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REPORT COVER
GAO 348 (July 68)

NEBRASKA'S EFFORTS TO PROVIDE ALTERNATIVES TO INSTITUTIONAL CARE FOR THE MENTALLY DISABLED

Kansas City Regional Office
Department of Health, Education, and Welfare

Caring for the mentally disabled in the community rather than State institutions can improve their lives Nebraska has made considerable progress in its efforts to provide community care

If mentally disabled persons in Nebraska are to achieve their potential for independent living, however, State and Federal agencies need to more carefully plan and coordinate their efforts and use of resources

UNITED STATES
GENERAL ACCOUNTING OFFICE

Kansas City Regional Office

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(Date)

UNITED STATES GENERAL ACCOUNTING OFFICE
REGIONAL OFFICE
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4TH AND STATE
KANSAS CITY, KANSAS 66101

Mr Max Mills
Director, Department of Health,
Education, and Welfare, Region VII

Dear Mr Mills

This report describes the reduction of Nebraska's institutional population of mentally retarded and mentally 111 persons and the development of alternative services and facilities in communities It describes problems in providing these community alternatives, the Influence of Federal programs, and assistance provided by Department of Health, Education, and Welfare agencies in Federal Region VII The review was made to determine the progress and problems experienced by Nebraska in providing community alternatives to institutional care and to assess actions by Federal Agencies to coordinate, monitor, and evaluate these efforts

Copies of this report are being sent to the Assistant Secretary, Comptroller, the Director of the Department Audit Agency, and to the Governor of Nebraska

Sincerely yours,

K L Weary
Regional Manager

Contents

ABBREVIATIONS

ENCOR	Eastern Nebraska Community Office of Retardation
GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
SSI	Supplemental Security Income

GENERAL ACCOUNTING OFFICE
REPORT TO THE REGIONAL DIRECTOR,
DEPARTMENT OF HEALTH, EDUCATION,
AND WELFARE

NEBRASKA'S EFFORTS TO PROVIDE ALTERNATIVES TO INSTITUTIONAL CARE FOR THE MENTALLY DISABLED

D I G E S T

Nebraska has made considerable progress in its efforts to provide for the mentally ill and mentally retarded in the community rather than State institutions However, many persons who could be served In the community enter or remain in the institutions, and others In the community do not receive needed care because

—-not enough community services and facilities are available,

—-some parents prefer the institution to community programs,

—-some persons refuse to accept or continue treatment 112 the community, and

—-financial support for persons who could be served 1n the community is lacking (See pp 8 and 12)

Nebraska began moving the mentally ill and mentally retarded out of these institutions in 1955 and 1968, respectively But major State development of community-based programs did not begin until the early 1970's Support from Federal programs such as HEW's Social Services and Community Mental Health Centers, aided the State in its efforts to develop community services and facilities (See p 3)

The population in Nebraska's institutions for the mentally ill reduced from 4,785 In 1955 to 748 by 1975 The population in the institution for the mentally retarded had declined by about one-half to 1,072 since 1968 (See PP 3 and 4)

Since 1969, 12 community mental health centers have been established for the mentally 111 Community programs for the mentally retarded mushroomed in 1971 and 1972 with Increased Federal, State, and local funds By 1974 community mental retardation programs were serving over 3,000 persons (See p 6)

However, about 1,700 mentally ill and mentally retarded persons remain in State institutions In addition about 1,000 mentally retarded persons reside in nursing homes, which, according to HEW, is nearly always inappropriate An unknown number of mentally ill and mentally retarded persons entered board and room homes that are inadequate (See pp 8 and 9)

State officials said that

--no one has prepared plans to insure that each mentally retarded person leaving the institution receives the care he needs in the community, and

--a system IS needed to assess the quality of care each individual is receiving in the community (See p 10)

A State interagency committee studying the problem recommended review of current nursing home placements To insure that future nursing home placements are appropriate, they recommended that institution officials identify the disabled person's needs and with community officials determine that facilities and services are available (See p 11)

Nebraska will need to further reduce the resident population of its institution for mentally retarded persons to 250 under an October 1975 Court approved agreement between the Governor and the U S Department of Justice The agreement includes a requirement for a statewide plan and teams to evaluate each person in the institution so that individual treatment and placement plans can be made (See p 20)

A variety of HEW programs have provided Nebraska support for the mentally disabled, but HEW programs to coordinate State efforts have had only limited influence Federal Medicaid regulations, which require discharge planning and appropriate placement in the community have not been effective in insuring that mentally ill and mentally retarded persons are appropriately placed (See pp 24, 25, and 26)

GAO believes that to assure that limited resources available are effectively used and to assure coordination of the many agencies involved in providing services, Nebraska needs to develop a comprehensive State plan, and to improve its monitoring and evaluating of community programs (See p 15)

Despite considerable emphasis and support the Congress and the President have given to providing community alternatives for the mentally disabled, HEW Region VII had not received substantive headquarters guidance or direction and had not mounted a coordinated effort to aid the States Although several HEW agencies provide funds which can be used to develop alternatives to institutional care, only two had given any emphasis to establishing coordinated efforts to provide alternatives to institutional care They are the Alcohol, Drug Abuse and Mental Health Administration and the Developmental Disabilities Office Officials of other agencies said very little had been done (See pp 27 and 28)

HEW officials established an objective for fiscal year 1976 to consolidate activities and resources for planning and technical assistance to States In October 1975 they held a regional symposium to develop and improve State strategies, and operational plans (See p 29)

GAO believes that continued emphasis by the HEW Regional Director will help to assure that efforts to provide financial aid and technical assistance to the States are coordinated and effective (See p 29)

CHAPTER 1

INTRODUCTION

In recent years there has been major nationwide concern favoring treatment of mentally disabled1 people in communities rather than State institutions or hospitals This shift has been brought about because of humanitarian concern about the poor conditions and limited treatment in some of these facilities and availability of new drugs which modify behavior of the mentally disabled and increase their receptivity to change Additional pressures and resources which have sustained and given further impetus to this shift Include (1) Increased Federal, State, and local government funds for community-level services, (2) pressures by advocacy groups and other interest groups, and (3) court actions and Federal legislation for better treatment and increased access to needed services, such as education and vocational training

Serving mentally disabled people in the community can improve their lives, but increases the complexities of serving them In an institution, one organization provides food, housing, and most other services such as psychotherapy, habilitation training, and education In the community many agencies, with their own program purposes, eligibility requirements, range of services, and priorities are or can be involved in fulfilling these same needs The mentally disabled person may need little or extensive help from one or more of the agencies and may be eligible under some programs but not others

PURPOSE AND SCOPE OF THE REVIEW

Nebraska 1s one of five States where we reviewed the progress made and problems experienced In providing community alternatives to institutional care and assessed actions by Federal agencies to assist States in these efforts

In Nebraska we contacted officials responsible for planning or providing services to the mentally disabled at the State, regional, and local level We visited one of three Nebraska institutions for the mentally 111 and the State institution for the mentally retarded Community-based programs for the mentally retarded In Omaha and Lincoln and two community mental health centers in Lincoln and Seward were also visited These community-based facilities provide specialized services for the mentally disabled in communities rather than institutions For information we obtained about one community program see appendix I In addition to institutions and these community-based facilities we also visited nursing homes, schools, and other agencies at the local level We traced to two communities 94 mentally disabled persons released from institutions and determined the services provided them (See app II)

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[1] The term "mentally disabled", as used in thus report, refers to mentally 111 and mentally retarded people

We also reviewed the Department of Health, Education, and Welfare agencies responsible for assisting States in planning and providing services for the mentally disabled in Federal Region VII This region includes Nebraska as well as Kansas, Iowa, and Missouri

CHAPTER 2

NEBRASKA EFFORTS TO PROVIDE ALTERNATIVES TO INSTITUTIONAL CARE

The decline of Nebraska's institutional population began before major expansion of community services and facilities To aid this expansion Nebraska changed legislation and improved procedures for the transition of mentally disabled people from institutions to communities

REDUCING INSTITUTIONAL POPULATION

Before 1955 the State institutions were the primary public means for serving mentally disabled persons Nebraska began moving the mentally ill and mentally retarded out of these institutions in 1955 and 1968, respectively But major State development of community-based programs did not begin until the early 1970's Subsequent support from Federal programs such as HEW's Social Services and Community Mental Health Centers, aided the State in Its efforts to develop community services and facilities

The inpatient population of Nebraska's institutions for the mentally ill was reduced from 4,785 in 1955 to 748 by 1975 And, as shown in the following table, the number of persons being admitted to these institutions has increased

Two years ending June 30th	Admissions, readmissions, and transfers-in	Yearend population
1963	5,423	3,729
1965	5,127	3,398
1967	4,074	2,729
1969	4,320	1,685
1971	6,904	1,324
1973	7,818	765
1975	7,258	748

These reductions in institutional populations were influenced by several factors

--A mid-1950's breakthrough in chemotherapy made treating mental Illness within a community setting possible in many cases and reduced the need for institutional care

--A 1960 report to Congress by the Joint Commission on Mental Illness and Health advocated treating the mentally ill in communities rather than institutions and Nebraska adopted this concept

