

Mental Retardation Services

in Nebraska:

A Century of Commitment

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Nebraska Department of Public Institutions

programs; and . . . basic and clinical research on the prevention and treatment of handicapping conditions in children" (Centennial History Committee, 1980, p. 92).

This research setting was to become the context within which normalization and development were applied as theoretical models for treatment in Nebraska. For example, Wolf Wolfensberger, a research scientist at NPI from 1964 to 1971, became one of the leading proponents of the normalization concept in this country (see Wolfensberger, 1972). Professionals from NPI along with professionals administering the community programs initiated a zealous advocacy of this new ideology.

This emerging professional paradigm was not the primary force behind the establishment of community programs in Nebraska. The major initiators were parents seeking alternative services and advocates pursuing human rights. However, the professional concurrence did lend an additional sense of legitimacy to the decentralized, community treatment movement. The model of normalization and development also had a tremendous influence on the course of treatment within community programs. The system of state-supported community programs in Nebraska served as an experimental setting for application of the model; normalization and the developmental model became the basic foundation for services in these programs (Lensink, 1976).

#### Community-Based Programs

In addition to special education programs for higher-functioning children with mental retardation and the institutional care provided at BSH, the State of Nebraska began providing public funds to community services for persons with

Significant state action with implications for mental retardation services occurred in 1967 when the Legislature created the Office of Mental Retardation (OMR) within the State Department of Health.<sup>119</sup> Initially, the Division operated with two staff members, the Coordinator/Director and a research assistant. The duties of the Office consisted of studying the existing community programs and establishing new programs where needed. OMR was limited in creating needed programs, however, since the Legislature appropriated a maximum of only \$50,000 from the General Fund for the creation and operation of both the Office and the programs.<sup>120</sup>

An even more significant event occurred in 1967 with the creation of the Citizens' Study Committee on Mental Retardation. The following sequence of events led to the formation of the Committee. In the spring of 1967, a NebARC committee proposed that a study be conducted of the residential facilities in Nebraska. This proposal, which was supported by Dr. Osborne, the Director of the Department of Public Institutions, was then presented to the Governor's Citizen Committee on Mental Retardation along with eight NebARC nominees to constitute a study committee. The Governor's Committee accepted the proposal and suggested four additional nominees to the study committee. These twelve members were officially appointed by Governor Tiemann as the Citizens' Study Committee on Mental Retardation which was to function as a sub-committee of the Governor's Citizen Committee on Mental Retardation. The Committee was forthright in specifying its ideological perspective listing five evaluative assumptions: 1) a person with mental retardation is a human being deserving of legal, human, and social rights and should be treated as other human beings; 2) intimate interaction should exist between services and communities; 3) maximal contact should exist between persons being served and their families; 4) services should provide an optimal environment for the

development and well-being of the individual; 5) each person being served should have access to an advocate who will safeguard her or his interest.<sup>121</sup>

As a result of extensive investigation of existing services, the Committee issued scathing criticisms of the current system.<sup>122</sup> Stated the Committee:

Nebraska today has an archaic and fruitless program for the mentally retarded. . . . The existing condition is one of the blackest pages in our state's book. . . . Public zoos traditionally spend more to care for their large animals than is spent to care for the mentally retarded. . . . Dehumanization of retardates is a result of our present Nebraska condition. Retardates who could be trained to use the bathroom; to wash and clean themselves, are often sentenced to living in their untrained condition and to waste away without attention (pp. 11-13).

The Committee proffered explicit and detailed recommendations. Several of the recommendations concerned the provision of more resources and authority to state agencies administering mental retardation programs. The Committee also urged the development of community services and protection of specific rights for persons with mental retardation. For example, the Committee advocated the repeal of sterilization laws discriminating against persons with mental retardation.

Responding to the Committee's report, the Nebraska Unicameral enacted significant legislation in 1969. One of the most important laws provided for the creation, funding, and coordination of community-based programs in the state. The legislation also moved the Office of Mental Retardation (OMR) under the Department of Public Institutions and created an advisory committee

to OMR consisting of professionals and lay persons.<sup>123</sup> The act defined the purposes of OMR, delineated the duties of the director, and enabled OMR to direct state funds to community mental retardation services. OMR could provide state monies on a grant basis to fund up to 60% of the community programs. The initial state appropriation for the community-based service component for FY69-70 was \$209,705. State funding increased dramatically thereafter.

