from State institutions, but that they do not have specific responsibilities for deinstitutionalization.

Some agencies have not determined the extent to which they are involved in deinstitutionalization nor have they determined how to meet the needs of former hospital patients. These agencies are either unaware of the problems confronting the mentally disabled, unaware of the number they serve, or unaware of their needs.

--Children's Services Division officials indicated they needed to place more emphasis on assessing the needs of mentally disabled children and the impact their programs can have on this client population. They said that they do not keep statistics on the number of referrals from mental health, and have done no assessments to determine the social service needs of mentally disabled children. They also noted that the agency requested funds from the Oregon Legislature to evaluate what their programs are doing in areas like deinstitutionalization.

--The Director of Adult Social Services (Public Welfare Division) said they did not have a formal deinstitutionalization policy, although the entire thrust of their program was aimed at community placement. She stated that their information is piece-meal and that they have not done a broad assessment of the social service needs of the mentally disabled. As a result, they were unable to identify the total number of mentally disabled they were serving, or the total array of services provided to each person.

--Employment Division officials stated that if the agency's mandate was clearer, they would do more to assess the mentally disabled's needs. The Employment Division did not have any documented information regarding the employment problems confronting the mentally disabled. They knew how many mentally disabled they served, but did not know how many referrals they had from State institutions.

The Mental Health Division needs to work more closely with some agencies so it can provide its expertise. According to a 1975 Department of Human Resources report, several agencies have insufficient knowledge about the deinstitutionalized population. For example, the Public

Welfare Division provides services and financial assistance to the mentally disabled. According to the report, Public Welfare Division does not provide sufficient training and direction for staff to properly carry out the sophisticated services needed by former hospital patients, and there is insufficient carry over of Mental Health Division expertise to assist the Welfare Division in meeting its responsibility to the former patients.

The Department of Education, Crippled Children's Division, Children's Services Division, and the Employment Division indicated that coordination with the Mental Health Division could be improved. The Director of Special Education, Department of Education, said they cooperate with Mental Health, but there is no formal joint planning between the two agencies. Crippled Children's Division officials said they do not work too closely with Mental Health probably because they are under different State departments. Employment Division officials stated they have contacts with Mental Health, but that nothing much has come from the contacts. They said each agency is too involved in its own area of expertise to deal effectively with employment problems of the mentally disabled.

The Mental Health Division has made efforts to develop closer working relationships. A Children's Services Division official said that they were negotiating a basic understanding with the Mental Health Division, whereby Children's Services will have case planning responsibility while Mental Health will have program responsibility. The official indicated the agreement being negotiated should improve the coordination of their programs. The Children's Services Division also has agreements with Public Welfare and Vocational Rehabilitation. These agreements should help to improve the transition to the community.

The limited effectiveness of leadership and coordination for deinstitutionalization is also reflected at the community level. Local welfare officials told us that they have not received any guidance or instructions directly concerning deinstitutionalization. They also agreed that they were generally unaware of what responsibilities other agencies had for deinstitutionalization.

Public welfare and mental health officials at the local level told us that there were no specific agreements with other agencies to serve discharged patients and that referrals or contact with other agencies is done on a case-by-case basis. County public health officials indicated coordination with mental health authorities is limited to a case-by-case involvement by individual nurses. Three of four local school districts we visited indicated they had little or no contact with the State institutions serving their area concerning the placement of the mentally disabled.

Although some local housing authorities we contacted indicated they cooperate with other agencies after a mentally disabled person becomes a tenant, three of the five housing authorities gave no special preference to the mentally disabled waiting for housing.

IMPROVEMENTS NEEDED IN
TRANSITIONS TO THE
COMMUNITY

An integrated community support system does not exist. Consequently, community agencies do not respond to former hospital patients' needs in a unified manner. The delivery system is fragmented, and better coordination between the hospital and the community is needed. In Multnomah County, for example, mental health officials noted in their fiscal year 1974-75 plan that agencies operate semi-independently of one another with no single system encompassing all services needed by the client. The plan indicated that no formal intersystem referral procedures exist and each client or therapist must take the initiative to develop relationships with as many agencies as it takes to complete a package of necessary services.

Our review of the release planning, referral, and followup procedures for persons released from Dammasch State Hospital and Fairview Hospital and Training Center showed the following: (1) no single document summarizes the individual's total needs; (2) release planning for the mentally ill is fragmented, but is more integrated for the mentally retarded; and (3) followup has been limited, especially for mentally ill persons and for discharged mentally retarded persons.

The following sections address the procedural problems identified during our tracing. Chapter 5 discusses the impact Federal programs have had on the transition process, while a description of our tracing efforts is presented in appendix VI.

Needs not adequately documented

The total community needs of released individuals were not clearly identified. Individual agencies, such as the mental health clinic, vocational rehabilitation and public welfare, had documented some of the individual's needs, but the person's total needs were not brought together and presented in a single comprehensive document.

Both the superintendent and the director of social services at Dammasch told us that it is useless to develop a detailed plan when it can't be carried out due to the lack of resources. From the standpoint of Social Service Department responsibilities, the director told us that

the discharge plan may be limited to referrals for outside followup but that these referrals reflect the patient's needs. Dammasch officials said better identification of needs is not likely to happen unless there is an increase in the community resources available to the discharged patient.

The Mental Health Division's Medicaid Coordinator said that release plans for the mentally ill were usually medically oriented. Also, during a review of patient files at Dammasch, she found that social service notes are more likely to be related to evaluation of the living situation and circumstances which brought the patient to the hospital rather than a consideration of personal or social needs.

Fairview's superintendent and the hospital's social service director, agreed that many placement summaries describe the services provided by referral sources, but do not document all of the individual's needs. A representative of the social service staff said, however, that documenting what doesn't exist is a waste of time and, therefore, she describes only the services that will be provided. The Mental Health Division's director of mental retardation programs said that the institutions should not have to document an individual's comprehensive needs at placement time. He said that the institution's social service staff only needs to decide which agencies to refer patients to, and then those agencies have the greater expertise to determine their specific needs.

Release planning fragmented

Release planning for mental hospital patients is fragmented. At Dammasch release planning consists mainly of referrals to several other agencies, each of which will meet only a portion of the patients' needs. A similar process is also used at the other State mental hospitals. Consequently, the patient leaves without a unified plan. Fairview appears to have a more integrated planning system for the mentally retarded; however, the other two hospitals for the retarded have not developed this system and rely upon a referral system.

Release planning for the mentally ill

Planning for the release of persons from Dammasch was split among the hospital staff, public welfare, children's services, vocational rehabilitation, and community mental health clinics. Neither the hospital staff nor any single community agency appeared to have responsibility for assuring that the overall release planning process adequately met the person's total community needs. For example, the director of social services at Dammasch said that when referrals are made, the responsibility for meeting the patient's needs is passed on to the

referral agency. She commented that one problem created by this process is the patient's needs are divided in the community among several agencies.

The referral method of release planning causes agencies to plan without a total perspective of a former hospital patient's needs. Multnomah mental health officials noted in their 1974-75 mental health plan that agencies collect data that reflects only a portion of the client's needs. The plan further stated that while agencies are able to document the client's need for their particular services, they lack information concerning the need for other services relative to their own, and the system lacks a single body empowered to consolidate and act on available information.

The following four paragraphs describe release procedures at Dammasch as explained in Mental Health Division or hospital documents or by hospital officials, personnel, and liaisons from related agencies.

Treatment teams determine when a patient can be released. These teams meet periodically and may include a social worker, physician, nurse, psychologist, and ward aides. Once the treatment team decides a person can be released, the social service department decides where the patient should be referred. Social workers must determine if the patient has a place to live, a means of support, provisions for medication follow-up, and if referrals should be made to community agencies. Voluntary patients must be released, however, within 72 hours after they request it, which gives very little time for release planning.

Referrals to public welfare are made for patients aged 65 and over, or under 22 years, as well as for patients who will need financial assistance. Referrals are made through two public welfare liaison workers who visit Dammasch once a week. The liaison worker contacts members of the hospital treatment team to determine the feasibility of returning the patient to his or her own home and if this is not possible, to determine the appropriate level of care needed. The liaison worker is also responsible to see that other referrals have been made, such as to community mental health clinics or follow-up medical care, and to be sure that prescriptions, medications, and orders are sent out with the client on release.

Vocational rehabilitation liaison workers visit Dammasch accepting referrals, investigating eligibility, and developing vocational rehabilitation plans for patients. The liaison worker decides whether patients will be accepted in the program, and also provides counseling, guidance, placement, and followup.

Staff from the McLoughlin Mental Health Center in Clackamas County and the Tualatin Valley Guidance Clinic in Washington County visit Dammasch Hospital once a week to plan for the patients who will be referred to them for aftercare. Staff from the other clinics in Region 1, however, do not make these visits. This has made the transition to the communities difficult. For example, no clinics in Multnomah County regularly send staff to the hospital. Referrals to mental health clinics are usually done by telephone and then are usually followed by a copy of the discharge summary.

The superintendent of Dammasch told us that Portland, which is located in Multnomah County and is the largest city in Oregon, has five catchment areas into which Dammasch discharges patients. He said relations with the catchment area clinics are weak. A 1974 Mental Health Division review in Multnomah County showed that referrals between State and county mental health programs was sporadic and not well coordinated.

Release planning for
the mentally retarded

Fairview has an integrated placement planning system for the mentally retarded which began in 1973. However, a similar planning process does not exist at the other two State retardation hospitals.

Each Fairview resident is assigned to one of six units which can best serve his needs. Each unit has a staff (representing the institution's medical, nursing, psychology, education, and social services sections) that prepares residents for community living and is responsible for recommending community placement.

The social worker and welfare liaison worker are responsible for matching residents ready for placement with available community resources. Once the needed living arrangements, day program, and other needed services have been tentatively located by the social worker and welfare liaison, a pre-placement staffing meeting is held. This meeting is attended by the mentally retarded individual, the Fairview field worker, welfare service worker, vocational rehabilitation counselor, home provider, and the resident's parents or guardians. At the meeting, the welfare worker may negotiate service payments, the vocational rehabilitation representative may discuss the day plan, and the Fairview field worker discusses how he can be reached and how often the client can expect a visit. These pre-placement staffing meetings started about January 1973.