—Nebraska's two largest cities—Omaha and Lincoln—were willing to accept persons from the institutions and to develop programs to serve them in the community

Institution and community officials attributed the increase in admissions of the mentally ill to an increase in (1) public acceptance of institutional treatment, (2) referrals from community agencies, and (3) a shortage of some community alternatives such as adolescent programs Although admissions have increased, the average length of stay has been decreasing for the last several years In one institution it has declined steadily from 112 days m 1972 to 84 in 1974

The population of the institution for the mentally retarded had declined to 1,072 by January 1975

Two years ending June 30th	Admissions, readmissions, and transfers-in	Yearend population
1963	324	2,224
1965	356	2,217
1967	245	2,203
1969	196	1,945
1971	139	1,482
1973	114	1,250
1975 (January)	24	1,072

The movement began in 1967 when overcrowded conditions, lack of professional staff, and inability of programs to serve even one-half of the resident population, became a growing concern of Nebraska citizens As a result a Citizen's Study Committee appointed by the Governor began work In 1967 The Committee, in July 1968, recommended redrafting Nebraska statutes pertaining to mentally retarded individuals, changing the administrative structure, establishing a mechanism to provide services, and reducing the institution population to 850 within 6 years by

—removing geriatric residents to nursing homes or homes for the aged,

—developing alternative community and residential facilities across the State, and

—Improving screening of applicants

CHANGING LEGISLATION

Nebraska has enacted and amended laws to aid development of community-based programs for the mentally disabled The legislature In the years indicated has

1963 - Enacted the Interlocal Cooperative Act This act allowed public agencies to contract with other public and private agencies to provide community-based facilities, programs, and services for the mentally disabled

1967 - Established the Office of Mental Retardation and made it responsible for identifying existing community-based facilities and the services they provided to the mentally retarded The Office was also given responslbllz&y for assisting in establishing needed services

1969 - Enacted legislation to further support establishing community-based facilities, services and programs throughout the State for the mentally retarded Other legislation created and assigned the Division of Medical Services the responsibility for administering the clinical programs and the services of the institutions for the mentally disabled This Division was also made responsible for planning, developing, and operating mental health and mental retardation c11nlcs, and for identifying the number of persons served and the need for additional clinics, programs, and services

1973 - Enacted legislation making the board of education of each school district responsible for assuring that educational programs were made available to all children regardless of physical or mental capacity

1974 - Enacted the Comprehensive Community Mental Health Services Act which further supported establishing mental health facilities, programs, and services throughout the State for the mentally ill This law also provided for methods of financing such facilities, participation of local communities in determining needs, and establishing six regional areas for delivery of services

EXPANDING SERVICES
AND FACILITIES

During the 1950's concerned citizens started providing in local communities education, training, and social opportunities for mentally retarded children and adults The institution was also involved in these early efforts and was responsible for both placement and follow-up in the community The number of community-based programs mushroomed in 1971 and 1972 with available Federal Social Services funds and Increased State and local funds By 1974 community-based retardation programs were serving over 3,000 persons The following table shows the growth in community-based programs

Service units	1968 and before	1970	1972	1974
Child developmental centers	5	10	19	23
Adult developmental centers	6	12	25	32
Child residential units	2	6	10	14
Adult residential units	1	10	39	49
Total	14	38	93	118
Persons served	220	660	2,160	3,145

Before developing community mental health centers, Nebraska had psychiatric clinics and hospitals to provide services to the mentally ill Since 1969, 12 community mental health centers have been established, 9 since 1974 Operating under the centers are 50 clinics, service centers, or affiliates

Nebraska officials stated that its institutions are also considered viable means for serving mentally retarded and mentally ill people Since 1969 increased State funding has enabled the institution for the mentally retarded to make improvements in the staff-client ratio, the programs and services available, and the physical facilities Institutions for the mentally ill have been remodeled and obsolete buildings have been razed Officials said that the services and programs provided to mentally ill people have also been expanded and improved during the last several years

IMPROVING PROCEDURES FOR TRANSITIONS TO COMMUNITIES

Since the decline of Nebraska's institutional population began, several procedural changes have Improved the transition of mentally disabled persons to community-based services Institution and community officials Jointly arrange each transition from institutions to communities during informal meetings This results in a link between persons released from the institution and a community agency which is to provide services

Agreements between the institution for the mentally retarded and community-based retardation programs provide that community-based programs will

——screen all applicants for admission to the institution for possible placement in community-based programs,

——have access to information and to all people in the institution for possible placement in community-based programs, and

——be involved in all placements by the institution

An agreement between an institution for the mentally ill and one community mental health center we visited provided that the center will be included In discharge planning meetings for persons the center will be serving after their release and will assume follow-up responsibxlitles as necessary Some contractual agreements have also been established between agencies at the local level to provide needed services

An interagency committee has recommended several changes to further improve procedures for the transition of mentally retarded people to communities (See p 11)

CHAPTER 3

MENTALLY DISABLED PEOPLE NOT RECEIVING NEEDED COMMUNITY SERVICES

Many mentally disabled people who could be served in the community are entering or remaining in institutions, while others in the community are not receiving needed care or services Many of these people are in nursing homes and board and room homes where the needed care and services are not available

MENTALLY DISABLED PEOPLE REMAINING IN INSTITUTIONS

In 1974 about 1,700 mentally disabled people remained in State institutions State officials said the Male reason was a lack of community services and facilities Other contributing factors cited were parental preference for the institution over community programs, refusal of some Individuals to accept or continue needed services in the community, and lack of financial support for people who could otherwise be released

Institution officials said the lack of community facilities to provide needed services to the mentally ill has resulted in frequent readmissions They identified 12 persons whose placement in the community had been delayed or Jeopardized for lack of financial support One person scheduled for release on January 31, 1975, was still in the institution awaiting financial support from Welfare and from Supplemental Security Income (SSI) on April 4, 1975 Following is some history of the case from institution records

January 8, 1975 -	Institution personnel notified county welfare and SSI personnel of placement plans A welfare representative instructed the institution to contact SSI representatives and have them send the welfare office an SSI form
January 31, 1975 -	No information had been received from either the Welfare office or SSI The placement goal was postponed to February 21, 1975
February 21, 1975 -	No information had been received The placement goal was postponed indefinitely
February 24, 1975 -	The institution received a letter from the county welfare office stating that the SSI form had not been received and no welfare benefits could be computed until the welfare office received a copy of the client's first SSI check

February 28, 1975 -	An SSI representative said the form had been misplaced, but a duplicate would be sent to the county welfare office He stated the client would be eligible for back payments to the date of application
March 7, 1975 -	The institution contacted the county welfare office to determine the status of the case The welfare social worker requested information on the placement and expected food costs
March 10, 1975 -	The institution contacted an SSI representative and was advised that no SSI payment would be made until the patient received his first welfare check
March 14, 1975 -	The institution contacted a Social Security representative and requested assistance m straightening out the problem The Social Security representative said the case had been closed, but would be reopened He stated that the client would not be eligible for back payments
March 24, 1975 -	No payments were received Placement was postponed indefinitely

An institution official stated the person involved was discharged on April 11, 1975, to his parents' home

USING INAPPROPRIATE RESIDENTIAL FACILITIES IN COMMUNITIES

Many persons who left State institutions entered nursing homes or other residential facilities where appropriate programs were not available because community facilities have not grown fast enough An estimated 1,000 mentally retarded persons reside in Nebraska nursing homes An unknown number of mentally retarded and mentally ill persons entered board and room homes that are inadequate

According to HEW placing a mentally retarded person in a facility geared to the aged is nearly always inappropriate An August 1974 HEW instruction provides that

> " * * * Mentally retarded individuals must be carefully evaluated before admission * * *
>
> "Placement * * * in an intermediate care facility geared to provide care primarily for the aged will nearly always be a violation * * * jeopardizing the certification of the facility "

State officials stated that until 1974 no one planned for the transition of mentally retarded people to communities and no system of follow-up existed after their release from the institution to assess the quality of community services

A State interagency committee began studying this problem in October 1974 and issued a report in May 1975 The Committee identified the following weaknesses

——Termination of State responsibility for individuals 6 months after leaving the institution and lack of a system of responsibility or follow-up of persons released to insure that needed care and services are provided The institution is responsible for persons leaving the institution for 6 months after placement at which time they are usually discharged Once the person was discharged, no State agency had responsibility or control to ensure that needed special services or appropriate care was provided Many were transferred to other facilities after placement, or simply left the original placement location To provide better monitoring of the needs of released persons, the committee suggested that the institution not discharge persons at the end of 6-months

——Lack of a parent or guardian to be responsible for persons released The committee suggested the appointment of guardians where appropriate

The Committee had not yet identified all of the mentally retarded people in nursing homes or other residential facilities Medicaid officials had identified 900 mentally retarded recipients, in such facilities, 462 of whom were identified as under age 65 Medicaid officials did not know how many of the mentally retarded recipients were inappropriately placed A 1975 study of 18 mentally retarded cases in 4 nursing homes showed there were no individual programs for the mentally retarded The study Indicated that this was typical of most nursing homes Also, our visit to two nursing homes showed they had not developed individual programs for the persons traced from the institution

