HISTORY OF GOARC

As late as 1967, there were few alternatives in Nebraska for parents of the mentally retarded. They could send their child away to the states's only institution for the mentally retarded, located in a small farming community in the southeast corner of the state, or, if they were wealthy enough, they could send that child to a private institution even further away from his family. If parents rejected institutionalization, they were left with virtually no support in the community to assist them in working with their child.

So parents of retarded citizens in Nebraska banded together, as did parents in other states across the nation, to share their frustrations, and to seek to provide for their children what their government and neighbors had failed to provide. The void was so great--no services in the community and deplorable conditions at the institution--that these parents committed themselves to bringing about change. The action they pursued caused an entire new system of services for the mentally retarded to evolve. (The full story is best told elsewhere. See Wolfensberger and Menolascino, "Reflections on Recent Mental Retardation Developments in Nebraska", Mental Retardation, December, 1970.)

As members of the Nebraska Association for Retarded Children, a group of parents in 1968 requested a study of the state's institution for the mentally retarded. Nebraska's governor appointed a Citizen's Study Committee to examine the conditions of the Beatrice State Home and to provide him with direction for future state action. The committee was comprised of parents of mentally retarded persons who then resided at the state's institution, parents whose children

lived in their own homes in the community, several state senators, and several cooperating professionals (who did not, by the way, chair the committee). The committee made reference to many conditions in the institution that needed immediate remediation, but their most urgent recommendation to the governor was that the population of the institution be reduced from 2300 to 850 citizens within six years.

They went on to suggest that such a reduction could only be achieved by establishing community services for the mentally retarded and their families throughout the state. During the 1968 legislative session, fourteen pieces of legislation were introduced. Parent lobbying was strong and probably responsible for the enactment of the legislation. One bill, the Community Mental Retardation Services Act, established a 60%:40% funding partnership between the state and local agencies. Other legislation revised, clarified and improved old laws relating to mentally retarded persons.

In the greater Omaha area, parents and professionals wrote a plan for services for the mentally retarded citizens of Douglas County. They outlined a comprehensive system of services, a system in which state and county dollars could be invested to facilitate the reduction of the institution's population, thus improving the lives of many mentally retarded persons. Their plan included descriptions of each component in a comprehensive system of services: models for residential services, family

guidance services, developmental services and vocational services. And they did it immediately--not after two years preparatory study and three years final drafting.

These planners, as citizens of a conservative Republican state, were faced with several staunch political realities, the first of which was that social services were not the target for unquestioning or overwhelming citizen approval in Nebraska.

Sensitive to the convictions and politics of their neighbors, members of these committees rooted their plans in reality. Because Nebraska is a fiscally conservative state, the designers of the Douglas County Plan and the Nebraska State Plan emphasized developmental programming as an <u>investment</u> in human potential as opposed to the subsidy of human dependence perpetuated by the institutional model. Based on data collected by the Citizens' Study Committee, the assertion was made that many residents of the institution could have been readily maintained in the community by means of services far less costly and much less dehumanizing than institutionalization. The plan pointed out that with the establishment of day services in the community, many persons would be able to remain with their families with no need for "total care". This advantage of service delivery in the community was emphasized in terms of fiscal economy as well as in terms of the human economy rendered by enabling families to stay together.

The establishment of community-based services requires little capital construction, another "plus" which parents made well

known to their government representatives. Children classified as "trainable" and "educable" mentally retarded could be enrolled in existing public school special education classes, industrial space could be leased for workshop establishments, and existing homes and apartments in the community could be utilized for residences. The group advocated spending local tax dollars efficiently and purposefully in the community.

An important Nebraska proverb admonishes the spenders of tax dollars to never, never duplicate services. And so the plans emphasized the use of generic services for recreation activities, for medical care, for dental care, for transportation.

A news documentary, shown in segments on the 6:00 evening news, exposed the public to the horrors of their institution for the mentally retarded. Town hall meetings were held across the state and citizen awareness and concern for the status of retarded persons were aroused. And before that concern subsided, parents were able to appeal to their friends and neighbors to take a stand, to write their state representatives, to join in a visit to the state capitol expressing their dissatisfaction with present conditions and suggesting a fundamental change in approach.