The Hospital Superintendent said that prior to release, each resident's placement plan is reviewed by a Community Placement Board.

The board was established by a 1974 State directive to review, determine, and recommend to the superintendent of Fairview appropriate action on proposed plans to discharge or release individual residents. Board members were to include multi-disciplinary members of the hospital staff and a representative from Oregon's Association for Retarded Citizens. The Executive Director of the Association said that their membership on the board was a tremendous breakthrough because now they can impact directly on the placement process.

Limited followup

Followup of former hospital patients has been limited. State hospitals have not been actively involved except in cases where mentally retarded persons have been released on trial visit. Much of the responsibility for followup has been placed with community agencies, but their followup efforts have been limited. No single agency appeared to be exercising overall responsibility for assuring that the different agency efforts were meeting the person's total needs.

Followup of the mentally ill

State mental hospitals have not done much followup. The Mental Health Division's Director of Programs for Mental and Emotional Disturbances told us that once referrals are made the hospital's responsibility for the patient ends. A 1975 Department of Human Resources report also stated that hospitals believed that the followup responsibility belongs to local mental health agencies.

The director of social services at Dammasch said that a number of the mentally ill patients they refer to county clinics never show up for their scheduled appointment. Clinic officials in Multnomah and Washington Counties told us that when Dammasch patients fail to keep their appointments, they generally try to contact these individuals once or twice by phone or by mail to reschedule the appointment. More intensive efforts are sometimes made for patients who have kept initial appointments.

The Multnomah County mental health program director told us that the clinics have not taken an aggressive followup role because they are limited in the services they can provide. The county's mental health plan said client service continuity existed only when individual therapists followed through on referrals to other agencies. The supervisor of one of the community clinics in Multnomah County noted that clinic staff rarely had the time to make followup visits. A Mental Health Division review in 1974 also showed that clinic staff in Multnomah County are spread thin, making followup difficult.

Other community agencies were also providing only limited followup for the mentally ill. Local public welfare officials in Multnomah and Washington Counties believed that better followup was needed. The Program Specialist for Adult Services in Multnomah County said that often nothing is done unless someone calls for assistance. A branch supervisor for service workers in Washington County noted that the workers try to followup if they have time. In our discussions with local public welfare service workers, we found that they had little or no contact with some of the people we were tracing.

According to the rehabilitation counselor assigned to Dammasch State Hospital, the Vocational Rehabilitation Division is only funded to serve the most motivated discharged hospital patients; as a result, individuals who are not highly motivated are seen less frequently (often only once per month); those showing significant motivation are seen an average of once per week.

Local representatives of the Employment Division in Portland said they accept referrals from Dammasch but have no formal written agreement with the institution. They said they may provide referred patients with job counseling and arrange for interviews, but, they do not have the staff or resources to provide support services for these people once they are on the job. They said they remind Dammasch staff that those referred must be competitive and placeable in the business community.

Followup of the mentally retarded

Service coordinators are responsible for followup of discharged mentally retarded patients. Service coordinators are also responsible for (1) assisting the mentally retarded and their family in obtaining and utilizing services, (2) disseminating information to the mentally retarded, (3) developing and maintaining data on the retarded and their service needs, and (4) advocating and facilitating program development.

However, the service coordinators have been limited in their efforts. The Polk County service coordinator said that she has difficulty providing followup to discharged Fairview residents because she doesn't have the time and is not kept informed about who has been discharged to her county. The Multnomah County service coordinator said that she only has time to followup on discharged individuals who she knows have problems. She said that she has a list of 218 Fairview individuals that have been discharged into Multnomah County, but she doesn't know what has happened to these people. In Marion County, an assistant to the service coordinator had identified about 320 individuals discharged from institutions. Some followup is provided, but it has been limited to those individuals who contact the service coordinator asking for assistance.

The Superintendent of Fairview Hospital said that followup provided to discharged people is weak. He said that the community service coordinators are responsible for people discharged and should be required to followup on a regular basis.

The Executive Director of the Oregon Association for Retarded Citizens said that insufficient followup provided to discharged individuals is hindering deinstitutionalization. He said that the discharged individual needs someone to make certain that problems dealing with his job or social life don't go unsolved.

The Mental Health Division has recognized the need for improved followup for discharged retarded persons. The Division reported it had established eight new service coordinator positions during the 1973-75 biennium. This brought the total to 18 service coordinators serving 23 of Oregon's 36 counties. The agency was proposing to further expand the number of service coordinators during the 1975-77 biennium.

For the mentally retarded released from Fairview on trial visit status, followup appears to be better than for discharged persons. Fairview officials said they review and evaluate each individual's progress on trial visit in the community at 6 month intervals. We were advised that in Polk and Marion Counties, the normal Fairview followup system has been supplemented by weekly meetings at group homes, activity centers and workshops. The purpose of these meetings is to do more than provide followup. The meetings are intended to encourage interaction, verbalization, and a sense of mutual sharing among the residents. Participating in these weekly meetings are representatives from Fairview, public welfare, and vocational rehabilitation.

A Mental Health Division official told us that the Division has developed an evaluation system to monitor the progress of each retarded person placed in the community. He explained that program standards covering the operation of nursing homes, group homes, TMR classes, and activity centers had been developed and that semi-annual reviews for all community residents residing in group homes and nursing homes, and for those attending activity centers or TMR classes were required. According to the official, the system is intended to evaluate the progress an individual is making in the community, show the comprehensive array of services individuals receive, and document which programs work the best and which should be expanded.

CHAPTER 5

IMPACT OF FEDERAL PROGRAMS ON DEINSTITUTIONALIZATION IN OREGON

The care and treatment of the mentally disabled is primarily a State and local government responsibility. The role of the Federal Government has traditionally been to provide support and assistance to the States to improve the delivery of services to the mentally disabled. The role of the Federal Government has grown significantly over the years, however, from that of sponsoring research, demonstration, and manpower training programs to providing a large portion of the direct service and maintenance costs for the mentally disabled in institutions and the community. As a result, the availability of Federal funding has become more and more influential in the development of the States' deinstitutionalization efforts.

The status of deinstitutionalization and the problems associated with continuing the effort in Oregon were presented in the preceding chapters. The objective of this chapter is to discuss how Oregon has utilized Federal programs to provide needed services and how Federal programs and requirements have influenced State actions. The following areas are discussed on management and patient transition problems:

- Oregon has been increasing its reliance on Federal programs to the point where Federal programs now represent a significant portion of the support for deinstitutionalization in Oregon.
- The fragmentation of funding and service responsibilities in Oregon stem, at least in part, from the proliferation of Federal programs serving the poor, disadvantaged and handicapped. Most of the Federal programs do not have the mentally disabled as a primary target group or deinstitutionalization as a program objective.
- Oregon has not effectively utilized the Developmental Disabilities program or totally embraced the Community Mental Health Center program as mechanisms for overcoming fragmentation by coordinating the many federally funded State and local programs.
- Medicaid, Supplemental Security Income, Vocational Rehabilitation, Employment Services, and federally funded housing assistance programs could be utilized to increase the availability of needed community-based services and facilities, and to identify inappropriately placed mentally disabled persons.

EVOLUTION OF FEDERAL
PROGRAMS SERVING THE
MENTALLY DISABLED

The Federal Government adopted a deinstitutionalization policy in 1963. Its approach to deinstitutionalization was to develop mental health programs for (1) planning to meet the comprehensive needs of the mentally disabled, (2) stimulating the construction of community-based mental health and retardation centers to help reduce the institutionalized mentally disabled population, and (3) funding to help offset the costs of staffing community-based mental health and retardation facilities. The specific Federal legislation established to carry out these responsibilities was the Mental Retardation Facilities and Community Mental Health Centers' Construction Act of 1963 and subsequent amendments in 1965. In 1970 the Developmental Disabilities Services and Facilities Construction program was established to further develop these types of programs for the mentally disabled.

Recently the Federal Government has been placing greater reliance on other non-mental health programs that were established to serve general population groups or to solve generic problems. These programs include Medicaid, Social Services, Vocational Rehabilitation, Comprehensive Health Services, Supplemental Security Income and Special Education For The Handicapped. These programs are administered by agencies outside the mental health field and generally were established to help reduce a person's dependency, increase their ability to support themselves, or improve their general health and well-being, including the improvement of their living environment. Helping the poor, the disadvantaged, and the needy to remain in or return to communities is included among the goals of almost all of these programs.

FEDERAL FINANCIAL
INVOLVEMENT IN OREGON

Oregon has increased its reliance on Federal programs to the point where they represent a significant portion of the support of deinstitutionalization. Appendix VII identifies the major Federal funding sources, the services provided and in some cases the amount of dollars and number of mentally disabled served.

Several federally funded Oregon State agencies were not able to identify the number of former residents of mental institutions they were serving. In other cases, State agencies did not know how many mentally disabled their programs were serving. As a result, we were unable to determine the total amount of Federal funds supporting deinstitutionalization in Oregon. However, Oregon's Department of Human Resources noted

in January 1975 that the availability of Federal funds has become a major factor in determining the future of deinstitutionalization in the State. As the following table shows, the Federal Government contributes a large share of the funding for the programs that were supporting deinstitutionalization in Oregon:

<u>Program</u>	<u>Federal participation rates</u>
Vocational Rehabilitation	80%, and in certain instances 90% and 100%
Social Services	75%
Medicaid	59%
Supplemental Security Income	100% (plus State supplement)

The following briefly describes the major Federal programs being used in Oregon:

- MEDICAID reimbursement was being utilized to support State mental and retardation hospitals, nursing homes, intermediate care facilities (ICFs), and mental health clinics. The bulk of the payments for the mentally disabled appeared to be going to the State institutions, nursing homes, and ICFs. For example, the Public Welfare Division estimated that the Medicaid claim for State institutions would exceed \$9.9 million in FY 1975. In contrast, the estimated reimbursement for clinic services for the mentally ill was about \$849,000.
- SUPPLEMENTAL SECURITY INCOME (SSI) can provide financial assistance to many of the mentally disabled placed in the community. For example, some of the mentally retarded we traced to group homes were receiving SSI payments of \$146.
- SOCIAL SERVICES (Titles IVA, IVB and VI) were being used to provide placement planning and followup for the mentally disabled. The Federal funds were also used to support activity center and sheltered workshop services for adult mentally retarded persons, and a wide range of social services for mentally disabled children. Oregon spent about \$27 million through its social service program in FY 1973-1974. Almost \$20 million of the total went to support direct services through Children's Services. Although the Children's Services Division was not able to identify the total number of mentally disabled children served, the agency did spend about \$1.2 million of Federal Title IVA funds to serve emotionally disturbed children and to provide transportation for the mentally retarded.