Participation in community training programs by persons in nursing homes may result in their ineligibility for Federal financial assistance Placement m a nursing facility Infers need for 24-hour medical supervision, whereas participation in the training program may indicate that such supervision is not required. Therefore, nursing homes were discouraged from allowing residents to participate in needed training programs

To insure that future placements In nursing homes are appropriate the Committee developed the following procedures

—-Officials of the institution or community-based programs will prepare a profile of the disabled person's habilitation needs

—-The profile of needs will be provided to the appropriate mental retardation organization, the welfare nurse, and the county welfare department

—-A joint determination will be made that the facilities to meet these needs are available—-in the nursing home or in the community—-and that the agencies are willing to provide the services

The committee report also recommended that the needs of each mentally retarded person now In a nursing home be evaluated at least annually by qualified personnel as part of the Medicaid program If these needs are not being met, the nursing home would be required to arrange for an appropriate treatment program or to transfer the person to an appropriate facility The Committee report stated that nursing homes are required to provide special services for the mentally retarded if more than 20 percent of their bed capacity or 15 persons, whichever is less, are mentally retarded Medicaid is available for nursing homes meeting these requirements

The State Health Department intends to provide a staff member to assure compliance with the procedures recommended by the Committee

The Committee report also discussed a problem of mentally disabled people in board and room homes, which had been licensed by the State Department of Agriculture Because of complaints by citizen groups concerning poor conditions in these homes, the Department of Agriculture investigated and subsequently withdrew licensing of an estimated 320 homes In the last several years, leaving them without State supervision or regulation State officials did not know how many people in these facilities were mentally disabled Legislation passed in 1974 now gives the Health Department responsibility to regulate these homes The Committee report stated that vigorous regulation should solve most of this problem

Procedures recommended by the Committee were directed toward the mentally retarded However, 1,712 mentally 111 Medicaid recipients are in intermediate care or skilled nursing facilities An additional unknown number of mentally 111 persons are also in board and room homes The Committee Chairman said that although similar procedures had not been developed for the mentally 111, they were being planned

CHAPTER 4

PROBLEMS IN PROVIDING ALTERNATIVES TO INSTITUTIONAL CARE

Although Nebraska has made considerable progress in providing alternatives to institutional care, further improvement and expansion of these alternatives is needed One of the primary needs is for a comprehensive statewide plan for providing these alternatives Other needs are for Improved monitoring and evaluation or community-based programs and services

COMMUNITY FACILITIES AND SERVICES NEEDED

Officials at nearly every level told us that because their need for additional staff and facilities are not being met many mentally disabled persons remain in--or are admitted to--State institutions rather than being served in the community Others in the community do without needed facilities and services Although Nebraska has used some HEW programs (such as Social Services, Vocational Rehabilitation, Developmental Disabilities, and Community Mental Health Centers) to increase community alternatives, it has not fully used others such as Medicaid

Additional facilities needed

An estimated 200 to 300 mentally 111 people in the 16-county area of Mental Health Region V needed supervision which could be provided in a halfway housing facility A Community Mental Health Center official stated that five or six such facilities for adults were needed in Lincoln The Director of the adolescent program at an institution cited a critical need for residential facilities for adolescents The National Institute of Mental Health did not approve a recent grant application to provide a halfway house for eight adolescents due to funding limitations but, advised institution officials to resubmit the application at a later date

Mentally retarded people lacked residential facilities Institution officials had developed information which showed that the following facilities and services would be needed in the community to serve the mentally retarded persons now In the institution

Facility or service	Number of persons
Adult developmental services for the severely or profoundly retarded	501
Training hostel, sheltered living, children's day care or foster care, and competitive employment	398
Behavior shaping unit	102
Nursing home or retirement hostel	56

The 1976 State plan submitted to HEW's Developmental Disabilities office Identified 193 mentally retarded adults and 112 mentally retarded adolescents needing special living arrangements in Nebraska Community-based program officials in Lancaster County identified 94 mentally retarded adults and children now living at home or In foster homes who will need residential care within 5 years Various State and local officials also identified the need for

--sheltered workshops and work stations,

--day care programs for the mentally 111, and

--social and leisure facilities and programs

A local housing authority official in Lincoln said his agency has not addressed the housing needs of the mentally disabled although the disabled and handicapped are eliglible for housing

Additional staff needed

Various State and local officials said that additional staff trained in treating and communicating with the mentally disabled were needed to

--provide medical and psychological services,

--provide emergency mental health services,

--attend institution prerelease planning meetings,

--make initial client contact In the community, and

--expand follow-up services

For example, Nebraska Office of Mental Retardation officials stated that the mentally retarded often have regular or intense medical needs But, It 1s difficult to locate physicians trained and willing to deal with the medical problems of these clients

In addition to medical professionals, a need exists for psychiatric professionals trained to communicate with the mentally retarded Region V Nebraska Office of Mental Retardation officials stated three mental health clinics and numerous other agencies within the region have the staff expertise to deal with most psychiatric problems But these staffs have not been trained to provide services such as counseling, therapy, and sex education to the mentally retarded

Along with these other problems the State has had difficulty In getting enough trained personnel to locate or remain in thinly populated areas of the State

The problems of facility and staff shortages were compounded in developing services for the severely and multi-handicapped Therefore, many such persons remain in the institution for the mentally retarded About 786 of 1,072 of the mentally retarded in the State institution are severely or profoundly retarded Only about 14 percent of 2,663 served in community-based programs are similarly handicapped

Office of Mental Retardation officials stated their community programs and facilities for the mentally retarded are not equipped to handle severe emotional behavior problems, the severely and profoundly retarded, or non-ambulatory adults The problem stems from a staff shortage, architectural barriers in the facilities, and the cost of developing the needed facilities They stated that serving multi-handicapped people requires a one-to-one staff-client ratio instead of a one-to-six or seven ratio for the less severely disabled

The Nebraska Medicaid program has been limited to services for the mentally disabled in institutions and nursing homes It only partially covers the other specialized needs of mentally disabled people in Nebraska communities

Nebraska's Medical program limits day care services for the mentally 111 to licensed hospitals But, the Director of a rural community mental health center said a community day care program would prevent about 25 percent of the institutional admissions from the seven counties served by the Center Medicaid funds for the mentally ill are also limited to 4 of the 12 Nebraska community mental health centers having cooperative agreements with the Medicaid agency to provide health services Small nursing homes of 15 beds or less have not been developed because State Medicaid officials said it 1s not economical to meet Medicaid requirements In such small facilities The program does not generally cover children under 18 and a 1975 Nebraska bill to provide such coverage was vetoed

STATEWIDE PLANNING NEEDED

Nebraska has not developed a comprehensive statewide plan for providing alternatives to institutional care To assure that the limited resources available now and m the future are effectively used a comprehensive State plan is needed to

--establish objectives and responsibilities,

--provide direction and coordination of the many agencies involved in meeting these objectives,

--provide a statewide inventory of programs and services to meet the needs of the mentally disabled,

--identify the mentally disabled whose needs are not being met, and

--establish priorities for developing facilities and services to meet these needs

Although several plans or documents have been prepared over the years by various groups and agencies, these plans did not establish statewide priorities and responsibilities, and did not identify the number of persons receiving services or the number needing services

Limited funds available to develop community-based services and facilities

Additional funding will be required to provide the needed community services and facilities In October 1975 the U S District Court approved an agreement between the Governor of Nebraska and the U S Department of Justice to reduce further the mentally retarded institutional population This will require additional funding for community services and facilities State officials did not know the specific sources or the availability of these additional funds as of October 1975

Estimated fiscal year 1975 expenditures of $14 3 million for community programs for the mentally retarded includes an increase of about 43 percent over the previous year About $2 6 million of the increase was from Federal sources Estimated regional mental health expenditures for fiscal year 1975 were about $7 4 million with nearly 50-percent Federal support Four community mental health centers were approved for Federal staffing grants in fiscal year 1975

During fiscal year 1975, the State reached the Federal funding limit of $18 million dollars for social services About 48 percent of the social services budget has been expended for services to the

mentally retarded, who represent about 19 percent of those served However, Social Services officials expect that the proportion spent on services for the mentally retarded will be reduced and other funding sources will be required to maintain the level of services to the mentally retarded