Most of these town hall meetings were positive, lively exchanges, but the process of change was not one void of opposition. The meeting held in the community in which the state's institution is located proved less than successful. The opposition to plans for alternative means of service were strong in this area of the

state. But the governor was supportive, and, because Nebraska is a small state with a one house legislature, legislative change required mustering the support of only 25 representatives.

The plans composed by this group of parents and professionals were based upon three very important philosophical guidelines: the normalization principle, the developmental model, and comprehensive services. The evolution of Nebraska's services for the mentally retarded was markedly shaped by parents' internalization of these principles and their strong conviction that the establishment of any services which did not meet the demands of these guidelines was another step backwards.

A developmental model of services is one which recognizes that every human being is capable of growth and development, taking as its responsibility the facilitating of that development and then accommodating such growth by providing (or securing in the community) program options within a developmental continuum of services. The service system proposed by the ARC members was one which would serve mentally retarded citizens of all ages, regardless of level of ability, encouraging each to advance to the next step in his individualized program.

The principle of normalization prescribes that the conditions and patterns of everyday life offered through services should be as similar as possible to the conditions and patterns of everyday life that other citizens of the area experience. In our society, a normal routine of life is characterized by leaving

our homes for work or school in the morning, returning in the evening, and participating in leisure time activities outside our homes. Mentally retarded persons, then, should have the same opportunities for broad exposure to the community.

No longer would mentally retarded children and adults live and play together, being treated as if they were all eternally children. No longer would a person sleep in a room with forty others, dressing or being dressed at 5:00 a.m. and shuffled off en masse to breakfast across the mall and then back to the wards or to work in another ward on the same "campus". All children would go to school and adults to work. Many adults would take public transportation to their jobs across town, and return to their homes in the evening for dinner, maybe to later finish a load of washing and ironing and then be off to a movie downtown or a quick ballgame or just a walk in the park down the street. Options would be available and many people would be making decisions for the first time in their lives.

A commitment to comprehensiveness requires the creation of a service system which meets at least the major service needs of consumers in appropriately sized geographical areas. A service system should be so complete and/or coordinated that a consumer never has to leave the service region in order to receive the services he needs, except for, perhaps, the most specialized ones. This administrative principle does not require that one agency provide every possible service, but rather that a central

coordinating agency be so structured that it readily fits into existing or projected systems in the community, capable of adequately coordinating services for consumers. A mental retardation agency should assume efforts to ensure that needed services are rendered and are rendered appropriately.

The Omaha parents approached their county commissioners with their plan, requesting funding for one year's operation of pilot programs. Their request was granted.

And still this evolutionary process did not end. Although public funding made them feel a little closer to having their programs perceived as a right for mentally retarded people, rather than as a benevolent gift, they felt that their volunteer parent administration of the service delivery system made it less than normal, and perhaps prevented the community from accepting its full and ongoing responsibility for the provision of services to all mentally retarded citizens. These parents had gone beyond simply seeing the needs of their own children met. They were working for the rights of all mentally retarded persons.

So programs (and the rest of the year's budget) were channelled to a staff of professionals. Afterall are not retarded citizens entitled to the same right of all children; that of being educated by a professional staff. These staff were to be governed by a group of county commissioners, elected representatives of the people. Today, the Greater Omaha Association for Retarded Citizens monitors services provided to retarded citizens, assuring that

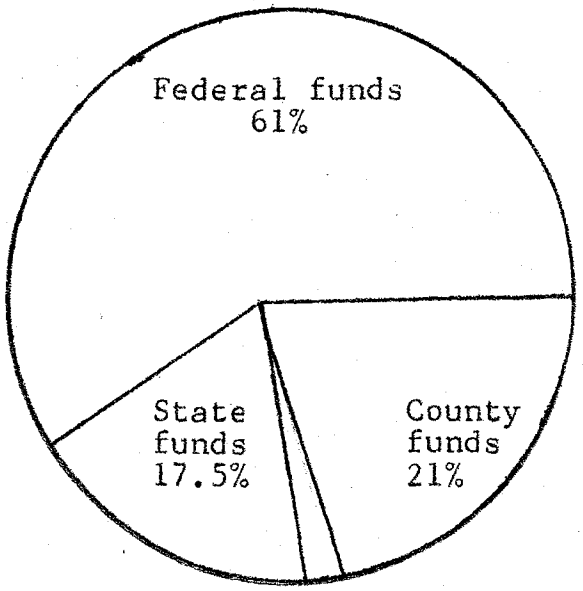
individual rights are upheld and that sound programs and positive community attitudes continue to develop.