In 1973, the Legislature enacted new legislation that established taxing authority and increased state funding to 75% of the community programs' costs. The law also completed the framework for the current system of community mental retardation services in Nebraska by establishing six mental retardation service regions in the state.<sup>124</sup> Under this structure, parent-initiated services became primarily state funded and new programs emerged.

In 1977, the Office of Mental Retardation began disbursing funds to regions on an aid payment basis. This method of funding regions was the result of a State Attorney General's opinion advising the Department of Public Institutions that the funding relationship with regions was one of disbursing funds to the regions within the fund amounts appropriated by the Legislature.<sup>125</sup> The opinion also indicated that such a relationship did not require a contractual agreement or the Department to reimburse regions based on services provided, such as reimbursing on a unit of service basis. This funding procedure, i.e. aid disbursement, is the current system used for state funding of regions.

In conjunction with this new found state support came increased support from counties and the federal government. Community-based program funding from a

county governmental body appears to have originally occurred in 1968 when Douglas County appropriated \$110,000 to the Greater Omaha Associations for Retarded Citizens (GOARC) program.<sup>126</sup> With the formation of mental retardation regions through the Interlocal Cooperation Act counties began to provide direct fund support to community-based programs. In 1969, the Legislature set the local/county contributions at forty percent of the total funding with up to three-fourths of the local contribution allowed to be in the form of "soft match," i.e. facilities, fixtures, etc.<sup>127</sup> In 1973, legislation changed the local rate to one local/county dollar for each three dollars from the state. The local match could include "in-kind services, and income from workshops and room and board payments."<sup>128</sup>

A surge of federal support occurred in the 1960s and early 1970s. President Kennedy created the President's Panel on Mental Retardation in 1961. This tremendously influential panel published a report in 1962 containing a number of recommendations pertaining to improvement in society's treatment of the mentally retarded. One of these recommendations urged the development of community-centered programs (Maloney & Ward, 1979). In 1963, Congress enacted the Mental Retardation Facilities and Community Mental Health Centers Construction Act which provided funds for treatment and research.<sup>129</sup> In October, 1970, Congress passed the Developmental Disabilities Service and Facilities Construction Act.<sup>130</sup> The legislation is notable for its developmental perspective. The amendments replaced the term mental retardation with the term developmental disabilities which referred to:

disabilities attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual ... closely related to mental retardation or to require treatment similar to that

required for a mentally retarded individual, which disability originates before such individual attains age 18, which has continued or can be expected to continue indefinitely, and constitutes a substantial handicap to the individual.<sup>131</sup>

In addition, the new legislation replaced references to clinical training with the term interdisciplinary training. This legislation was intended to: 1) assist states in developing plans to meet the needs of persons with developmental disabilities; 2) provide funds to construct facilities for the provision of developmental disability services; 3) provide funding for the implementation of services for the developmentally disabled; 4) support local planning and assistance applied to developmental disability services; 5) support training of personnel required to provide services for the developmentally disabled and encourage research regarding staff and personnel needs; and 6) support research regarding the effective provision of developmental disability services.<sup>132</sup>

Federal support also became available directly to community programs. In 1968, Douglas County received a Facility Establishment Grant from the Federal Rehabilitation Services for increasing staffing and purchasing additional facility equipment.<sup>133</sup>

In 1970, community-based programs received a source of federal funds which quickly became the second largest source of funding for community-based programs: Title XX of the Social Security Act.<sup>134</sup> Originally, Title XX was limited to non-medical social services for persons categorically related to federal entitlement programs. Title XX allowed the state to purchase social services from approved service providers and receive seventy-five percent

federal funds for the expenditures. Community-based programs (after 1973, the mental retardation regions) were approved by the state's Department of Social Services as service providers under Title XX regulations.

Other forms of federal funding also became available. Medicaid became an important funding source for persons in the community-based component of the state's mental retardation system. For eligible persons served in community-based programs, Medicaid provides fifty-eight percent of the funding for medical services. Each person's eligibility is determined by her or his income, resources, and disability. A person's categorical eligibility for Medicaid is through the Aid to the Disabled Program.

Persons with mental retardation also became eligible to receive Supplemental Security Income (SSI) benefits and/or State Supplemental Assistance (SSA) to SSI.<sup>135</sup> As with Medicaid, eligibility for SSI or SSA is determined by income, resource guidelines, and disability. Funding from SSI and SSA is received directly or in behalf of individuals. Such funds are perhaps the single most important sources of payment from persons to community-based programs for payment of room and board for operation of community-based facilities. In addition, persons in the community-based service component, as well as those in the ICF/MR component, became eligible for Social Security benefits through the parent's Social Security account as a disabled dependent.