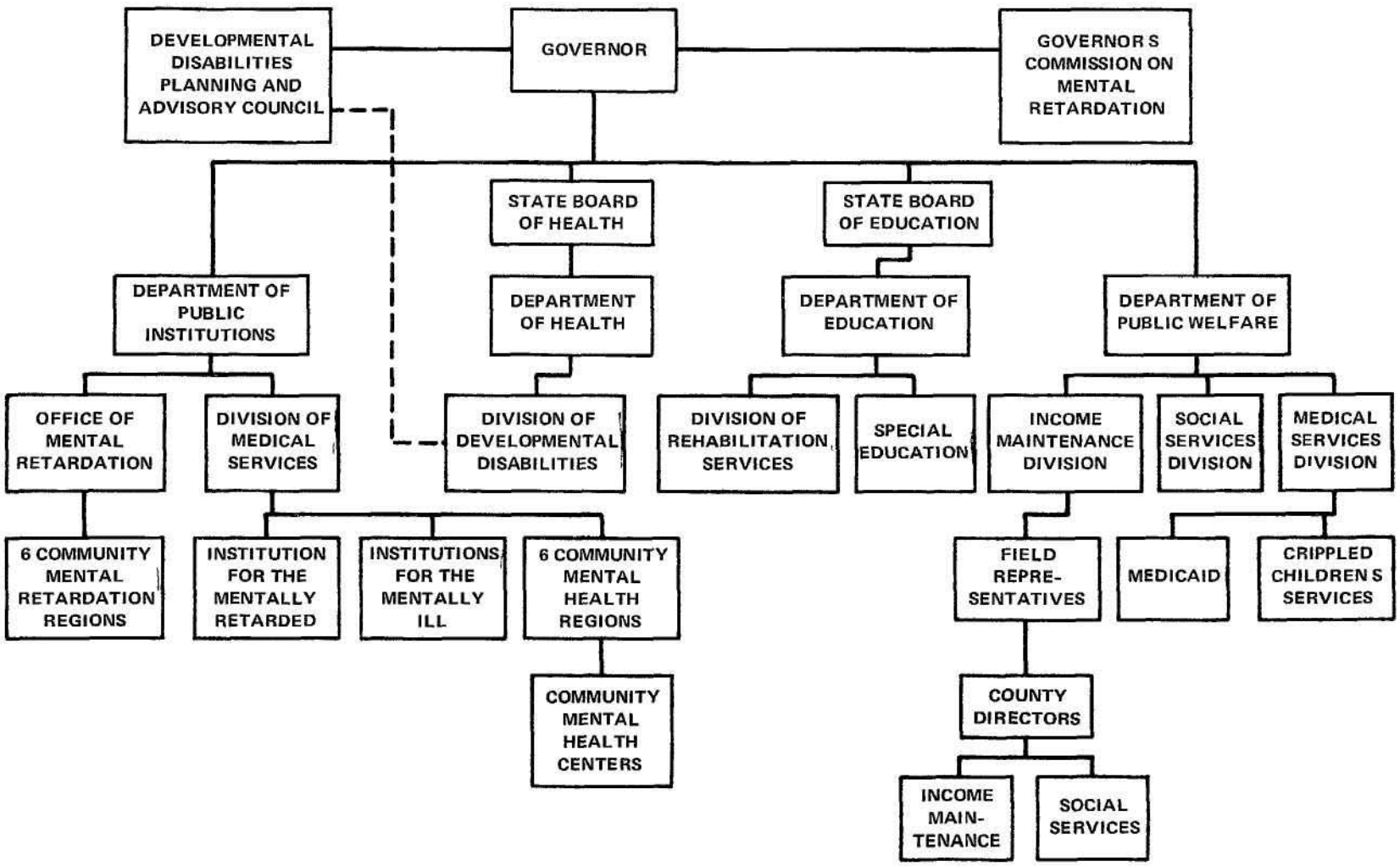
HEW auditors have questioned eligibility for reimbursements of nearly $2 million spent by community-based programs for mentally retarded persons In fiscal years 1974 and 1975 under the Social Services program Amounts questioned relate to residential staff training, depreciation, overhead, uncertified clients, and duplicate charges Both HEW audit and State officials said that the applicable regulations are subject to widely varying interpretation This matter had not been resolved as of November 1975

Despite some shifting of funds and some possible disallowance of amounts claimed, a State Budget official advised us that State funds spent exclusively for the mentally retarded ~1.11 Increase He said that recent legislation placing responsibility for the education of all children, including the mentally retarded, on the local school district will also Increase State funds used for the mentally retarded

Coordinating many agencies required

The many agencies Involved in providing funds and services make It difficult for State officials to coordinate planning, development, and administration An organization chart of State agencies providing services to the mentally disabled follows

STATE AGENCIES PROVIDING SERVICES TO MENTALLY DISABLED PERSONS



In addition to these State organizations many others at the county and local levels are Involved 111 providing services to the mentally disabled The Division of Medical Services and the Office of Mental Retardation are responsible for coordinating agencies which offer programs and services

An official of a Community Mental Health Center, Division of Medical Services stated that there has been no cooperative planning effort on how to meet the comprehensive needs of the mentally ill The Center is trying to determine how to coordinate resources and services but no Interagency effort was underway to clarify the agencies' responsibility for follow-up of the mentally ill in the community

Center officials and institutional personnel in Lincoln were directly involved in placement planning But other local agencies such as the County Department of Health, and agencies for family or elderly services said they also need to be involved in such planning Prerelease coordination between the institutions and a community mental health center in a rural area was more limited because of a lack of funds to attend prerelease conferences

Touche, Ross, and Company and Nebraska officials completed a study of the community-based mental retardation program under the Office of Mental Retardation in January 1975 They reported that

> "Many of the problems * * * can be attributed In part to the number of State agencies involved in the community based mental retardation program and the lack of a clear definition of each agency's specific responsibility to serve mentally retarded clients "

They also reported that

--financial and program monitoring 1s being done by several agencies each responsible for a different group of clients,

--many clients were in more than one program being monitored by more than one agency,

--different laws direct different agencies to do the same, or similar, functions, and

--Federal requirements, State legislation and service descriptions overlap to a large degree

Local officials said there was also an overlap of services at the local level

The Touche, Ross, and Company report showed a problem of coordination among agencies In maintaining and sharing accurate data

--The Office of Mental Retardation has attempted to collect basic data on persons served from the regions However, procedures for data collection have not been enforced and the data's accuracy is questioned Officials said they had not shared data with other agencies because it was inaccurate

--The Developmental Disabilities Division of the Department of Health has received Federal grants to collect data on current and potential community-based program clients An official said they have attempted unsuccessfully to share their information with other agencies, but other agencies questioned its reliability

The Developmental Disabilities Council has not been effective in promoting coordination among agencies Agencies do not like to relinquish or even share data with each other and, the Council does not have the authority to require agencies to coordinate their activities

Many agencies had no clear understanding of other agency responsibilities because State and Federal laws promote overlap of functions Both State and local agency officials were concerned about a lack of coordination among agencies serving the mentally disabled

Judicial and legislative actions
which require planning

The need for statewide comprehensive planning was also recognized in recent judicial and legislative actions The State will need to increase its efforts to provide more community-based facilities, services, and programs to comply with a recent U S District Court approved agreement between the Governor and the U S Department of Justice

In September 1972, the Nebraska Association for Retarded Children, in behalf of the residents of the Nebraska institution for the mentally retarded, filed a class action suit against the Governor and other State off3.cials The plaintiffs alleged that while 1n the institution they had not received their "constitutional minimal level of habilitation"[1] and were not allowed to exercise the& constitutional rights including personal liberty The suit further alleged that five plaintiffs had regressed while in the institution

[1]Habilitation incorporates care, treatment, education and training

The U S Department of Justice entered the suit as a friend of the court m 1974, and the Nebraska Association for Retarded Children withdrew as a plaintiff that same year In 1975 the Department of Justice became a plaintiff intervenor—a third party not originally a party to the suit

An October 1975 U S District Court-approved agreement between the Governor and the U S Department of Justice provides that

—All mentally retarded persons in the State institutions for the mentally disabled will be transferred to community-based programs commensurate with their needs and abilities, consistent with available community-based programs

—The mentally retarded resident population of the institution will be reduced to 250 or less within 3 years

To achieve the reduction, the agreement requires the Governor to

—prepare a statewide plan to address the population reduction goal and the timeframe necessary to achieve the goal,

—identify the method by which the reduction is to be achieved,

—establish teams to evaluate each mentally retarded person in an institution and prepare individualized evaluation and treatment plans and placement recommendations, and

—insure that current services are not curtailed to meet the requirements of the agreement

Under the agreement the objections of parents and legal guardians are not to preclude placement indicated to be in the individual's best interest The agreement will not be violated even if the State does not meet it if the failure is because the State legislature fails to provide funds to implement it or because the Federal Government reduces its aid

A 1974 Nebraska law also requires long-range planning for service to the mentally disabled The Office of Mental Retardation and the Medical Services Division were preparing plans in accordance with this law to determine long-range goals and objectives, the number to be served, and the level of required services

MONITORING AND EVALUATING NEEDED

Virtually every State agency we visited is required by State or Federal law to evaluate or monitor services for the mentally retarded A major effort to evaluate community-based programs for the mentally retarded was completed by State officials and Touche, Ross, and Company in January 1975 Their report and other information we obtained during our review indicated a need for improved monitoring and evaluation of community programs Some examples follow

--The Office of Mental Retardation is responsible for monitoring and evaluating community-based programs The Touche, Ross, and Company report showed the office spending most of its time policing program activities and no specific agency could be found that was monitoring program effectiveness Some agencies were performing compliance reviews to see If programs were complying to standards and regulations The Office has recently taken action to more fully evaluate Its community programs