HISTORY OF ENCOR AND STRUCTURE

From the plans and efforts of involved and concerned parents, the Eastern Nebraska Community Office of Retardation (ENCOR) was incorporated in July of 1970. ENCOR provides services to mentally retarded citizens of Cass, Dodge, Douglas, Sarpy and Washington counties in eastern Nebraska. One county board member from each of the five counties serves as a member of the ENCOR Governing Board, responsible for the appointment of the agency's executive director, creation and enforcement of agency rules, the adoption of annual budgets, and the general management of the agency. Base funds for ENCOR operations are allocated by the counties, and state dollars are allocated through the State Office of Mental Retardation. These local dollars draw federal matching funds. (See funding chart - next page.)

Today, six regional offices in Nebraska coordinate services for mentally retarded citizens across the state. Each regional program is designed to provide a continuum of services to meet the individual needs of the mentally retarded citizens it serves, from the mildly to the profoundly retarded, from infancy to old age. Services are located in communities throughout Nebraska, in facilities integrated into neighborhoods, industrial areas, and recreational areas across the state. Citizens receive residential, educational, vocational and/or family support services, with each

July 1, 1972 - June 30, 1973



other ½%
(parent client payment,
contributions, etc.)

program designed to facilitate movement into mainstream community education, employment, or independent living.

Nebraska is, of course, a lightly populated state, so the numbers of mentally retarded citizens in community programs may seem small when compared to the needs for service which face other states. But the percentage of mentally retarded persons receiving services in the community through regional mental retardation programs or through other established community channels (e.g., public schools) is growing in significance. ENCOR is now serving over 1000 mentally retarded persons from a geographical region whose total population approaches 600,000. Across the state, 2,100 retarded persons receive services through their regional system of community services, while the population of the state's institution remains to be achieved. Between January and December of 1972, 117 persons entered the institution while 114 returned to the community. In the ENCOR region 14 persons entered the institution while 46 returned to community programs. The systems for delivering services in the community have been established in Nebraska; the challenge of expanding these systems to the extent where they can accommodate all citizens who require service remains.

ENCOR is the oldest of the regional programs and has developed most of the service components necessary for a comprehensive system of services. For mentally retarded children who are still excluded from public school participation because of their young age or the extent of their handicap, ENCOR provides developmental and educational programs. Six developmental centers are operated throughout the region to serve children

living in the neighborhood area of each of these centers. The educational program lasts from 9:00 to 3:00, just as do public school programs in the area. Children are grouped into classrooms according to their chronological age. In terms of normalization, in a community public school classroom a child of 6 and a teenage, 14, would never be in the same classroom; they are emotionally and physically different. And so, developmental programs are also conscious of activities and grouping which are appropriate for a child's age.

The Adolescent Education Program emerged as both parents and professionals recognized the need for improved programs for adolescents who had been served at the developmental centers. This new program helped to eliminate many of the problems encountered at the developmental centers. By providing a centralized setting for all adolescents, it is possible to provide age-appropriate materials, activities, and instruction. It now became possible to put an even greater emphasis on normalization and development of skills necessary for successful adult living in the community.

ENCOR's new Coordinated Early Education program places pre-school age children in early education programs in the community. A resource/consulting teacher, trained and employed by ENCOR, and four or five young delayed children move into an early education day care center. The delayed children are not introduced as "special" or retarded, but simply as children. They play and

learn with the other children. The resource/consulting teacher manages several individualized educational programs--language development, self-care, motor development--with each delayed child to provide the amount of specialized support each might need. Most of the child's school day is spent in activities with other children. Children make great teachers!

The Behavior Shaping Unit is a specialized program for children whose behavior prevents them from participating in other programs within ENCOR or the community. Individualized objectives, emphasizing deceleration of destructive or unacceptable behaviors and the development of self-help skills, are determined for each child. When antisocial or destructive behaviors occur infrequently or have subsided entirely, children move to other residential settings and attend an ENCOR developmental center or public school class.