Also, the agency's FY 1975-77 budget request indicated that 136 emotionally disturbed children would be served in 7 residential treatment centers throughout the State during FY 1975. The Public Welfare Division's Adult Social Service section was using social service dollars to develop alternate care plans for the mentally disabled during FY 1973-74. The agency indicated that approximately 450 mentally retarded persons were served in activity centers in 1974-75, while some 175 mentally retarded persons from institutions were served in sheltered workshops. The Division's statistics show that the program has kept individuals in the community who otherwise would have been placed in State institutions.

--DEVELOPMENTAL DISABILITIES or ALCOHOL, DRUG ABUSE, and MENTAL HEALTH ADMINISTRATION programs have provided funding for (1) comprehensive planning for the mentally disabled in Oregon, (2) improvements to hospital programs with special emphasis on improving the transition into the community, (3) two community mental health centers, and (4) filling some of the gaps in the existing delivery system for the mentally retarded.

--VOCATIONAL REHABILITATION and EDUCATION programs were also providing services to the mentally disabled in Oregon. Vocational Rehabilitation was providing evaluation services, training in workshops, and job placement. Education funds have been utilized in both the institutions and the community. Federal funds have been supporting TMR classes in local schools.

FRAGMENTED AND UNCLEAR RESPONSIBILITIES

Oregon's Mental Health Division does not administer all of the funds needed to place and support mentally disabled persons in the community, and, therefore, must rely on other agencies and programs to provide funds and services. However, the other State agencies had (1) not embraced deinstitutionalization of the mentally disabled as a formal operational objective, or priority and (2) only serve the mentally disabled as a part of a much larger target population, such as the poor, the handicapped, the disabled, the elderly, or children.

The number and variety of State programs that the Mental Health Division must rely on to meet the needs of the mentally disabled stem, at least in part, from the Federal Government's increasing reliance on a number of funding sources aimed at meeting the generic needs of a diverse population. Each Federal program generally calls for a single State or local agency to be accountable for the expenditure of funds, the accomplishments of program objectives, and compliance with program requirements.

Fragmentation of responsibilities and services have been addressed by both the Developmental Disabilities and Community Mental Health Centers programs. These programs are intended to coordinate and stimulate deinstitutionalization efforts at the State and local level, as well as to provide community services. Both programs have had a positive, but limited, impact on deinstitutionalization in Oregon.

More effective use of the
Developmental Disabilities
program possible

The Developmental Disabilities program was established in 1970 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 to the retarded and (3) fill gaps in services and facilities. Deinstitutionalization is a goal of the program.

Oregon's Developmental Disabilities program has developed information on the needs of the mentally retarded, the number of mentally retarded in two of the State's institutions that could be placed in the community if appropriate services were available, and the specific types of services and facilities that are needed for deinstitutionalization, but are not available. Oregon's 1974 Developmental Disabilities plan states that funds to provide services and facilities to the mentally disabled are inadequate. In FY 1974 the Developmental Disabilities program only received \$279,177. Gaps identified by Oregon include alternative living facilities, sheltered workshops, activity centers, and education programs. To help support the mentally disabled a number and variety of other programs are needed and used to meet their needs. There is a definite need for comprehensive planning, multi-agency participation and coordination.

The Oregon Developmental Disabilities program has not been effective in developing a comprehensive multi-agency action plan for:

- filling the gaps and services that have been identified, and
- stimulating other agencies to adopt specific goals, objectives, or priorities for deinstitutionalization.

The Developmental Disabilities role of influencing other agencies to support improvements in the delivery of services to the mentally retarded has been recognized in Oregon. Through the joint efforts of the Research and Training Center in Mental Retardation at the University of Oregon and the Oregon Developmental Disabilities Council a strategy was developed during 1973 involving planning, influencing, and evaluating. The Research and Training Center described the term "influencing" as the

vehicle through which the council implements its objectives. Lacking direct control over other programs, the Council engages in activities that will lead the responsible agencies to improve the delivery of services in accord with the goals and objectives of the State Developmental Disabilities State plan.

State agency officials did not indicate that specific actions to emphasize the mentally retarded had been initiated as a result of the Council efforts. For example, despite the fact that it is difficult to find suitable employment for the developmentally disabled, the Employment Division did not have a representative on the Developmental Disabilities Council. Employment Division officials said that they have had contacts with the Council and that from time to time the council sends questionnaires to the agency asking for an analysis of various aspects of their program. The officials stated, however, that if the employment agency's mandate was clearer they could do more to assess the needs of the employable mentally disabled. They further indicated that they could do more to help the mentally disabled if closer linkages existed between the employment offices and institutions.

Although the shortage of community residential facilities has been identified, the Council had apparently not influenced local housing authorities to assist in the deinstitutionalization of the mentally retarded. The following examples describe the situation.

- Only one of four communities we contacted that were receiving Federal housing assistance funds had assessed the needs of the mentally retarded residing in or expected to reside in the community and had included the housing needs of the mentally retarded in its Housing Assistance Plan required by the Department of Housing and Urban Development (HUD).
- The Housing Program's Manager in Portland, Oregon's largest city, said that his agency had not included the needs of the retarded in its Housing Assistance Plan because no one had contacted the planning staff to suggest that the needs of the institutionalized retarded who could be placed in the community be considered and the staff had not thought to consider their needs for community-based housing.
- The Salem housing authority, which is planning to develop housing units for the retarded, initiated its own efforts as a result of its awareness of a number of retarded being released in the community. The State's largest institution for the retarded is located in Salem. Contact had not been initiated by the Mental Health Division or the Developmental Disabilities

Council and in fact the director of the Housing Authority was not aware of the Developmental Disabilities Council. The director said that after the decision was made to develop special housing units for the retarded, they found themselves embroiled in a "bottomless pit of regulations and requirements."

The Director of the Mental Health Division's mental retardation and developmental disabilities program and the Executive Director of the Oregon Association for Retarded Citizens, both members of the Council, agreed that the program has been ineffective as a mechanism for influencing other agencies to give more emphasis to the mentally retarded. The Director said the Council does not have the financial resources to effectively cause other service agencies to shift more attention to the mentally retarded.

The Executive Director of the Oregon Association for Retarded Citizens said the Council cannot effectively influence changes in State agencies because the Council is an "insystem advocate." He noted that the agency representatives that make up the council are not in policy making positions in their own organizations.

Community Mental Health Centers Program

The major federally supported program directed toward deinstitutionalization of the mentally ill is the Community Mental Health Center (CMHC) program, which provides funds to the states to support the construction and staffing of mental health centers at the local level. These centers were to act as a community-based focal point for coordinating the delivery of services to the mentally disabled. The CMHC program has only had limited impact in Oregon.

Oregon has adopted a comprehensive mental health approach to serving the mentally disabled in the community. But, the Oregon legislature has chosen to use State and local funds instead of Federal funds to establish most of its county mental health programs. Oregon has only two federally funded mental health centers. Portland, which is the largest metropolitan area of the State, is not served by a Federal center.

Mental Health Division officials stated that additional Federal centers have not been developed because of the legislature's concern that State and local funds would not be available to continue the centers after the Federal funds were no longer available. 1/

1/ The Federal funds are available on a declining match basis. The intent is that the centers will eventually become financially self-sufficient.

Officials provided the following additional reasons for Oregon's reluctance to participate in the CMHC program:

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

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

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

NEED FOR BETTER TRANSITIONS
TO THE COMMUNITY

The Federal Government has taken steps to require discharge planning, followup, aftercare, and clear delineations of responsibilities for these functions. To meet Federal requirements States must:

--develop and implement cooperative arrangements or agreements between various State agencies, and

--prepare post-institutionalization plans which include provision for appropriate services, protective supervision, and follow-up for persons in institutions whose care is supported by Medicaid or Medicare or for whom social services were provided under Titles IV and VI of the Social Security Act.

Cooperative agreements

Oregon has established and implemented various agreements which require that release planning and follow-up be provided to released hospital patients eligible for Federal programs in the community. The following joint agreements existed between Oregon's Mental Health,

Public Welfare, Children's Services, and Vocational Rehabilitation Divisions establishing the agencies' responsibilities for release planning and followup.

- Public Welfare/Mental Health agreement providing: (1) Title XIX funds for eligible patients aged 65 and over or under 21 years of age in mental hospitals and for patients of any age in a State retardation hospital, (2) Adult Social Services (Title VI) funds for community placement of each eligible patient, and (3) a continuity of care for eligible persons who return to the community. The two agencies also implemented an agreement in July 1974 to utilize Title XIX funds to provide community mental health services for eligible persons.
- Public Welfare/Vocational Rehabilitation agreement providing adult social services (Title VI) to subsidize a sheltered workshop program for severely disabled persons, as well as helping to provide housing, day care, and other appropriate support in the community. The agreement calls for followup by the two agencies to determine each person's progress, to develop new goals, and to review the rehabilitation plan.
- Children's Services/Mental Health/Public Welfare agreement to provide services to eligible Medicaid (Title XIX) recipients under the age of 18. However, the agreement states that the Children's Services Division's responsibility for providing liaison child service at State hospitals was dependent on the agency getting the necessary staffing positions, which have not all been obtained.
- Vocational Rehabilitation/State Hospitals agreements requiring that the former: (1) assign a counselor to the hospitals, (2) accept referrals, investigate eligibility, and develop vocational rehabilitation plans, (3) provide counseling, guidance, and placement, and (4) supervise aid and evaluate extramural rehabilitation activities.