--Federal regulations require the Social Services Division, Department of Public Welfare, to determine the quality and effectiveness of the mentally retarded services The agency has relied upon the Office of Mental Retardation to monitor services to the mentally retarded The Department of Public Welfare funded the Touche, Ross, and Company study which showed that the Office of Mental Retardation had little accountability over the community-based programs and that there was no uniformity in the services being provided by the community-based program5 across the State A Social Services agency official stated his agency would be performing more monitoring of the community-based program services

--The State Medicaid Agency, Department of Public Welfare, has not enforced the Federal requirement for discharge plans for mentally retarded persons leaving the institution Agency officials said in the past they did not believe it to be their responsibility to require discharge plans The officials stated they will require discharge plans in the future

--The Developmental Disabilities Division, the Department of Public Health also has the responsibility for monitoring services for the mentally retarded This agency has had difficulty in carrying out its responsibility because other agencies have not cooperated with it

--The two community mental health centers that we visited and the Division of Medical Services had no data available to evaluate effectiveness of the Community Mental Health Center program An official of one Center stated that he did not know how to determine program effectiveness

State officials said that many of the problems discussed in preceding pages stem from the multiplicity of service organizations A budget official said that various Federal and State programs require establishing service areas for various purposes For example, the State is divided into 6 regions for mental health services, 12 mental health areas for construction and staffing grants and programs, and 26 areas for other health programs According to the budget official State organizations to plan, monitor, and administer community programs for the mentally retarded have been ineffective because of the strong Influence at the local level The State is trying to obtain greater accountability he said by requiring that a county commissioner from each county be on the governing board of regional organizations

CHAPTER 5 INFLUENCE OF FEDERAL PROGRAMS

The care and treatment of mentally disabled people is primarily a State responsibility with the Federal Government providing support and assistance to improve services This role has grown over the years from research, demonstration, and manpower training programs to providing funds for direct service and maintaining the mentally disabled in institutions and in the communities

We previously identified some of the Federal programs involved In Nebraska's efforts This chapter will focus more directly on how these Federal programs have been used and how they have influenced State activities through

--funding of services for mentally disabled people in institutions and communities,

--special programs intended to coordinate or stimulate developing alternatives to institutions, and

--requirements governing the transition of the mentally disabled people from institutions to communities

FEDERAL FUNDING OF SERVICES

Because some programs serve mentally disabled people as part of a larger population group, the total amount of funds used for the mentally disabled was not available The following table shows estimated funds used in Nebraska in fiscal year 1975 exclusive of income support payments and medical payments for persons not in institutions

	Funds		
	Total	Federal	Percent
	(millions)		
Mentally retarded persons			
Institutional care	$10 2	$ 2 1	20
Community care	14 3	8.2	57
Mentally ill persons			
Institutional care			
Community care			
Total			

16	7	7	4
7	4	3 8	51
$48	6	$14 8	30

The following programs provide most of the support for mentally disabled people in Nebraska

--MEDICAID funds are used to provide services for the mentally disabled at State Institutions, nursing homes, and community mental health centers An institution official estimated that $2 million annually will be used to provide services in the institution for the mentally retarded Medicaid funds used in the institutions for the mentally ill and In community mental health centers are nominal The amount of Medicaid funds spent for the care of about 900 mentally retarded and 1,700 mentally ill persons living in nursing homes was not available

--SOCIAL SERVICES funds are used to provide special services for the mentally retarded in communities Federal funds for special social services for mentally retarded people has grown from $250 thousand in fiscal year 1970 to about $6 9 million in fiscal year 1975

--VOCATIONAL REHABILITATION funds used for mentally disabled people in institutions and communities in fiscal year 1975 were estimated at $660,000 and $577,000, respectively

--DEVELOPMENTAL DISABLILITIES funds of about $235,000 were used in fiscal year 1975 to collect information on services provided or needed and to act as an interagency link to find appropriate resources

--COMMUNITY MENTAL HEALTH CENTERS staffing grants have been provided eight of 12 such Centers About $3 8 million in Federal funds were used during fiscal year 1975

In addition to these amounts, an official of the Office of Mental Retardation said that persons m their programs received about $600,000 annually from Supplementary Security Income funds

The Influence of Federal funds in a community program was shown by information obtained about the Eastern Nebraska Community Office of Retardation During fiscal year 1974 the budget of $4 million included $2 5 million in Federal funds of which $2.3 million was Social Services funds (See app I)

SPECIAL PROGRAMS TO COORDINATE STATE EFFORTS

The Developmental Disabilities Program and the Community Mental Health Centers program have had a positive but limited influence over community services for the mentally disabled

Developmental Disabilities Program

The principal effort of the State Developmental Disabilities agency has been to Identify developmentally disabled persons including the mentally retarded needing services, types of services provided, unmet needs and resources available

The agency found that in fiscal year 1972 approximately $18 million was expended In Nebraska for services for the developmentally disabled, but estimated only 30 percent of those needing services were being reached

The agency has had limited success in getting other State agencies to use its information Other State agency officials question the value of the information and told us the agency could better use Its funds to provide services Developmental Disabilities officials said that part of their problem has been the lack of cooperation but this 1s improving Some agencies were reluctant to give up responsibillties to other agencies and the agency has not had statewide comprehensive data to demonstrate the advantages of Its Information system

Community Mental Health Centers Program

The Community Mental Health Centers Act of 1963 authorized Federal grants for constructing centers and was amended in 1965 to provide assistance in staffing the centers The centers are to act as a focal point in the community for coordinating the delivery of services to the mentally ill Their development in Nebraska has proceeded much slower than expected, and most were not opened until 1974 and 1975

The Lincoln-Lancaster Community Mental Health Center is the principal provider of mental health services in Lancaster County The county has a population of 167,000 and includes Lincoln, the State's capitol The Center and its three satellites provide

—Outpatient services including individual counseling, marriage and family counseling, drug and alcohol counseling, group sessions, psychological testing and evaluation, medication, and biofeedback training

—Inpatient psychiatric services on a 24-hour basis --

Emergency mental health services on a 24-hour basis

—Vocational counseling, testing, training, and job placement

—Volunteer resources including a Companion Program and many specialized group and volunteer activities

—Mental health consultation and education

Although Community Mental Health Center officials are responsible for providing after-care and follow-up services to the mentally ill, they did not have the resources or legal authority to provide these services Institution officials attributed frequent readmissions of the mentally ill to the inability of the community mental health centers to provide needed follow-up and after-care services In a sample of 65 persons released, 38 had from 1 to 12 previous hospitali-zations

FEDERAL REQUIREMENTS GOVERNING TRANSITIONS TO COMMUNITIES

The Federal Government has established requirements to aid the transition of persons released from institutions to the community through discharge planning, appropriate placement, and development of community alternatives But, these requirements have not been fully effective m Nebraska

Discharge plans which include provisions for appropriate services, protective supervision, and follow-up of persons released from institutions have not been prepared State Medicaid officials said previously they did not believe It was their responsibility to require these plans but ~111 require them in the future

The Medcaid program also requires States to insure that

—-people are not placed in or remain in facilities that are inappropriate to their needs,

—-people inappropriately placed or not receiving needed services are identified and alternatives are explored, and

—-steps are taken to develop and use appropriate alternatives to institutional care

In Nebraska, this program has been ineffective in meeting these requirements, for example, a State interagency committee found that many mentally retarded people in nursing homes are inappropriately placed The committee has recommended use of the program's control process to identify such people State Medicaid officials said nursing home officials involved in the process rarely recommend transfers to the community, do not determine whether persons are receiving appropriate services, and usually recommend continued care at the current facility The control process at the institution for the mentally retarded identified persons ready for placement But, these results were not provided to the Office of Mental Retardation to develop and encourage using appropriate alternatives to institutional care Very few mentally ill persons in the State institutions are subject to the process because Medicaid coverage for such persons 1s limited to those over 65 Moreover, one of the three State institutions for the mentally ill was not approved for Medicaid

CHAPTER 6

COORDINATING FEDERAL EFFORTS

Since 1963 the Congress has expressed m several laws[1] a preference for community care instead of institutional care for the mentally disabled Additionally, Federal courts have ordered several States to provide care with as little restriction on the freedom of the mentally disabled as practicable The Congress has provided funds under a variety of programs which the States can use to provide services to the mentally disabled In the community In 1971 the President stated that all Federal agencies would evaluate their programs and provide maximum support to a coordinated effort to return the mentally retarded to the community

Despite this considerable emphasis and support, the HEW Regional Office had not received substantive headquarters guidance or direction, had not mounted a coordinated effort to aid the States in providing alternatives, and had performed only very limited monitoring or evaluation of State and local efforts

Although several agencies provide funds which can be used to develop alternatives to institutional care, HEW has assigned the principal responsibility to

--The Alcohol, Drug Abuse, and Mental Health Administration, responsible for assisting in developing community mental health centers for the mentally ill

--The Developmental Disabilities Office, Office of Human Development, responsible for assisting the States to determine the unmet needs of the mentally retarded