With the opening of the Developmental Maximation Unit, severely and profoundly retarded children with multiple handicaps and complex medical problems can be served in the community. These are not symbolic "placements" for the sake of a community setting, but movements into a program pledged to "maximizing the development" of each child, thus enabling children to move to other programs in the community as soon as possible. Most of the children participating in this program have some medical problems. Therefore, the program seeks to minimize these physical problems so that the children can get on with learning! A pediatrician extends needed

medical care to the children on a part-time basis and refers them to appropriate specialists when necessary. Although the unit operates in a remodeled wing of a hospital and has emergency access to medical staff and equipment, it is an educationally geared program.

ENCOR operates five vocational services centers or workshops located in industrial or commercial areas of the community. The location of the workshop is extremely important; an industrial setting capitalizes on the community's perception that the shop is a real work setting rather than a simulated one.

Because real work is, in fact, performed within the shop, the interior environment is industrial as well. Manual and hydraulic lift trucks, machines, work areas, time clocks, and Bradley sinks are in daily use and emphasize the fact that valuable production occurs.

ENCOR competitively bids on local industry's sub-contract work and brings it into the workshops. This sub-contract work is not just a visual aid. It is real and important work for which clients are paid for what they produce. By doing jobs with industrial demands such as quality controls, work tolerances, and production schedules, the demands of industry can honestly and realistically be placed on the workers.

The Douglas County Plan did not outline for all eternity what a good system of services should be. Because of continuing scrutiny, change has occurred. For example, it has been recognized that

vocational service centers do not meet all demands of the normalization principle. The workshops are segregated settings that offer few appropriate models and little opportunity for integration. Thus, a new alternative in vocational training was devised.

Minimally supervised employment is offered through Work Stations in industry. In these settings, vocational training occurs through completion of sub-contracts under the direction of an ENCOR staff member in the midst of an actual industry or business. As retarded and non-retarded workers come to work, clock-in, drink coffee, eat lunch, work and produce together, normalization is readily witnessed. Placement of as many persons as possible into the community's work force is a major goal of all vocational programs.

A mentally retarded person who is unable to live with his natural family has a right to live in a setting similar to that in which other persons his age live. ENCOR offers an array of residential services designed to provide this opportunity. These placements include foster-adoptive placements for children, small group residences in the community, special purpose residences, and semi-independent living arrangements for adults.

The "home environment" of a mentally retarded child or young adult living with his natural family or with a foster or adoptive family while participating in educational or vocational activities outside

the home is very similar to that of other persons his age. The residential settings provided by ENCOR for mentally retarded persons are designed to be similar to other homes in the community, to be as "normative" as possible. Service components in the continuum of residential services are designed within the operation guidelines of the normalization principle.

ENCOR residential facilities are dispersed throughout the region, not clustered in one neighborhood. They are not separate and distinguishable from other homes in the neighborhood. In fact, residences are usually established in existing homes, rather than in specially constructed facilities.

The use of family homes also determines the number of persons that can be served in one residence--a small group of people, usually 6 to 9 persons, and houseparents live in one home.

Small facilities enable ENCOR to provide services which are geared to the needs of the individual. That means that residential programs can be specialized as to age appropriateness, degree of disability or the need for structure or prosthetic environment.

Another service component not envisioned in original plans was residential alternatives beyond structured settings for adults. When an adult has demonstrated a degree of self-sufficiency in a residence, he may elect to move into a board and room home, or perhaps, a staffed apartment. A staffed apartment is generally shared by two mentally retarded adults and a non-retarded peer.

The three people share living expenses and household tasks. Paid by ENCOR, the roommate-staff person assists the others in mastering even more skills related to independent living. Grocery shopping--grocery shopping within a budget--rent paying, bill paying, cooking, a mature and responsible use of freedom, the use of a laundromat, are all skills to be learned in a staffed apartment.

Once adults have mastered these skills and manage their own lives with a degree of independence, the staff member can move out. At that point, back-up counseling support is offered as it is needed.

Medical, psychological, speech therapy, and physical therapy services are provided or acquired in the community for consumers of ENCOR services. Whenever possible, maximum use of existing community resources is made. For example, six physicians in the region serve ENCOR residences just as they would any family needing their services. There are no special expenses involved, just the same care and treatment made available to a person who is retarded as would be offered to any other citizen.

Transportation services are coordinated and provided for retarded citizens attending ENCOR or public school programs when these persons are too severely handicapped to make it to work or school on their own or their families are unable to manage alone. In addition, the transportation services extend to training in the utilization of public transportation for adults, to enable them to use public transportation in moving about the community.