The Children's Services Division, which has the responsibility for Title IVA and IVB social services, did not have a formal agreement with Mental Health for providing release planning and community-based social services to eligible institutionalized children. A Children's Services Division official said that released children are provided social services planning and support, but on a case-by-case basis. She noted, however, that Children's Services and Mental Health were working on a joint agreement identifying these specific responsibilities, and that the agreement should be signed shortly.

Although the agreements have helped to insure a better transfer of responsibility from the institution to the many community-based service agencies, as noted in chapter 4, (1) no single document at the institution or community level clearly identified the individual's total needs, (2) release planning is split between the hospital staff and other State agencies and is not adequately integrated, and (3) no single agency was exercising overall responsibility for ensuring that the person's total needs were being met in the community.

USE OF FEDERAL PROGRAMS AND INAPPROPRIATE PLACEMENTS

As noted in chapter 3, many mentally disabled persons remain in institutions who do not necessarily need that level of care or have been placed into settings that are inappropriate to their needs or without the provision of needed services. Oregon could utilize the Medicaid, SSI, Vocational Rehabilitation, Employment Service, and federally funded housing assistance programs to increase the availability of needed community-based services and facilities and to identify inappropriately placed mentally disabled persons.

Medicaid

It appears that the structure of the Medicaid program is inadvertently encouraging institutional and nursing home placement in Oregon, especially for the mentally retarded. Costs of institutional and nursing home care have been heavily supported by Medicaid, while the costs of the specialized services needed by the mentally disabled in alternate settings are only partially covered under Medicaid. Oregon's Medicaid program includes coverage of the following:

- Inpatient hospital services, with a 21-day limit annually.
- Inpatient mental hospital care for persons 65 or older or under 21 (or 22 in certain cases).
- Skilled nursing facility services.
- Intermediate care facility services for the mentally retarded and persons with related conditions, including services in public institutions.
- Clinic services.

Information is not available on the total number of mentally disabled persons in skilled nursing or intermediate care facilities or the quality of care they are receiving on a case by case basis. However, it appears

that many of these persons have been placed into these facilities because they were the only available alternative. As a result, some are not receiving the services they need. According to Oregon's nursing home ombudsman, this resulted in two major problems--mentally disabled persons were placed into nursing homes that were not staffed or prepared to handle their special needs; while other persons, such as the elderly needing placement in nursing homes, could not get in because the beds were taken by the mentally disabled from institutions.

Development of alternatives
under medicaid

Coverage of alternatives to State hospitals under Medicaid appeared limited and in some cases were not available. A significant portion of the Medicaid funds in Oregon support the costs of the retarded in institutions and both the mentally retarded and mentally ill in nursing homes. The following comparison of the fiscal year 1974-75 Medicaid budget for State institutions and clinic services gives some idea of the limited use of Medicaid for community-based services for mentally disabled in Oregon:

	<u>Federal portion</u>
Institutions for mentally retarded	\$8,705,000
Institutions for mentally ill	1,139,000
Clinic services	849,000
Nursing homes	amount not known

Although Oregon has used Medicaid to support a large portion of its institutional, skilled nursing and intermediate care facilities, the State has only recently started to use the program to develop needed community services. For example, clinic services were not covered under Medicaid until July 1974. Day care services for the mentally disabled and small, community-based ICFs of 15 beds or less have not been developed although the Federal Medicaid program covers them.

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

Many mentally retarded persons remain in State hospitals because of the lack of residential facilities. The State, however, has not developed small ICFs (for under 15 persons) to help fill this need. The Mental Health liaison in Public Welfare said they have not developed these ICFs because of the confusion surrounding the Federal regulations. He noted that the regulations cover all ICFs, including ICFs in institutions and ICFs of 15 beds or less. The Mental Health liaison said Public Welfare has not wanted to move on licensing in this area because of the confusion.

The Director of the Mental Health Division's mental retardation and developmental disabilities program said another reason for not participating in the small ICFs program is that the Federal regulations are too medically oriented. He noted that the retarded person's needs are more socially oriented, and that the emphasis on the medical model is not required.

Opportunities for improving
utilization controls

Oregon could use more effectively its utilization control processes for its deinstitutionalization efforts. The processes could identify better (1) mentally disabled persons who are inappropriately placed because of the unavailability of alternatives, (2) the specific alternative facilities and services that are needed, and (3) mentally disabled persons who are not receiving appropriate services to meet their mental health needs.

The Federal Government has imposed a number of Medicaid requirements on the States to ensure that

- persons are not placed into or remain in facilities that are not appropriate to their needs,
- efforts are undertaken to identify persons who are inappropriately placed or who are not receiving needed services, and to explore alternate placement, and
- States are taking steps to develop and use appropriate alternatives to institutional care.

A Federal mechanism for these purposes is the utilization control process. Federal legislation requires that States 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. Three types of reviews are required: utilization, independent medical, and independent professional.

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. Independent professional reviews are required in ICFs and ICFs for the mentally retarded.

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

In addition, for persons in ICFs and ICFs for the mentally retarded the State Medicaid agency is required to evaluate the availability of community resources. If community resources were determined to be unavailable and if these unavailable resources could meet the person's needs, the State Medicaid agency must document their unavailability and initiate plans for active exploration of alternatives .

The utilization control process in Oregon does not appear to be resulting in many alternate placements of the mentally disabled. The Administrator of Public Welfare noted that the medical/independent professional review has resulted in few alternative placements. The Manager of the Division's Medical and Utilization Review said the reviews in ICFs were not expected to generate many alternative placements.

The reason for the limited number of alternative placements generated as a result of the utilization control process appears to be the lack of alternative services and facilities in the community. For example, in response to HEW's internal audit report that showed that 10 of 33 mentally retarded persons reviewed were not receiving appropriate care in ICFs, the Administrator of Oregon's Public Welfare Division stated that they are short of ICF beds and cannot guarantee that every patient will receive the recommended care and services. The manager of the utilization reviews in ICFs said that Oregon did not have the community resources, so it did not make a lot of sense to push too hard for alternative placement.

The way Oregon's utilization control process is documented seems to reflect the attitude that alternatives are not available in the community. The reports generated by Oregon's independent medical and professional review team do not readily identify mentally disabled persons who could be placed in other than an institution, skilled nursing or intermediate care facility or the alternative services and facilities that are needed.

The team's reports are on pre-printed forms that have over 300 areas that must be evaluated. In most instances, compliance or noncompliance with a requirement is noted by a mark in the appropriate column. Based on our review, the report does not provide a means for determining whether a mentally disabled person is at that level of care because they need it or because other more appropriate alternatives were not available. In addition, the report does not identify the specific services and facilities that were unavailable in the community. For example, a special study funded by the Developmental Disabilities Council showed that 63 percent of the persons at Fairview could be placed in the community and identified the type of services they would need. But, the most recent independent professional review completed at Fairview did not determine the total number of persons that could be placed in the community or the specific services they would need. One reason for this was that only 25 percent of the residents had been evaluated. HEW identified this problem in its review of Oregon's utilization control program in November 1974, and the State has agreed to take corrective action if funds are available.

Further illustrating the lack of emphasis given the identification of the need for alternative placement and the service needs of the mentally disabled in skilled nursing and intermediate care facilities is the fact the medical/independent professional review team in Oregon does not include a mental health professional to evaluate the appropriateness of the care being provided to meet the needs of the mentally disabled in skilled nursing facilities or ICFs.

Supplemental Security Income and Social Services

Mentally disabled persons can be released on SSI, but funds for needed social services may not be available. There is no Federal ceiling on the number of people who can be placed in the community under SSI. However, there is a ceiling on the amount of Federal dollars that can be used for social services and Oregon spends its limit. 1/ The Director of Adult Services said that the limit on social services funds under Title VI was hindering the State's ability to provide needed services to the mentally disabled in the community.

With certain exceptions, the Federal Government has not required that SSI recipients have a treatment plan or be provided with needed services. Therefore, persons can be placed in the community and

1/ Mentally disabled adults receiving SSI qualify for social services.

supported with SSI funds without assurance that they receive needed social rehabilitation, or other services. This problem has been partially resolved for mentally retarded persons in group homes in Oregon. The State adopted new standards in January 1975 to ensure that quality group care is provided by group homes. The new standards require that each person placed into a group home have a treatment plan and that there be one training coordinator for every 10 residents.

Oregon officials also noted other problems in the SSI program:

- Delays in getting SSI payments for institutionalized persons have caused problems for those persons after their release and for group home operators.
- The Director of the Adult Social Services program said that SSI requirements are too restrictive. She noted that the agency was having problems getting SSI to approve the applications of the mentally disabled leaving State institutions. The Director said SSI does not consider the individuals' social functioning; their evaluation is limited to medical aspects. If a person is not approved for SSI, they are also cut-off from social services (Title VI).
- The Director of Social Services at Fairview noted that SSI could be used to increase the foster rates for the mentally retarded child so that needed foster parents could be recruited. However, he said that the Children's Services Division is not taking advantage of the SSI program. A Children's Services Division official told us that no one in the agency understands the SSI program well enough to take full advantage of it.
- Implementation of an HEW regulation under Title XIX of the Social Security Act could result in the reduction or loss of SSI for persons in group homes who receive more than room and board but less than skilled nursing care.

Vocational Rehabilitation

Oregon's Vocational Rehabilitation agency serves the mentally disabled in institutions and in mental health clinics. For the mentally ill, the Vocational Rehabilitation agency has been shifting emphasis from institutions to mental health clinics in response to the significant reduction in institutional populations. With respect to the retarded, however, there is some confusion regarding whether services should be diverted from the "borderline retarded" in the community to the more severely retarded in the institutions.

Oregon's Vocational Rehabilitation psychological consultant said that many of the mentally retarded persons served by Oregon's Vocational Rehabilitation program are not retarded according to the criteria established by the American Association for Mental Deficiencies in 1973. The Association dropped the "borderline" retarded classification (IQ 70 to 85) in order to eliminate the labeling of borderline persons as being mentally retarded. The psychological consultant estimated that many of the retarded they serve fit in the borderline category, and that many of these people are already in the community. On the other hand, he noted that most of the retarded in State institutions they serve are moderately or severely retarded.