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[1]The following laws, for example, indicate a preference for community care in lieu of institutional care

Public Law 88-164, the Mental Retardation Facilities Construction Act, Section 133 and the Community Mental Health Centers Act, Sections 203, 204 Public Law 90-170, Mental Retardation Amendments of 1967,
Sections 3 and 4 Public Law 93-112, Rehabilitation Act of 1973 as amended,
Section 101 Public Law 93-647, the Social Services Amendments of 1974,
Title XX, Section 2001 Public Law 94-103, Developmentally Disabled Assistance and
Bill of Rights Act, Title I, Sections 111, 145, 128 and Title II

We talked to officials of the following Region VII HEW agencies to ascertain their involvement

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

Public Health Service
- Alcohol, Drug Abuse, and Mental Health Administration Branch
- Family Health Branch

Social Security Administration
- Bureau of Health Insurance

Office of Education

Office of Human Development
- Administration on Aging Office
- of Child Development
- Developmental Disabilities Office

Office of Long Term Care

The Alcohol, Drug Abuse, and Mental Health Administration and the Developmental Disabilities Office were the only agencies that had given emphasis to establishing coordinated efforts to provide alternatives to institutional care Officials of other agencies said very little had been done

The monitoring and evaluation of State programs did not specifically address development of alternatives for institutional care

The Developmental Disabilities office did not have the necessary information or criteria to assess State efforts A regional Medical Service Administration official told us that they do evaluate whether persons are properly placed, but had not evaluated Medicaid requirements aimed at using or developing community alternatives to institutions He stated that they had given little emphasis to these requirements because they had received no guidance or direction as to how they should be implemented

At the Community Mental Health Center we visited In Lincoln, Nebraska we found no indications of any evaluation of the Center's involvement In discharge planning, referrals, services provided, or institution admission procedures for persons admitted to or released from State institutions

In July 1974 the Regional Director established an interagency committee to establish an objective for developing community alternatives Agencies represented on the Committee included Developmental Disabilities, Office of Human Development, and Public Health Service On April 17, 1975, the Committee proposed an objective to consolidate activities and resources for planning and technical assistance to States The objective was adopted by the HEW Regional Director for fiscal year 1976

To implement this objective the Committee in May 1975 held a 2-day conference with State and local government officials and private service providers to plan a regional symposium which was held in October 1975 The symposium was to develop strategy and conduct separate governor's conferences to design work plans The HEW Region VII Regional Director and the Assistant Secretary for Human Development addressed about 200 State public and private participants at the symposium

The main output of the symposium is expected to be reports to regional Governors for developing or improving State strategies, and long- and short-range operational plans Kansas officials have furnished such a report to their Governor The Regional Director requested the Governors to advise him of any HEW laws or regulations which inhibit developing and using alternatives to institutional care Possible inhibitions were discussed at a September meeting of Nebraska Governor's office staff and HEW regional agency staff requested by the Governor

We believe that continued emphasis by the Regional Director will help to assure that HEW's efforts to provide financial and technical assistance to the States are coordinated and effective

EASTERN NEBRASKA COMMUNITY OFFICE OF RETARDATION--AN ALTERNATIVE TO INSTITUTIONS

Contents

BACKGROUND

The Eastern Nebraska Community Office of Retardation (ENCOR) serves mentally retarded citizens of Cass, Dodge, Douglas, Sarpy and Washington Counties In Eastern Nebraska, including the metropolitan Omaha area ENCOR, established as a community alternative to institutions, is a joint venture of the five counties made possible by the Nebraska Inter-Local Cooperation Act

In August 1967 a Citizens' Study Committee on Mental Retardation was appointed by the Governor to study laws, services, and facilities and to provide direction for future State action The committee recommended that the institution population be reduced and community services for the mentally retarded and their families be established throughout the State

During the 1968 State legislative session the Community Mental Retardation Services Act was passed which was Intended to establish a funding partnership between the State and local agencies for community-based services The act also relieved county government of the responsibility of paying up to 60 percent of the cost of maintaining a person in the State institution for the mentally retarded

In the greater Omaha area a citizens group made up of parents and professionals developed a plan for services to the mentally retarded citizens of Douglas County Their plan, which included descriptions of each component In a comprehensive system of services, was funded for 1 year's operation of pilot programs by the county commissioners The program operation was turned over to a professional staff and the planning organization, known as the Greater Omaha Association of Retarded Citizens, continued to monitor the services provided and assure individual rights of the retarded citizen These early efforts were expanded to the 5-county area with the creation of ENCOR in July 1970

A further step in developing community programs was taken in January 1974 when the Eastern Nebraska Human Services Agency was established combining the administrative functions of ENCOR with those of three other area agencies for mental health, aging, and youth services This umbrella agency also provides a central information and referral service for the community

ENCOR OBJECTIVES

ENCOR strives to provide mentally retarded persons the same educational, vocational, residential, and other social environments available to all citizens

ENCOR officials said it is their goal to provide community-based alternatives to enable all mentally retarded persons from institutions to live in their communities They recognize that some mentally retarded persons ~~11 choose to remain in institutions, particularly the long-term residents

Existing services In the community are used to the greatest extent possible for ENCOR clients They Include individuals and any community agency or institution that is willing and able to serve anyone, such as medical services of physicians and hospitals, churches, planned parenthood, city recreation facilities, and welfare or social agencies

ORGANIZATION

As of December 1974 ENCOR had 481 employees, 379 full time and 102 part time The number of employees by division follows

Division	Employees
Developmental and Vocational Services	199
Residential Services	160
Family Resource Services	98
Program Development and Training	13
Administrative staff	11
Total	481

The ENCOR facilities used for developmental training, education programs, vocational training, and residences are dispersed throughout the region The vocational services centers are located in industrial or commercial areas, while the residential facilities are more widely dispersed

FUNDING

ENCOR receives funds from county, State, and Federal governments and from the public According to an ENCOR financial statement amounts received for fiscal year 1974 were as follows

Sources	Amount
Federal	
Social services funds through the State Department of Public Welfare	$2,312,724
Vocational Rehabilitation funds through the State Office of Education (note a)	121,510
Other Federal funds	
HEW staffing grant from the Office of Education	66,603
Developmental Disabilities grant	21,845
Total Federal	$2,522,682
State, county, public, and other State and county funds through the Office of Mental Retardation for matching social services funds	$ 701,675
Direct funding support to ENCOR from Douglas, Sarpy, Cass, Dodge and Washington counties	662,617
Public	6,288
Other	28,925
Total State, county, public and other	$1,399,505
Total funding	$3,922,187

[a]Includes 20 percent State funds

The major expense was personnel costs of $2 9 million with no other single expense Item exceeding $300,000 Expenses by division for fiscal year 1974 were as follows

Division	Expenses
Developmental/Vocational Services	$1,981,852
Residential Services	578,320
Family Resource Services	1,117,711
Central Administrative	363,151
Total	$4,041,034

ENCOR officials said that under the new Title XX of the Social Security Act the State's income eligibility requirements will be much more restrictive and will likely result in ENCOR services not being available to many persons now receiving them They were not certain of the full affect of the new Title XX services, but they believe there will be major personnel reductions Nebraska is at the maximum level for these funds

OPERATIONS

ENCOR provides services to those persons living in or a legal resident of the ENCOR area whose primary disabling condition is mental retardation The intake advisor was responsible for initially determining each applicant's eligibility for ENCOR services If not eligible, the advisor will assist the individual in locating services outside of ENCOR Residential admission priorities include

--emergency referrals, i e , persons awaiting admission to the institution and those cases involving abuse, physical welfare, or unusual stress,

--people in the institution from the ENCOR area eligible for services,

--people from the ENCOR community area, and

--residents of public institutions for the mentally 111, nursing homes, and private institutions

Admissions

The number of applicants and admissions to ENCOR for 3 fiscal years are shown in the following table

	Fiscal year		
Age group	1972	1973	1974
0-2	7	38	39
3-18	103	340	239
19-35	67	96	68
36-65	25	46	34
66 and older	0	0	0
Unknown	1	76	46
Total applications	203	596	426
Less individuals not admitted	6	20	92
Total admitted	197	576	334

During March 1975, there were 1,166 persons enrolled in the ENCOR program Some persons received only social services but information on the number of social service contacts was not readily available The following services were provided to 968 persons during March 1975

Service	Number
Adults	
Residential	116
Vocational	
Family resource	223
Total adults	710
	1,049
Children	
Residential	88
Developmental	
Family resource	176
Total children	805
	1,069
Total	2,118

As of March 31, 1975, ENCOR had 58 children in their programs from the institution for the mentally retarded, 49 were In residential programs At the same time there were 185 adults from the institution in ENCOR programs, 89 were in the residential program

The number of individuals terminated from ENCOR during 3 fiscal years are shown m the following table

Reason for terminating	Fiscal year 1972	1973	1974
Became Independent	37	103	76
Moved	22	41	26
Obtained other services	4	5	3
Returned to institution	3	2	2
Death	6	11	4
Totals	72	162	111