With this support from county, state, and federal resources, community-based mental retardation programs flourished. In Region I, consisting of eleven panhandle counties, all programs regionalized by mutual agreement on July 1, 1976. These parent-initiated programs continued to offer quality mental retardation service, but with the assistance of public funds.<sup>136</sup> By 1977,



Region I served 139 clients.<sup>137</sup> Region II consisted of 17 counties in the southwest part of the state and had its regional office in McCook. With public funding, new programs and program expansions occurred in North Platte, McCook, Ogallala, Cozad, Imperial, and Elwood.<sup>138</sup> One hundred sixty-eight clients were receiving community-based services in Region II by 1977.<sup>139</sup> By 1971, the 22 counties in Region III had signed agreements under the Interlocal Cooperation Act. By 1975, the Region had seven community programs<sup>140</sup> that two years later, were serving 375 clients.<sup>141</sup> In Region IV, serving 22 counties in the northern part of the state, the regional Office of Developmental Disabilities was incorporated in December of 1971. The office reorganized in 1974 as a governmental inter-local cooperative. In addition to parent-initiated programs in Norfolk and Columbus, services emerged in Wayne, South Sioux City, Bloomfield, Valentine, O'Neill and Lyons. On May 24, 1979, Keya Paha and Cherry counties withdrew from the Region IV interlocal agreement and, through a separate interlocal agreement, administered services through the Keya Paha-Cherry County Mental [Retardation] Service. By 1979, approximately 350 clients were receiving services under the supervision of the Region IV office.<sup>142</sup> In the southeastern portion of Nebraska, Region V initially consisted of 14 counties. Two more counties were added in 1974. By October 1974, the sixteen counties had signed interlocal agreements. By 1976, five community programs were being funded through the regional office in Lincoln<sup>143</sup> and by 1977 were serving 479 persons with mental retardation.<sup>144</sup> In 1970, the five counties in Region VI formed the Eastern Nebraska Community Office of Retardation (ENCOR)<sup>145</sup> which became a model service delivery system providing residential, vocational, educational, social, and support services to all five counties (see Lensink, 1976). By 1977, 639 clients received mental retardation services in Region VI.<sup>146</sup>

This growth was not unadulterated, however. In 1975, Congress placed a national expenditure ceiling on Title XX funds. For Nebraska, this action reduced Title XX funds to community-based mental retardation services by more than \$1.6 million between FY74-75 and FY75-76. This funding reduction had pernicious effects on community services: Many services were entirely eliminated.<sup>147</sup> However, through continued state support, the regional programs soon resumed their growth.

In the middle 1970s the responsibility for serving school-aged children shifted to the public schools, and community programs began to specialize in adult services. This shift in emphasis started in 1973 when the Nebraska Legislature, anticipating federal legislation, enacted a law requiring the State Board of Education to provide appropriate educational programs for all handicapped children, ages 5-18 by October 1, 1976.<sup>148</sup> The upper age limit was extended to 21 in 1976.<sup>149</sup> The anticipated federal legislation was the Education for all Handicapped Children Act.<sup>150</sup> Congress passed this Act in 1975 (effective by 1978) to require a free appropriate education for all handicapped children. In 1978, Nebraska extended the school system's responsibility to the education of preschool handicapped children.<sup>151</sup>

In the early 1980s, a number of private community-based mental retardation programs emerged. Martin Luther Home developed community programs at Beatrice, Omaha, and York. Bethphage Mission established programs in Holdrege and a group home in Lincoln. Other community programs that evolved include Youth Care, Inc. in Omaha and Developmental Services Corporation in Hastings. Community-based programs continued their growth and evolution through the early 1980s. By 1984, 2,290 clients were being served by private and public

community mental retardation programs. These programs established a standard of excellence that was recognized throughout the world.

## 8. The Human Rights Model

### Ward T1

Twenty-five small boys and girls and 2 staff on ... the day room noise level is tremendously high ... no place for privacy ... TV blaring away but nobody watching it ... urine on the floor.