The psychological consultant said the situation created by the Association's change is that the agency must either:

--discontinue service to the people with IQs over 70. However, the agency's psychological consultant stated that persons in the community who have IQs between 70 and 85 have greater potential for being rehabilitated, can be rehabilitated in less time and less effort, and have better chances for placement than the more severely disabled in the institutions. He concluded that if the Vocational Rehabilitation agency diverted more of its resources to the more severely retarded, it would adversely affect its ability to help the less severely retarded in the community who also need Vocational Rehabilitation services, or

--not use the Association's classification system. The agency's consultant said that the Association's criteria is optional and that the psychologists the agency contracts with to evaluate an individual's retardation level do not have to use the Association's system. He also noted that IQ is not the only factor used to determine the level of retardation. HEW program instructions provide that a combination of IQ and functional ability should be considered in determining retardation levels.

The agency's psychological consultant said that the Association's change was made unilaterally and that the State agencies were not contacted. He stated that HEW is attempting to work with the Association to resolve the situation. In the meantime, State agencies have been notified by HEW not to make any drastic changes. As a result, Oregon's Vocational Rehabilitation agency is continuing to consider anyone with an IQ under 85 as being mentally retarded.

Employment services

To ensure that Federal contractors (contracts in excess of \$2500) take affirmative action to employ the handicapped, Section 503 of the Vocational Rehabilitation Act of 1973 was passed. The legislation allows any handicapped person who believes he has been discriminated against to file a complaint with the Department of Labor.

The Oregon Employment Division indicated nothing had been done to implement the law because the Department of Labor had not provided appropriate guidelines and there is no data base for identifying contractors receiving between \$2,500 and \$10,000.

Housing and urban development

The five housing authorities we reviewed were providing federally assisted housing that could be used to provide community-based residential facilities for the institutionalized disabled. However, three of the five housing authorities gave no special preference to the mentally disabled waiting for housing. The local housing authorities did indicate, however, that they do cooperate with other agencies after a mentally disabled person becomes a tenant.

Title I of the Housing and Community Development Act of 1974 (P.L. 93-383) consolidates several programs into one block formula grant to States and local government. Local governments must submit a housing assistance plan to qualify for Federal funds under the 1974 Act. The plan is supposed to assess the housing needs of lower-income persons, including the elderly and handicapped.

The City of Salem was the only one of the four communities we visited to address the needs of the mentally disabled in its Housing Assistance Plan. Salem officials noted they receive more than their fair share of the mentally disabled because Fairview and Oregon State Hospital are located in the city. As a result, housing officials have been aware of the needs of the mentally disabled for sometime. The city's housing plan proposes to develop 28 housing units for the mentally disabled under Section 8, Title II of the Housing and Community Development Act.

Another potential source of funds is the community development program under HUD which can be used to develop some of the services needed by the mentally disabled under certain conditions. Deinstitutionalization, however, has not been recognized as a "community development" problem by local agencies that administer HUD programs.

CHAPTER 6

NEED FOR MORE EMPHASIS ON DEINSTITUTIONALIZATION BY REGION X AGENCIES

Deinstitutionalization of the mentally disabled has been a national goal since 1963. In that year Congress authorized funds for States to develop plans to meet the comprehensive needs of the mentally disabled. In the same year, President Kennedy highlighted the need for community-based service for the mentally disabled and gained Congressional acceptance for the comprehensive community mental health centers and mental retardation facilities program, which was intended to enable hundreds of thousands of persons confined to the Nation's institutions to be returned to the community.

The needs of the institutionalized mentally retarded were reaffirmed by President Nixon in 1971 when he called for the return to the community of one-third of the more than 200,000 retarded persons in public institutions. The President stated that all Federal agencies would evaluate their programs and provide maximum support to a coordinated national effort to return the mentally retarded to the community. The President specifically directed HUD to assist in the development of special housing arrangements to facilitate independent living for retarded persons in the community. The goal was again affirmed by President Ford in 1974 when he stated that the Government's housing agencies would help the retarded persons obtain suitable housing and urged employers to use the Employment Service to assist in hiring the retarded.

Congressional preference for community-based care rather than institutional care has been expressed in several major pieces of legislation since 1963. In addition, several States are under court mandates to provide care to the mentally disabled in the least restrictive environment.

Even though Presidential and Congressional concerns have been expressed about reducing institution populations, Region X agencies were not directing their efforts toward deinstitutionalization of the mentally disabled. The Federal Regional Council had not identified the area as one in need of inter-agency coordination; HEW agencies were not emphasizing, coordinating, or monitoring their programs' impact on the problem; HUD was not aggressively responding to its Presidential mandates to assist in returning the retarded to the community; and legislation requiring Federal contractors to take affirmative action to hire the handicapped was not being aggressively implemented.

Many regional officials we contacted stated that the lack of a clear headquarters mandate to emphasize deinstitutionalization and the lack of Region X staff and resources to initiate an effective effort were the main reasons why they were not emphasizing deinstitutionalization.

FEDERAL REGIONAL COUNCIL

In 1972 Federal Regional Councils were established in the 10 Federal regions to develop closer working relationships between Federal agencies and State and local governments and to improve coordination of the categorical grant-in-aid system. The Councils consist of several Federal agencies in each Federal region.

The Councils were established to coordinate Federal efforts at the regional level, develop short and long-term inter-agency and inter-governmental strategies to better respond to State and local community needs, and to evaluate programs in which two or more member agencies participate. Office of Management and Budget guidance states that "Councils are visible spokesmen for national policies * * * they explain national policy, and facilitate its implementation by State and local governments."

The Federal Regional Council in Region X had not addressed deinstitutionalization. The Staff Director for the Council said they have not identified or worked on achieving any program for coordination of Federal agencies involved in deinstitutionalization. He noted that the problem has never been mentioned as an area in need of interagency coordination.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

HEW Region X agencies contacted had not emphasized deinstitutionalization of the mentally disabled. Efforts to coordinate activities to focus on deinstitutionalization had not taken place, and the agencies were not systematically or routinely monitoring the impact of their programs on the problem. Many Region X officials indicated that they were not taking specific actions for deinstitutionalization because they lack clear headquarters mandate to emphasize it, and lack the staff and resources to initiate an effective effort. However, recent special efforts had been made by the Regional Director of HEW, and the Social and Rehabilitation Services Commissioner to give increased emphasis to deinstitutionalization.

The following Region X HEW agencies were contacted during our review:

Social and Rehabilitation Service (SRS)
Medical Services Administration (MSA)
Community Services Administration (CSA)
Rehabilitation Services Administration (RSA)
Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA)
Office of Nursing Home Certification
Bureau of Health Insurance
Social Security Administration (SSA)
Office of Education
Family Health Branch
Office of Aging
Office of Child Development
Family Planning and Maternal and Child Health

Lack of emphasis given
deinstitutionalization

HEW Region X agency officials stated that they were not emphasizing deinstitutionalization because there was no mandated priority for it. In addition, they did not have the staff or resources to emphasize it. Many of the agencies indicated they were not in a position to initiate assistance to the States on deinstitutionalization.

The Regional Director advised us as follows: HEW agencies deal in categorical programs established by law, there is no Federal program called deinstitutionalization, and there are Federal programs that provide funds to States which can be utilized by the States to return institutionalized persons to the community. However, the States have the responsibility for determining how these funds are to be utilized within Federal law and regulations. In Region X, there has been a very strong movement toward removing persons from institutions to the community.

Only ADAMHA and Developmental Disabilities program officials indicated they were giving specific attention to deinstitutionalization. According to the Regional Director, only Title XX of the Social Security Act (which replaced Title IVA and VI), the Community Mental Health Centers Act, and, to some extent, the Developmental Disabilities Act address prevention of inappropriate institutionalization or deinstitutionalization as goals.

Region X ADAMHA officials said that deinstitutionalization is reflected in the Community Mental Health Centers' Act and in the agency's implementation of the Act. They had identified deinstitutionalization in their fiscal year 1974 regional work plan, but dropped it in 1975 because other mandated activities absorbed most of their time. The

officials stated that most of their time is devoted to deinstitutionalization-related activities if their community care programs are considered to be oriented towards deinstitutionalization. They noted that more emphasis was being placed on the relationship between the hospital and community mental health centers. They added, however, that unless ADAMHA's involvement includes a federally funded Community Mental Health Center or Hospital Improvement Project, or unless a State requests deinstitutionalization assistance, they have no authority to initiate assistance to States. Other than activities related to the Federal projects, they had no plans to assist State deinstitutionalization efforts.

Region X RSA officials stated that although they could not recall receiving specific instructions, deinstitutionalization has been a priority area of the Developmental Disabilities program for the last few years. They identified deinstitutionalization in their fiscal year 1975 work plan in anticipation of amendments to the Developmental Disabilities Act. The regional plans called for 60 percent of RSA staff time to be devoted to activities which include rehabilitation of the severely handicapped and deinstitutionalization of persons now confined. The RSA officials, noted, however, that deinstitutionalization is a State responsibility and that the State Developmental Disabilities Councils are responsible for establishing priorities. The regional officials indicated that they have a supportive role in relation to State activities and that they can respond to State requests for technical assistance on areas such as deinstitutionalization.

The RSA officials stated that both the Vocational Rehabilitation and Developmental Disabilities programs impact on deinstitutionalization. The officials noted that Vocational Rehabilitation regulations (45CFR401) that went into effect December 1974 will have a beneficial impact on deinstitutionalization. The officials indicated that institutionalized people will probably receive a larger share of the Vocational Rehabilitation budget as a result of the new regulations. The Developmental Disabilities program has facilitated community placement by establishing councils which plan and develop deinstitutionalization priorities and has provided deinstitutionalization planning funds and small amounts of seed money to help start community-based programs. A Region X Developmental Disabilities official said, however, that their staff is too small and funding for the States is insufficient to have much impact on the problem.

Other HEW Region X officials contacted indicated they devoted very little time or effort to deinstitutionalization. For example, Region X Supplemental Security Income officials said the region had not taken

specific actions relating to deinstitutionalization. The officials said district offices are encouraged to participate with State and local agencies, as time and resources allow, but that the district offices are not to take the initiative.

Special efforts to increase
emphasis on deinstitutionalization

Although the HEW agencies were not emphasizing deinstitutionalization of the mentally disabled, the HEW Regional Director and the SRS Regional Commissioner had initiated attempts to give increased emphasis to deinstitutionalization.