Residential services

ENCOR provides an array of residential services designed to support a family which has a mentally retarded child living at home until he reaches an age appropriate for living away from the natural home When circumstances prevent a child from remaining with his family, other living arrangements are available These facilities include foster-adoptive placements for children, small group residences and special purpose residences for children and adults, and semi-independent living arrangements for adults

ENCOR uses the term Alternative Living Unit to describe the living arrangements available to a mentally retarded person Examples are group homes, developmental homes, staffed apartments, cluster apartments, intensive training home, apartments, duplexes, condominiums, single family houses, and foster homes

A special residential service has been established for mentally retarded offenders through a Law Enforcement Assistance Administration grant ENCOR hopes to demonstrate that with the structured correctional residence they will never have to return anyone to the State institution for unacceptable behavior or for involvement with the criminal justice system

To support the families of mentally retarded citizens ENCOR provides crls~s assistance This service includes a home in the community with houseparents and other staff where parents can temporarily place their mentally retarded child

Family Resource services

Staff of the Family Resource Division provide, or arrange for, services to mentally retarded persons and their families These services include intake, counseling, psychological and medical services, speech and physical therapy, transportation, recreation, and records Family Resource staff members are assigned to family service offices dispersed throughout the region

Family resource services include

——Central inquiry which facilitates entrance Into ENCOR services, and serves as a referral point for other programs

——Child and adult advisors who assist clients and their families in seeking out and receiving other appropriate services in the community, facilitate entry Into the ENCOR system, coordinate individual program plans for clients, contract for direct services and provide follow-along services to clients who have left direct service programs

——Medical services through two nurses who maintain contact with students in Developmental Centers and clients in residences, and with physicians and psychiatrists

——Speech and language specialists who serve students in Developmental Centers and adults in Vocational Service Centers and teach other ENCOR staff members the skulls needed to accelerate language development of clients

—-Transportation for retarded citizens

—-Recreation services for any mentally retarded child or adult

—-Toy lending library to encourage children to develop a positive self-image

--Psychological services

Developmental and vocational services

ENCOR provides developmental centers and vocational services centers throughout the five county area for mentally retarded individuals needing special training or individualized programs

Recent legislation in Nebraska guarantees all children between 5 and 16 years of age a "meaningful education program", placing the responsibility for education of the handicapped directly on the local school boards School districts are required to have a program in effect by October 1976 and may directly educate these children or contract for educational services for them

ENCOR will continue to provide some educational services for preschool children and the more severely handicapped children

The education programs now provided by ENCOR are as follows

—-Coordinated Early Education Program - places preschool children in early education programs in the community The retarded children play and engage In learning activities with other children and receive specialized support in language development, self-care, and motor development

—-Infant/Home Training Program - stresses early identification of and intervention with very young retarded children Day care 1s offered for infants (ages 1 month to 24 months) focusing on cognitive, language, motor, and social adaptive development Instruction 1s offered to interested parents and a mobile teacher offers in-home instruction

—-Developmental Centers - provide an educational program on a school day schedule, 12 months a year to mentally retarded children under age 12 who are now excluded from attending or participating in other public school or generic services The centers, geographically dispersed, serve approximately

25 children each The programs focus on general areas of education with training also provided in daily living skills according to the childrens' individual needs This program is to graduate students to public or private schools within the community

--Developmental Maximation Unit - located in a wing of the Douglas County Hospital, serves severely and profoundly retarded children with complex medical problems This combined residential and developmental program provides an educational program with medical support by a consulting pediatrician and specialists when necessary Most of the children participating In this program have some serious medical problems This program's objective includes bringing the child's medical problems under control and fostering the acquisition of self-help skills, ambulation, and social-personal awareness The major goal is to move children to more normalized residential and educational settings

--Adolescent Education - program serves students between the ages of 12 and 18 years who are denied admittance to public school programs because of the severity of retardation or multiplicity of handicaps Each child receives an individually tailored educational program, with special emphasis placed upon developing prevocational skills

--Motor Development Services - provide the physically handicapped person proper physical therapy, programing and individual prosthetic equipment necessary for helping them obtain functional upright positions One of the unique services 1s the customizing of wheelchairs for any ENCOR client, child or adult

The vocational programs now provided by ENCOR are as follows

--Industrial Training Centers - prepare the mentally retarded persons for use of the same vocational environments available to all citizens in a community Persons over age 16 are trained on work generated through paid subcontract work from local business and Industry

--Work Stations in Industry - enable persons to be integrated within a normal work force, provide group training experience In business or Industry, and offers specific skill training 1n a variety of employment options Work Stations serve trainees over age 18 ENCOR officials emphasized this program uses one ENCOR coordinator at each work station who 1s paid by ENCOR But, the cost of the training and the salaries of the clients are borne by the industry

--Industrial Training Support - provides resource instructors to work with adults enrolled in ENCOR Industrial Training and Employment programs These instructors provide short-term intensive instruction designed to develop skills which help an individual's movement to more normal work stations

--The Placement Program - provides integrated job opportunities and successful placements in business and Industry

--Adult Evening Program - is for ENCOR clients participating in work training programs to further develop their skills in academic and job-related areas Placement assistance will also be provided to individuals interested in attending other community educational services

Program development and training

The ENCOR program development and training division provides staff training and coordination and planning for new service programs within ENCOR The first is done by in-service teaching assistance and workshops, and the second 1s accomplished through staff meetings, committee work, and management training programs

Client follow-up procedures

ENCOR officials stated that no time limit had been placed on client follow-up because the Intent of follow-up action 1s to meet the needs of the client Follow-up procedures are

Vocational program - Follow-up will be made for 90 days to assure a successful Job placement by the vocational staff, then the advisor will follow-up for at least a year, or longer if necessary

Children - For those who move into public school follow-up is made by the Development Specialist with the school and by the advisor with the family for at least a year, and they will let the family know that ENCOR 1s still available to assist them if they need it

Residential program - Follow-up will be made for 90 days and then the advisor will continue contact with the former client as long as is necessary to meet the person's needs

COORDINATION

The ENCOR Executive Director coordinates between Federal agencies and the State Office of Mental Retardation The ENCOR staff consults the institution for the mentally retarded, the State Welfare Department, and other State agencies

ENCOR has assigned two staff members to be liaisons between the institution and its residents One advisor is assigned to work with children in the institution and the other is assigned to work with adults They obtain existing information regarding the person's performance, determine their potential needs, and work with the institution staff on a continuing basis to aid in making determinations concerning the persons condition and status before they are placed into ENCOR programs

EVALUATIONS

ENCOR requested the Joint Commission on Accreditation of Hospitals Accreditation Council for Facilities for the Mentally Retarded to evaluate its services The evaluation was done October 9 through 19, 1974, and ENCOR was notified by letter dated March 24, 1975, that they had been accredited for 1 year, or until a subsequent survey is conducted. The report mentioned one of the agency's strengths is its young, dynamic, and committed staff but pointed out a need for as much stability as possible, given the dynamic change that pervades the agency's operations Their letter stated that attention should be directed to achieving improvements in

—involving the client, family, and relevant staff in developing the individual program plan,

—completing the initial plan within 30 days after entry, and identifying the individuals responsible for specific interventions,

—assessing affective development and dental evaluations as part of an inter-disciplinary team process,

—protecting the rights of its clients, and

—recordkeeping to provide data that are precise, functional, and useful in enhancing development of each client

ENCOR has been monitored by various agencies Although no comprehensive evaluations have been done some individual professional observations have been made during the past year The professionals were the directors of community mental health and mental retardation programs in other States

These observations were generally complimentary, but they also Included some comments on the high personnel turnover rate and a need for more clearly delineated staff functions

ACCOMPLISHMENTS

ENCOR officials view their role as simply reversing a mistake that was made when the person was placed in the institution One ENCOR official stated that many people are placed in institutions less for their own benefit than for the benefit of others The main barriers cited by an ENCOR official are public attitudes, the attitude of family or parents, and the present maintenance of two separate service delivery systems—- institutions and community-based programs Also, he cited a lack of funds to care for the retarded family member in the home as a reason for placing and leaving an individual in an institution He pointed out that a family needs help in crisis relief, training, and transportation

According to ENCOR officials measuring accomplishment involves the progressive movement from the institution This would include

—-movement from a more restrictive to a less restrictive environment,

—-community acceptance of the mentally retarded,

—-the number of persons able to live in their own homes with or without ENCOR support,

—-the number of persons being served, the lack of reentry, and the lack of new admissions to an institution from the area served by a community-based program, and

—-the number of persons competitively employed, enrolled in public school, or returned to their parents' homes or independent adult living

ENCOR did not have complete data regarding all of these factors Those for which information was available follow

According to ENCOR officials as of July 1, 1974, 57 children and 236 adults had entered ENCOR programs from the institution for the mentally retarded ENCOR staff said that as of March 1975 there were 61 children and 254 adults in the institution from the ENCOR region They believe all could be served by ENCOR if funds were available and the relatives would agree

Information was not available on the number of total admissions into ENCOR from the community since the program beginning Total admissions for the last 3 fiscal years by age group are on page 34 Those in ENCOR programs as of March 31, 1975, were as shown in the following table