- Robert Perske

The human rights model has been expressed most conspicuously in litigation. However, state legislative action and private social activism have also been prompted by this perspective. The human rights model originated in civil rights activity in the 1950s. At this time, black Americans sought equal opportunity and treatment through social activism, litigation, and legislative change. Although initially associated with racial equality, the human rights model eventually became a banner for other oppressed groups. By the 1960s, groups identified by religion, gender, national origin, and age actively pursued their constitutionally protected rights. It was not until the 1970s, however, that advocates made substantial progress in safeguarding the human rights of persons with developmental disabilities (including persons with mental retardation) and mental health problems. Litigation involving mental institutions established and defined a right to treatment,<sup>152</sup> a right to refuse intrusive treatments,<sup>153</sup> and procedural rights in commitment proceedings.<sup>154</sup>

Society had long singled out persons with mental retardation for disparate treatment in such areas as marriage, child-bearing, adoption, child-rearing, voting, and obtaining a drivers' license. Representatives of persons with mental disabilities began questioning the rationality of this discrimination. Advocates also identified the absence of human rights protections in mental retardation service programs. Some of the rights that representatives

advocated protection of were: 1) the right to procedural due process in commitment procedures including the right to representation in an adversarial hearing; 2) the right to effective habilitation or treatment; 3) the right to treatment in the least restrictive manner; 4) the right to refuse certain types of habilitation; 5) the right to be free from labor constituting involuntary servitude; 6) the right to privacy; and, 7) the right to associate with persons without mental retardation.<sup>155</sup> (See Yohalem & Manes, 1983; Cook, 1983.)

The legal concept that became the most popular with human rights activists and litigants was the least restrictive alternative. This concept is actually a judicial test of state action rooted in certain amendments of the United States Constitution. In litigation involving the rights of persons with mental retardation, the Fourteenth Amendment has been preeminent. This amendment states in part that, "No state ... shall deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws." As interpreted by the judiciary, the first clause, referred to as the due process clause, involves two protections. One, procedural due process, requires that certain procedures be followed in a hearing or trial before a state may deprive a person of life, liberty, or property. The second, substantive due process, restricts certain state actions apart from the procedures used to attain the state objectives. The second clause, referred to as the Equal Protection Clause, requires states to treat equally persons similarly situated or to show a rational basis for not doing so. These protections have various applications for the regulation of mental retardation services (see Turnbull, Ellis, Boggs, Brooks & Biklen, 1981). The appropriate analysis under the Fourteenth Amendment is the least restrictive alternative (see Bastress,

1974). Where two options exist that will meet a state objective, the principle of the least restrictive means requires the state to choose the option that is less restrictive. In the area of developmental disabilities, the least restrictive alternative principle began to be referred to as an extralegal professional concept closely tied to the developmental/normalization perspective as one can see from the following statement:

The least restrictive alternative requires that any intervention be the least intrusive into, and least disruptive of, the individual's life, and represent the least departure from normal patterns of living, that can be effective in meeting the individual's developmental needs.

(Accreditation Council, 1978, p. 42)

The principle became the rallying cry for persons advocating deinstitutionalization. For these advocates, the least restrictive alternative meant that:

a person should not be hospitalized, with drastic curtailment of liberty involved, if he can be treated in a community ... The right to be treated in a setting less restrictive than an institution [is] required by the constitutional principle of the least drastic means [a term synonymous with least restrictive alternative]. (Mental Health Law Project, 1973, pp. 27-28).

Another popular concept, derived more from a human rights as opposed to a legal perspective, was dignity of risk. This theory proposed that overprotection of persons with disabilities robs those persons of

individuality and potential for growth. Custodial care of people with mental retardation in a safe protective environment is dehumanizing. Only through encountering normal risks can persons exhibit such attributes as courage and dignity. Although interaction with the real world may be dangerous, it is the right of all persons and necessary to achieve self-respect (Persky, 1972). The dignity of risk concept became an additional rationale for deinstitutionalization.

By the 1970s, journalistic exposes were portraying institutions as deathtraps and snakepits. Stories of mistreatment, financial exploitation, deteriorating facilities, and dehumanizing effects abounded (National Institute of Mental Health, 1976). This picture of institutions, combined with the professional concept of normalization, the legal concept of the least restrictive alternative, the human rights concept of dignity of risk, and the availability of community options created the atmosphere for the deinstitutionalization movement.

#### The Beatrice State Home

Since the inception of institutional care for persons with mental retardation in Nebraska, the institutional population grew unabated until the late 1960s. One can identify sporadic references concerning dissatisfaction with the large institutional model before this period. For example, in the 1939 biennial report,<sup>156</sup> Superintendent Burford noted:

There is a belief among some psychologists that a person's ability to adjust into normal society will lose effectiveness upon confinement in an institution for the feeble-minded. This is because the background of the

individual is such that he does not have to meet the challenge of higher levels of performance. So that it is better for those who are subnormal mentally, especially on the upper levels, to attempt to make an adjustment in society rather than to thrust them into an institution where they may lose what little social experience they have had. After all, by far the biggest percentage of those who are subnormal mentally are not confined in state institutions, but are making some kind of adjustment in society. (p. 268)

Despite this admonition, the institutional model continued to dominate in Nebraska and the rest of the nation.