The Regional Director submitted a series of issue papers to headquarters in January 1975 on behalf of all Regional Directors as their contribution to the agency's planning cycle. Deinstitutionalization was identified as an issue that cuts across the responsibilities of various HEW programs. The Regional Director's transmittal memo noted the following about deinstitutionalization:

--HEW has not pushed for clear, consistent State/local action plans and has not developed a coherent, forceful strategy to support constructive State and local efforts. HEW should take a closer look at its programs in terms of the impact on State and local efforts, and find ways to eliminate or mitigate any disincentives to deinstitutionalization.

The Regional Director has the responsibility to examine and analyze problems that are crosscutting in nature. Recognizing deinstitutionalization as one such issue, the Regional Director said he determined that there was a lack of sufficient information to make decisions or recommend changes. As a result, the region's Office of Planning and Evaluation proposed an evaluation of deinstitutionalization to the Assistant Secretary for Planning and Evaluation in November 1974. The proposed evaluation was to be done in Washington and Idaho. Areas to be covered included (1) the extent that tracking mechanisms exist between the institutions and the community, (2) the cost of providing community-based services versus the cost of institutional care and which level of government is paying these costs, and (3) the definition of what are adequate community services. Approval of the proposal was expected by October 1975, and after bids were received, the evaluation would begin in late November or early December 1975.

The Commissioner of SRS in Region X had made an effort to evaluate how his program could assist deinstitutionalization. A study of Federal

restrictions, ambiguities, and practices as they impacted upon Oregon's deinstitutionalization efforts was done in 1975. The study was done in response to the Commissioner's desire to reorganize his programs to give more emphasis to deinstitutionalization. SRS officials said, however, that the study indicated that there was nothing SRS programs could do to further impact on deinstitutionalization. The proposed reorganization emphasizing deinstitutionalization was dropped because of the study and several other reasons.

Coordination for deinstitutionalization

Most HEW Region X officials indicated there had been no coordination to specifically benefit the deinstitutionalization of the mentally disabled. ADAMHA and Developmental Disabilities officials were not coordinating deinstitutionalization efforts at the regional level for the mentally ill and mentally retarded. Also, the designated HEW person representing the Office for Handicapped Individuals was doing little to direct or coordinate regional activities for deinstitutionalization of the mentally disabled.

Region X ADAMHA officials said they have not attempted to coordinate at the regional level, because they rely on State and local agencies to coordinate their efforts at the implementation level. Region X RSA officials stated that deinstitutionalization is not a high priority with other agencies so they have not attempted to coordinate with them. The Regional Developmental Disabilities representative said he does coordinate with other regional staff on a frequent basis, but not specifically to benefit deinstitutionalization. He noted, however, that it is not a high priority in other agencies and that the agencies do not devote much time and resources to the area. The official stated that the Developmental Disabilities staff is not in a good position to influence other agencies because they do not have sufficient staff or funding.

Each regional office was directed to designate a person to represent the Office for Handicapped Individuals as a focal point for the handicapped. The Administrator of RSA who was serving as the HEW Handicapped Representative in Region X said, however, that he had not been assigned specific duties or responsibilities as handicapped representative since being appointed several years ago.

Deinstitutionalization not adequately monitored

According to the Regional Director, by law, HEW is responsible for overseeing categorical programs and assuring that they are administered

within the law and regulations. He said that because of the categorical nature of HEW programs, regional program officers have little, if any, authority to go looking at a State policy that crosscuts many programs.

Most HEW Region X agencies contacted were not systematically or routinely monitoring their programs' impact on deinstitutionalization or State and local efforts to implement deinstitutionalization. For example, Medicaid and SSI can provide payments for the care and treatment of the mentally disabled in institutions and the community. However, the two Region X programs were not monitoring release planning, followup, or the progress States were making in developing alternatives to institutionalization.

Region X personnel involved in the Medicaid program represent MSA, the Office of Nursing Home Certification, Bureau of Health Insurance, and the SRS Special Initiatives Unit. MSA officials said that because of a lack of staff they have no on-going monitoring effort relating to deinstitutionalization. The agency had not evaluated the following Medicaid requirements which affect how a State implements deinstitutionalization:

- discharge planning as required by HEW regulations effective December 1974. MSA officials said they have not evaluated discharge planning because the requirements were new and they were unsure how to enforce them.
- followup and aftercare for persons 65 or older or under 21 who have been released from mental hospitals and institutions for the retarded. MSA officials stated that the regulations for persons under 21 are still in draft form.
- State cooperative arrangements for using Title V agencies (CMHC's, Vocational Rehabilitation, neighborhood health centers, and others). MSA officials indicated they have no authority to evaluate the content of the agreements.
- State cooperative arrangements for (1) developing and using community alternatives for persons 65 or older in mental hospitals and those facing the risk of institutionalization; or (2) developing and implementing a comprehensive mental health program for persons of all ages. MSA officials noted that the States are no longer required to submit an annual progress report which covered these two topics and as a result, it is difficult for MSA to know what is happening in the

States. Progress reports still are called for by 45CFR208. One MSA official noted that they did not have the authority to question the adequacy of the State agreements. The MSA representative for Oregon said there was adequate coordination between the State agencies.

--State cooperative efforts for developing and using community alternatives for the retarded in public institutions.

--progress made in the development and use of alternatives in the States in Region X.

The Director of the Office of Nursing Home Certification stated that they have no program responsibility for deinstitutionalization, and that he was not aware of the roles of other HEW agencies. The Director noted that the agency had conducted a workshop to explain recent instructions prohibiting the mentally retarded being placed in ICFs which cannot meet their needs (MSA-PI-75-4). He stated, however, that the agency had not narrowed in on the mentally retarded or on ICFs for the mentally retarded because they represent a small portion of their total responsibility. He also noted that the agency has no staff experienced in dealing with the mentally retarded. The Director indicated that evidence of discharge planning is looked for by the agency's staff when they inspect a facility, but that it is the State's responsibility to move a person when they are not receiving appropriate care.

The Special Initiatives Unit, under the Region X SRS Commissioner, had completed a review of Oregon's Utilization Control System for Medicaid in November 1974. The review was intended to ensure that procedural requirements were met. It did not include discharge planning or whether alternate care in the community was being adequately considered. Their findings included the following: (1) utilization review for ICFs did not meet the requirement for involvement of medical personnel; (2) some skilled nursing facilities had failed to comply with utilization review requirements, and (3) Independent Professional Reviews in ICFs were done on a 25 percent sample basis, because Oregon did not have sufficient staff to do a 100 percent review of every ICF by March 1975.

SSA officials said they have made no attempts to monitor or evaluate the impact that the SSI program has on returning the mentally disabled to the community. For example, neither Region X officials nor the three district offices we contacted in Oregon had information indicating whether or not SSI referrals to Vocational Rehabilitation were receiving services. The three district offices also were not following-up referrals to local social service agencies to ensure that the individuals received

needed services. Regional SSA officials said their responsibility is to get SSI payments to eligible recipients, but that they do not have the same level of responsibility for the person's social needs. The SSI officials also said they do not have the leverage to get the States to act on deinstitutionalization.

Although other HEW agencies were not monitoring deinstitutionalization on a regular basis, we did identify the following examples of HEW evaluation which address certain aspects of deinstitutionalization.

--An ADAMHA official said they review CMHC and Hospital Improvement Program applications with a focus on community development, which they feel is directly related to deinstitutionalization. He also noted that Hospital Improvement projects and CMHC applications are reviewed and monitored in terms of the problems of transition from the hospital to the community.

--In 1974 the HEW Audit Agency reviewed private ICFs under Medicaid in Oregon. They noted that 10 of 33 mentally retarded patients reviewed were placed in ICFs which did not provide care needed by the patients. The agency indicated that as a result of these improper placements, there were discipline problems with the retarded patients and disruption of the well-being of the other ICF patients. The audit report recommended that (1) a post-institutional plan of care should be required for each retarded patient entering an ICF; (2) retarded patients not receiving the care specified in the post-institutional plans should be transferred to suitable institutions or ICFs; and (3) a followup should be made periodically of each retarded patient. The Administrator of Oregon's Public Welfare Division responded that the agency agreed with the three audit agency recommendations. He noted that Oregon is short of ICF beds and cannot guarantee that every patient will receive the recommended care and services. The Administrator indicated that they will continue to provide the optimum service available and will provide periodic followup to insure to their best ability that the patient is receiving the most adequate care available.

--A National Institute of Mental Health evaluation at Oregon State Hospital was completed by the Oregon Mental Health Division in June 1974. The review team concluded that: (1) both community and hospital staff agree that many patients are discharged prematurely, that the communities are not yet equipped to handle large caseloads of sick patients, and that

there is a high return rate of such patients to the hospital; (2) it is not always clear whether patients are admitted because psychiatric hospitalization is the "treatment of choice" or an easy alternative; (3) historically, there have been very little formal aftercare services provided patients who leave Oregon State Hospital by staff members from the hospital, nor have there been "teams" from the hospital traveling to communities to assist clinics or other community agencies to develop resources to provide alternatives to hospitalization; (4) there were gaps in communication channels between the State level, the regional level, and the hospital organization, as well as within the hospital itself; and (5) there is also concern about the continued adequacy of financing of county services because some county commissioners have indicated a wish to "level off" their contributions.

DEPARTMENT OF HOUSING
AND URBAN DEVELOPMENT

HUD was directed by President Nixon to assist in the development of special housing arrangements to facilitate independent living for retarded persons in the community in 1971. President Ford further stated in October 1974 that Federal housing agencies will do whatever they can to help retarded adults obtain suitable homes.

Little has been done to give emphasis to the housing needs of the mentally disabled at the region or area office level. Persons had been designated in HUD to give emphasis to the handicapped in Region X, but they have not emphasized the needs of the mentally disabled. The Region X handicapped coordinator told us that HUD had appointed elderly and handicapped specialists in each of its major program areas, and at the area office. One person at the regional level had been assigned overall responsibility for coordinating efforts in the region. However, this person had done very little since appointed in 1972, while the Portland Area Office Elderly and Handicapped coordinator had no idea what his responsibilities included.