	Children	Adults
From community From	597	326
the institution	58	185
Total	655	511

With community acceptance, ENCOR has provided an alternative to institutional care for many mentally retarded citizens According to an ENCOR official only three area residents have been admitted to the institution in 1974 and 1975 Of 293 placements from the institution for mentally retarded to ENCOR only 23 have been returned to the institution, the last one in September 1973

ENCOR has also moved several persons to independent living and work situations During fiscal year 1974, ENCOR reported **that** the residential staff has assisted 78 persons in moving to more independent residential situations

In fiscal year 1974 the Coordinated Early Education Program involved 8 pre-school programs serving 56 children The developmental centers operated 6 facilities serving 200 youngsters The adolescent education program has graduated seven students to public school and one student to a vocational training program

In March 1975 there were 57 persons from the ENCOR programs employed In 5 Industry work stations In the quarter ending March 31, 1975, ENCOR reported 25 progressive moves to competitive employment and 11 backward movements As of March 31, 1975, the majority of ENCOR adult clients were In employment or vocational training **status.**

Status	Number of clients
Outside employment	144
Employed by ENCOR	3
Work stations in industry	28
Training centers	203
Total	378
Not yet employed or In vocational training	133
	511

Central inquiry staff refers about 50 calls a month to ENCOR advisors The medical services nurses contact about 180 persons a month Approximately 350 persons receive language and speech services each month In fiscal year 1974 some 658,350 miles of transportation were provided to 592 persons Recreation services are provided to about 430 persons a month The psychological staff serves approximately 80 persons a month

PROBLEMS IN PROVIDING
ALTERNATIVES TO INSTITUTIONS

Problems identified by ENCOR officials included ——The rights of the

parents versus those of the child in an institution

ENCOR's ability and willingness to accept a child into their program is sometimes not enough to achieve placement The parents often have not approved the release and some do not want their child released from the institution Under the recent court approved agreement, the objections of parents and legal guardians are not to preclude placement indicated to be in the best Interest of the individual

——The availability of funds

ENCOR officials said that the funding problem results from a lag in cash flow due to the State welfare system of payment in arrears and from uncertainties of reimbursement due to changes in certification requirements

——Education of the public about community-based programs.

The education problem 1s one of convincing legislators, parents, institutional staff, and the public that it is both possible and desirable to serve mentally retarded persons through community programs

ENCOR staff stated that another problem they have had is placing mentally retarded persons in the ENCOR area without notification They stated that in 1968 the State began placing mentally retarded persons from the State institution into nursing homes and, until 1973 there was no requirement to Inform the local community program of such placement However, since 1973 the institution is required to notify the State Office of Mental Retardation of all nursing home placements and since December 1974 regulations require the approval of the Office of Mental Retardation Region

In December 1973 the State Office of Mental Retardation furnished the Regions the results of a study of the institution's placement of patients The report showed the institution had placed 773 patients in the 5 fiscal years 1968 through 1973, 204 were from the ENCOR area The study stated that the majority of the 773 placements were into nursing homes, and included young adults as well as senior citizens An ENCOR report on the study showed that 143 people were placed into the ENCOR area, of which only 37 were being served by ENCOR In December 1973

An ENCOR official pointed out that one problem with the study was that patients were listed by county of legal residence when admitted to the institution rather than by the county where placement was made

ENCOR staff stated that they still lack complete information on placing mentally retarded persons m their area in nursing homes, board and room accommodations, or with relatives Of 117 nursing home placements more recently reported by the institution in their *area,* ENCOR staff have identified 92 such placements The remaining 25 reported placements had not been located as of April 1975 Of 47 other placements, all but 2 have been located

TRACING THE MENTALLY DISABLED TO COMMUNITIES

To determine the procedures used and the services provided to mentally disabled persons transferred from State institutions to communities, we traced 29 individuals released from Beatrice State Home for the mentally retarded and 65 from Lincoln Regional Center for the mentally 111 The tracing was to two counties, Lancaster, an urban county and Seward, a rural county

MENTALLY RETARDED

From April through October 1974, 193 people were placed or discharged from the institution We selected for tracing all persons who went to either Seward (7 persons) or Lancaster County (22 persons) Of these 29 persons 12 were borderline or mildly retarded, while 9 were moderately retarded and 8 were severely retarded They had been In the institution from 2 months to 54 years The community facility and year of placement are shown in the following table

Community facility	Year placed						
	1969	1970	1971	1972	1973	1974	Total
Nursing home	1	3	5	1		3	13
Foster home						1	1
Private school						1	1
Community-based program hostel		2	1			6	9
Board and room	1	2	1				4
Natural home						1	1
Totals	2	7	7	1	0	12	29

Current living arrangements and services or support provided were as follows

Residential arrangement	Total	Services or support provided: County welfare: Social services	County welfare: Income maint	Medicaid	Vocational Rehabilitation	Supplemental Security Income	Community-based program
Nursing home	11	0	8	9	0	1	0
Foster homes	3	2	0	0	1	1	3
Private school	1	0	0	0	0	0	0
Community-based program hostel (note a)	9	9	7	0	8	7	9
Terminated (note b)	2	0	0	0	0	0	0
Natural home	1	1	1	0	1	1	1
Private apartment	2	2	1	0	1	1	2
Totals	29	14	17	9	11	11	15

[a] Two clients in the program were residing in board and room facilities

Terminated from community-based programs One individual was independent in the community The other moved out of State

Those m community-based programs are provided various services ranging from periodic counseling to a full-time residential program The private school for the retarded provided full academic training as well as residential facilities and life-skills training The two nursing homes we visited where SIX of the selected persons were residing provide nursing care and recreational facilities

MENTALLY ILL

From May through October 1974, 324 persons were separated from the institution We selected a total of 65 individuals placed in 2 counties--7 in Seward and 58 in Lancaster County We excluded from our selection persons whose primary diagnosis was alcohol or drug abuse

Of the cases selected 37 involved primarily schizophrenia or personality disorders, the remaining 28 included neurosis, behavior disorders, and other problems The length of stay ranged from 1 to 721 days Thirty-eight of the persons had been previously hospitalized from 1 to 12 times

People released from the institution are normally referred by the institution to a Federal, State, county, or community agency for services and financial resources to aid in the movement back into the community We classified these referrals as follows

Primary referral - The agency identified by the institution for after-care services such as Community Mental Health Centers, nursing homes, or community-based programs

Additional referrals - Additional agencies other than the primary agency identified by the institution to provide services These are normally flnancial and housing resources

Secondary referral - An agency designated by the primary referral agency for providing services

The primary referrals for the selected cases were as follows

Community agency	Referrals
Lincoln-Lancaster Mental Health Center	37
Pioneer Mental Health Center, Seward County	5
Nursing homes	4
Courts	3
Lincoln-Lancaster Child Guidance Center	2
Lincoln Regional Center (note a)	3
Courts/Child Guidance (Jointly)	1
Lancaster Office of Mental Retardation	1
Region 5, Office of Mental Retardation	1
Family Services Association of Lincoln	1
Lincoln Information Services for the Elderly	1
No referral made	6
Total	65

[a]Lincoln Regional Center provides some programs and consultation to released patients on an outpatient basis

Of the 59 cases where a primary referral was made, the community agencies were aware of the referral in 55 cases The designated agency for four persons had no record of the individual In five of the six cases where a community agency had not been designated, a Community Mental Health Center provided services The other person was readmitted to Lincoln Regional Center shortly after release Community Mental Health Centers did not routinely document all of the services provided each of the persons traced from the institution Services available at one of the Centers, however, were discussed on page 25

In addition to the services made available by the Center to persons released from institutions, other community agencies or facilities may also provide services For example, the Lincoln-Lancaster Child Guidance Center, a local agency affiliated with the Lincoln-Lancaster Mental Health Center provides assistance to children, teenagers, and parents Nursing homes provided nursing care, residential, and recreatlonal facilities Courts provide services including counseling, referral, and tutoring programs

In addition to the primary referral agencies, we found that 36 received services from the State Division of Vocational Rehabilitation, and 9 received services from the Lancaster County Department of Health Services recommended by the institution and services provided by the various community agencies were as follows

Service	Recommended	Provided
Chemotherapy	37	32
Nursing home	8	7
Individual, family, and group therapy	36	40
Vocational programs	12	36
Other	13	8

The number of contacts and services provided by the community agencies varied according to client needs or their willingness to accept or to continue services

Additional institution referrals were made for lodging services and financial support in the community as follows

Lodging arrangements	Number of cases
Own home	37
Room and board home	17
Nursing homes	7
Foster homes	3
Court	1
Total	65

Services or financial support	
Public assistance	
Social Services	12
Income Maintenance	16
Supplemental Security Income	16
Medicaid	5
Total	49

Some received services or support from more than one source We also noted that other Federal resources such as Social Security, Veterans Administration, Railroad Retirement, and Medicare were being used Due to the number of agencies providing services and the lack of documentation of secondary referrals made by the primary referral agencies, we did not attempt to summarize the secondary referrals