Officials at HUD's Portland Area Office were not aware of the November 1971 Presidential statement requiring HUD to assist in the development of special housing arrangements in the community for the retarded, and they had never received any directives to take such action. Area office officials indicated that they had not attempted to determine the housing and community development needs of the mentally disabled nor had they coordinated with HEW or any State or local mental health authorities for deinstitutionalization. No directions, mandate, or

guidance to determine the number of mentally disabled needing housing assistance had been received. Area office officials noted, however, that they were already doing everything they could but had no statutory, regulatory, or program basis to determine the needs of the mentally disabled. Also, they noted that the statutory and regulatory definitions of handicapped were either silent or excluded the mentally disabled until 1974 when the definition was broadened to include mental retardation, cerebral palsy, epilepsy, and other neurological conditions.

DEPARTMENT OF LABOR

To ensure that Federal contractors take affirmative action to employ the handicapped under contracts in excess of \$2,500, Section 503 of the Rehabilitation Act of 1973 was passed. The legislation allows any handicapped person who believes he has been discriminated against to file a complaint with the Department of Labor.

However, in March 1975 the Region X official responsible for monitoring Federal contractors' actions to hire the handicapped said that he had done little because (1) central office had not provided adequate direction for implementing the legislation, (2) he did not have the staff or funds to implement the act, (3) information identifying Federal contractors was not available and (4) criteria for determining when an employer is not complying is weak. He noted that only three complaints had been filed by developmentally disabled individuals, but that these cases were dropped because the employers were not Federal contractors. The official stated that Section 503 could be an effective means of obtaining employment for the mentally disabled if the resources were available to implement the legislation.

In August 1975 another person became responsible for the program. The agency had provided more emphasis on the program by providing a training session, which the new person attended. However, he still lacks staff and information concerning Federal contracts between \$2,500 and \$10,000. As of August 29, 1975, he had 27 complaints, and four were from Oregon. Only one of those four had a mental disability, but he did not know if the person had been in an institution.

BARRIERS TO DEINSTITUTIONALIZATION

The regional agencies generally agreed that inadequate Federal funding of community services and facilities is the main barrier to deinstitutionalization. Coupled with this is the lack of Region X staff and resources to initiate an effective effort. Underlying all barriers is the lack of a clear mandate to emphasize deinstitutionalization.

The following is a list of other barriers to deinstitutionalization identified by Region X officials:

- SSA officials said that SSI criteria are restrictive. They noted that when an individual is released from an institution the question is whether he is still medically disabled despite the fact the individual may still be socially disabled. Other problems hampering SSI's impact on deinstitutionalization include: (1) inability to respond fast enough to the financial needs of the mentally disabled when they are placed in the community; (2) difficulty obtaining patient information from State hospitals, and (3) problems developing cooperative arrangements with State and local social service agencies.
- CSA representatives said the \$2.5 billion ceiling on social services is hindering the release of additional mentally disabled. Every State in Region X is spending its social service allotment, and their share will not change as a result of Title XX. In contrast, CSA officials noted that there are no limits on the Federal matching funds available to State institutions for Medicaid recipients.
- Medicare officials noted that nursing homes are not equipped and personnel in the homes are not trained to handle the mentally disabled.
- The Director of the Office of Nursing Home Certification said that ICF operators feel Federal regulations are too demanding for small community-based facilities. The regulations are best met by large State institutions.
- An ADAMHA official indicated that better coordination of community-based support systems is needed. He noted that the social service program is very complex and confusing and that an individual needs assistance in obtaining services.
- Research is needed to determine, by diagnosis, who can be successfully deinstitutionalized. Tied to this is the need to improve local diagnostic skills to better evaluate individual needs. Also, an evaluation and monitoring system to identify changes in an individual's progress once they enter the community should be developed.
- There is a basic lack of community services and facilities to adequately support deinstitutionalized patients. Insufficient

employment opportunities, leisure time activities, transportation services, and residential facilities are all hampering deinstitutionalization efforts. Local communities need training and assistance to handle the mentally disabled. For example, foster parents need training and supportive services to handle the mentally disabled.

AVERAGE DAILY POPULATIONS OF OREGON
HOSPITALS FOR THE MENTALLY ILL
(1957 to 1974)

Year	Average Daily Population				Total	Change from prior year	
	Oregon State	Dammasch	Eastern Oregon	Columbia Park		Number	Percent
1957-58	3,545		1,520		5,065		
1958-59	3,541		1,499		5,040	- 25	- 0.5
1959-60	3,389		1,521	65	4,975	- 65	- 1.3
1960-61	3,105	42	1,468	95	4,710	-265	- 5.3
1961-62	2,724	274	1,361	95	4,454	-256	- 5.4
1962-63	2,449	312	1,212	90	4,063	-391	- 8.8
1963-64	2,044	346	1,035	90	3,515	-548	-13.5
1964-65	1,824	360	834	60	3,078	-437	-12.4
1965-66	1,640	399	652	3	2,694	-384	-12.5
1966-67	1,518	402	564		2,484	-210	- 7.8
1967-68	1,375	397	521		2,293	-191	- 7.7
1968-69	1,236	408	486		2,130	-163	- 7.1
1969-70	1,090	401	454		1,945	-185	- 8.7
1970-71	897	414	417		1,728	-217	-11.2
1971-72	758	391	365		1,514	-214	-12.4
1972-73	702	389	333		1,424	- 90	- 5.9
1973-74	589	399	275		1,263	-161	-11.3

AVERAGE DAILY POPULATIONS OF OREGON
HOSPITALS FOR THE MENTALLY RETARDED
(1959 to 1974)

<u>Year</u>	<u>Average Daily Population</u>			<u>Total</u>	<u>Change from prior year</u>	
	<u>Fairview</u>	<u>Columbia Park</u>	<u>Eastern Oregon</u>		<u>Number</u>	<u>Percent</u>
1959-60	2,384	65		2,449		
1960-61	2,579	125		2,704	+255	+10.4
1961-62	2,688	149		2,837	+133	+ 4.9
1962-63	2,715	154		2,869	+ 32	+ 1.1
1963-64	2,494	346		2,840	- 29	- 1.0
1964-65	2,466	431	22	2,919	+ 79	+ 2.8
1965-66	2,319	489	124	2,932	+ 13	+ 0.4
1966-67	2,160	498	298	2,956	+ 24	+ 0.8
1967-68	2,143	505	384	3,032	+ 76	+ 2.6
1968-69	2,130	507	392	3,029	- 3	- 0.1
1969-70	2,033	482	449	2,964	- 65	- 2.1
1970-71	1,927	462	456	2,845	-119	- 4.0
1971-72	1,725	450	533	2,708	-137	- 4.8
1972-73	1,559	398	509	2,466	-242	- 8.9
1973-74	1,448	337	437	2,222	-244	- 9.9

FEDERAL, STATE AND LOCAL AGENCIES
PROVIDING AND SUPPORTING DEINSTITUTIONALIZATION SERVICES

Service provided	State Department of Human Resources						State Department of Higher Education	State Department of Education	County Public Health	Federal Social Security (SSI)	Local housing authority
	Mental Health Division	Public Welfare Division	Children's Services Division	Vocational Rehabilitation Division	Employment Division	Health Division					
Housing (including basic living skills)	X	X	X	X						X	X
Mental Health Services	X	X		X							
Medical Services		X		X			X		X		
Activity Programs	X	X	X								
Sheltered Workshops		X		X							
Training (work, education)	X			X	X			X			
Employment Placement				X	X						
Release Planning	X	X	X	X							
Followup	X	X	X	X	X		X		X		
Monitoring and evaluation	X	X		X							
Program Standards	X			X				X			
Licensing and certification			X							X	

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 PROVIDING AND SUPPORTING DEINSTITUTIONALIZATION SERVICES

Service provided	State Department of Human Resources					State Department of Higher Education	State Department of Education	County Public Health	Federal Social Security (SSI)	Local housing authority
	Mental Health Division	Public Welfare Division	Children's Services Division	Vocational Rehabilitation Division	Employment Division					
Housing (including basic living skills)	X	X	X	X				X		X
Mental Health Services	X	X		X						
Medical Services		X		X		X		X		
Activity Programs	X	X	X							
Sheltered Workshops	X			X						
Training (work, education)	X			X	X		X			
Employment Placement				X	X					
Release Planning	X	X	X	X						
Followup	X	X	X	X	X		X			X
Monitoring and evaluation	X	X		X						
Program Standards	X			X						X
Licensing and certification										X

MENTALLY ILL PERSONS SERVED IN
CLINICS AND HOSPITALS IN OREGON
(1971 to 1974)

<u>Fiscal years</u>	<u>Program</u>		<u>Total</u>
	<u>Clinics</u>	<u>Hospitals</u>	
1971	22,632	8,285	30,917
1972	26,665	7,736	34,401
1973	30,441	7,715	38,156
1974	35,831	7,296	43,127

Clinic figures include clients carried over at the beginning of the year and admissions during the year.

Hospital figures include patients in residence at the beginning of the year and all intake during the year, except returns from escape.

These figures do not include persons seen in local hospitalization or day treatment programs.

MENTALLY RETARDED PERSONS SERVED IN COMMUNITIES
BY MENTAL HEALTH DIVISION PROGRAMS
(1971 to 1974)

<u>Program</u>	<u>Fiscal year</u>			
	<u>1971</u>	<u>1972</u>	<u>1973</u>	<u>1974</u>
Trainable Mentally Retarded	739	907	1,096	1,171
Pre-School .	0	63	181	252
Activity Center	0	91	133	557
Community Residential Facilities	0	75	77	112
Diagnosis and Evaluation	<u>0</u>	<u>478</u>	<u>478</u>	<u>630</u>
Total	<u>739</u>	<u>1,614</u>	<u>1,965</u>	<u>2,722</u>

DESCRIPTION OF
GENERAL ACCOUNTING OFFICE
PATIENT TRACING EFFORT

We traced 64 individuals released from Dammasch and 25 from Fairview as part of our analysis of the procedures employed to shift people from State hospitals to community living. The transition process is discussed in chapter 4. This appendix explains our tracing effort and provides additional information about the individuals we traced, the community level agencies involved, and the types of services they provided to the released persons.

MENTALLY ILL

We selected Dammasch for tracing mentally ill patients because the hospital had a high number of admissions and readmissions and served the most populated county in the State. Dammasch, opened in 1961, provides acute psychiatric hospital care for persons from Clackamas, Columbia, Multnomah, and Washington counties. These counties represent 43.4 percent of Oregon's population. Patients are admitted either voluntarily or by court commitment. With a daily bed capacity of over 400, the hospital served over 3,000 individuals in 1974. About 50 percent of those treated were readmissions. The hospital's Medical Records Administrator estimated that 50 percent of the persons served by Dammasch have general psychiatric problems, 40 percent have alcohol problems, and 10 percent have drug problems.

Multnomah and Washington Counties were chosen for our tracing. Multnomah County is the most populated county in Oregon and we were told it accounts for 80 percent of the admissions to Dammasch. Adjacent Washington County has a population about 33 percent of Multnomah County's.

During August and September 1974, Dammasch released 319 individuals to the two counties. About 170 of the individuals were mentally ill (the rest, according to Social Service Department records, had alcohol or drug abuse problems), but only the 64 we selected had been referred to community agencies for additional service. Forty-five of the 64 persons had an average of 4 previous admissions to Dammasch. One 29-year-old patient had been admitted 7 times between 1968 and 1974.

The primary agencies used in the community for the people traced were mental health clinics and public welfare. The following table shows how many referrals each agency received out of the 64 patients traced.

<u>Agency</u>	<u>Number of referrals to agency</u>
Mental health clinic	49
Public welfare	36
Vocational rehabilitation	5
Children's service	4

More than one referral agency was used for many of those traced. The following shows the array of referrals for the 64 patients.

<u>Referral agencies</u>	<u>Number of people referred</u>
Mental health clinic	24
Mental health clinic and public welfare	19
Public welfare	12
Mental health clinic, public welfare, and vocational rehabilitation	4
Mental health clinic and children's services	2
Children's services	2
Public welfare and vocational rehabilitation	<u>1</u>
	<u>64</u>

Our tracing showed that 8 of the 64 mentally ill persons referred for services in the community had already returned to Dammasch. We also found that 13 of 49 persons referred to mental health clinics were not receiving services. Of the 13, the clinics showed no record of referral for 5 people; for 3 people the clinics had a record of referral but had done no followup; in 2 cases the clinics were unable to locate the person; and 3 people refused service. The 36 people still receiving clinic services were getting primarily medication followup. The following table shows the clinic services provided:

<u>Service</u>	<u>Number of persons receiving service</u>
Medication	25
Medication and other services	10
Counseling program	<u>1</u>
	<u>36</u>

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Medication	25
Medication and other services	10
Counseling program	<u>1</u>
	<u>36</u>

DUPLICATE

DO NOT FILM

Other agencies also provided services to the mentally ill persons GAO traced. Public Welfare Division's service workers provided a variety of services, such as housing placements, money management services, and referral services. Public Welfare had closed eight of the cases and was no longer providing social services to those individuals. Children's Services Division workers also provided service such as placement in a foster home or assistance to help individuals with their problems. Vocational rehabilitation workers were helping the persons get vocational training in workshops or training programs.

We observed generally acceptable sanitary conditions at four residential facilities we visited (i.e., a nursing home, room and board, home for the aged, and a hotel). However, managers told us their residential facilities provided limited organized activities for the former mental hospital patients. They said activities available included watching television, reading, listening to the radio, and bingo. We were told three of the four residences provide housing for other ex-hospital patients. For example, 22 of 100 persons living at one hotel were said to be former mental hospital patients.

MENTALLY RETARDED

We selected Fairview for tracing mentally retarded persons because it has been the most active institution in releases and has the largest retarded population.

Fairview had an average daily population of 1,415 in 1974. In that year Fairview had 94 admissions or readmissions and 161 discharges or deaths. In April 1974, 60 percent of Fairview's resident population was severely or profoundly retarded, and 30 percent was multiply disabled. The estimated median age was 20 years old and the estimated average length of stay was 10 years.

We selected three counties for tracing mentally retarded persons released during July through September 1974. Marion and Multnomah were selected because they received most of Fairview's releases. Polk County was included because it was the only rural county receiving several Fairview patients during the period we used for tracing.

We selected 25 individuals who were put on regular trial visit or discharged status into Marion, Multnomah and Polk Counties during the period July through September 1974. The terms regular trial visit and discharge are used to describe different degrees of the institution's supervision of the patients released. Regular trial visit refers to the period after a person leaves the institution but is still subject to

supervision. Regular trial visit status usually lasts about 2 years. Discharge refers to the period after the hospital's supervision ends.

During the same period, Fairview had placed a total of 57 individuals on trial visit or discharge status. Twenty-three of the 25 persons we traced were mildly or moderately retarded, while 2 were severely retarded.

We found that 20 of the 25 retarded persons were referred for services in the community. The five not referred for service had been discharged and either had a competitive job at the time of discharge or had refused further service. Most of the 20 referrals were to public welfare and/or vocational rehabilitation. The following table shows the referral agencies:

<u>Referral agency</u>	<u>Number of people referred</u>
Public Welfare	13
Vocational Rehabilitation and Public Welfare	5
Children Services Division	1
Vocational Rehabilitation	<u>1</u>
Total	<u>20</u>

Seventeen of the 20 were receiving services at the time of our tracing. Public Welfare paid for services such as supervision, personal care, health care, social adjustment, and transportation. Two of the remaining three not receiving services had returned to Fairview because of misbehavior, while the third person refused service.

Group homes were used for 19 of the 25 persons, 3 went to foster homes or to relatives and 3 went to ICFs. We visited four group care facilities and one ICF during the tracing of the mentally retarded. The living condition of the group homes and the ICF appeared adequate. Some of the group homes were large older homes, most of which had three floors with several bedrooms on each level. The number of residents living in each home visited ranged from 3 to over 20.

MAJOR FEDERAL FUNDING SOURCES USED TO
SUPPORT DEINSTITUTIONALIZATION IN OREGON a/
(Rounded to nearest 000's)

<u>FEDERAL SOURCE</u>	<u>YEAR</u>	<u>PROGRAM</u>	<u>DOLLAR AMOUNT</u>	<u>NUMBER OF MENTALLY DISABLED SERVED</u>
Medicaid (Title XIX)	FY 1975 (budget)	Mentally Retarded Institutions	\$ 8,705,000	December 1974 Skilled Patients 11 Semi-Skilled 760
		Mentally Ill Institutions	1,139,000	December 1974 96 Patients
		Mental Health Clinics	849,000	December 1974 586 Persons
		Mentally Retarded Misc. Medical	<u>60,000</u>	
			<u>\$10,753,000</u>	
Developmental Disabilities PL 91-517	FY 1974	Formula grants for:		
		1. Admin. & Plan	\$ 6,000	<u>b/</u>
		2. Activity Centers	1,000	97
		3. Group homes	34,000	37
		4. Service Coordinators	109,000	3,430
		5. Other projects	45,000	293
		6. Not identified	<u>35,000</u>	
	<u>\$ 280,000</u>	<u>3,857</u>		
Community Mental Health Centers Act	FY 1975	Eastern Oregon CMHC	\$ 1,381,000	<u>c/</u>
		Lane County CMHC	<u>109,000</u>	
			<u>\$ 1,490,000</u>	
Public Health Service	FY 1974	Aid to Community Mental Health Clinics	\$113,000	<u>d/</u>

<u>FEDERAL SOURCE</u>	<u>YEAR</u>	<u>PROGRAM</u>	<u>DOLLAR AMOUNT</u>	<u>NUMBER OF MENTALLY DISABLED SERVED</u>
Hospital Improvement Projects (PL 78-410)	FY 1974	-Increasing efficiency of vocational training for the severely retarded	\$ 17,000	
		-Cost analysis and program budgeting of community residential facilities and rehab. programs.	70,000	
		-Community living for the institutionalized retarded	<u>68,000</u>	<u>c/</u>
		Total	<u>\$155,000</u>	
	FY 1975	-Independent living experiences for chronic patients	100,000	
Adult Social Services (Title VI)	FY 1974	Housekeeping/Homemaker Home Delivered Meals Activity Centers		Approx. 143 MR persons
		Sheltered Workshops Subsidy Program Social Service Support	<u>b/</u>	Approx. 153 MR persons
Children's Social Services (Title IVA & IVB)	FY 1974	Protective, Preventive, Family Foster Care, Emotionally Disturbed, Purchase of Care, Child Care Center, Homemakers, Transportation of MR, Campships, Adoptions, Juvenile Camps, Juvenile Community Services, Daycare	<u>b/</u>	<u>d/</u>

<u>FEDERAL SOURCE</u>	<u>YEAR</u>	<u>PROGRAM</u>	<u>DOLLAR AMOUNT</u>	<u>NUMBER OF MENTALLY DISABLED SERVED</u>
Elementary & Secondary Education Act (ESEA-Title I)	FY 1975 allo- cations)	Local School Districts	\$432,000	972
		Mentally Retarded Institutions	383,000	863
		Child Residential Centers	83,000	186
		Mentally Ill Institutions	26,000	38
		Mentally Retarded Group Home	<u>21,000</u>	<u>47</u>
			<u>\$944,000</u>	<u>2,106</u>
Elementary & Secondary Education Act (ESEA-Title VI)	FY 1975	Local School District Programs for MI & MR	\$245,000	704
Vocational Rehabili- tation	FY 1974	Mental Health Activities	664,000	July 1974 to Feb. 1975 Referrals 550 New Plans 305 Rehabs. 86
Employment Services	FY 1974		<u>b/</u>	FY 1974 Placements 343 Referred to work 686 Training 63 Tested 145 Counseling 307 Referred to other services 81
Social Security Administration		Supplemental Security Income	<u>b/</u>	<u>d/</u>

a/ This list is not intended to include all Federal funding sources utilized in Oregon for the mentally disabled.

b/ Statistics were not available to identify expenditures for the mentally disabled.

c/ Statistics were not obtained.

d/ Statistics were not available to identify the number of mentally disabled served.