An impetus toward deinstitutionalization occurred with the formation of the Citizens' Study Committee on Mental Retardation in 1967. The Committee made detailed recommendations concerning BSH. It suggested a reduction in the number of residents from approximately 2300 to 850 in six years. The committee also advocated improved conditions for residents remaining institutionalized. For example, the committee recommended an improvement in staff/resident ratios and creation of developmental training programs for residents.<sup>157</sup>

In the succeeding years, the population at the Beatrice State Home decreased dramatically. However, this reduction resulted from a federal funding scheme rather than recommendations by the Committee. Title XIX of the Social Security Act (Medicaid) allowed eligible certified medical facilities to receive payment for medical services provided to eligible persons.<sup>158</sup> In 1969, BSH was certified as an Intermediate Care Facility (ICF) which allowed the institution to be paid as a licensed medical facility for services



provided to eligible persons. This provision allowed as much as fifty-eight percent of care costs to be reimbursed with federal funds. The impact to the state was to obtain over fifty percent federal funding for the total operating costs of BSH and eventually other state-operated ICF/MR units. Title XIX, however, required that an Independent Professional Review team determine whether long-term institutional care was appropriate for each resident. For each person found ineligible for Title XIX funds, the facility administration had a duty to locate an appropriate placement (Scheerenberger, 1976, p. 79).

Many persons at BSH in 1969 were found not to be eligible for Title XIX funds and were transferred out of BSH and into community-based programs, nursing homes, and other services.<sup>159</sup> From June 30, 1969 to June 30, 1971, the resident population decreased from 1,945 to 1,485.<sup>160</sup> By the next year, however, this institutional exodus had slowed considerably.<sup>161</sup>

When the state became involved in providing community services, parent groups such as NebARC shifted their function from providing services to advocating the rights of persons with mental retardation. On March 24, 1972, NebARC created the Committee on the Human and Legal Rights of the Mentally Retarded. The purpose of the Committee was to examine state mental retardation facilities and to report violations of the rights of persons with mental retardation.<sup>162</sup> The Committee reported its findings on July 8, 1972. After a detailed examination of the Beatrice State Home, the Committee concluded, "... even at its best, Beatrice presents a panorama of warehousing and storage."<sup>163</sup> The Committee criticized the perceived lack of privacy, absence of sanitary conditions, and disregard for resident rights and freedoms. The existing treatment philosophy was readily identifiable: "Custody, instead of development, illustrates the life of a resident at Beatrice."<sup>164</sup> The

Committee recommended that the Governor be given 30 days to respond to the allegations. Should the Governor fail to do so, the Committee suggested court action. The determination of the Committee was evident from the report's concluding phrase -- "cooperation yes, compromise no!"<sup>165</sup>

When the Governor did not respond as the Committee wished, NebARC filed a class action lawsuit on September 28, 1972, in the United States District Court for the District of Nebraska. Thus began protracted litigation in the case of Horacek v. Exon.<sup>166</sup> The complaint alleged violation of federal civil rights statutes and seven constitutional amendments and sought declaratory and injunctive relief. The defendants, Governor James J. Exon; Director of DPI, Michael LaMontia; Director of Medical Services, Jack Anderson; Director of OMR, William Falls; and Superintendent of BSH, M.E. Wyant, filed a motion to dismiss which Judge Urbom denied on March 23, 1973.

In the succeeding years, the composition of the plaintiffs changed. Initially, the plaintiffs included the Nebraska Association for Retarded Citizens and the parents of five institutionalized youths representing the class of others similarly situated. Because of organized parental opposition to deinstitutionalization and the law suit, 69 residents opted out of the plaintiff class by July 18, 1975. On June 5, 1974, the Court dismissed the Nebraska Association for Retarded Citizens as a plaintiff for lack of standing (absence of sufficient interest or injury). The Association subsequently joined with the National Center for Law and the Handicapped as amicus curiae (a group with special interest or expertise that the Court allows to file a brief on behalf of one of the parties). On March 28, 1975, the Court allowed the United States Department of Justice to become a plaintiff-intervenor or a party to the action.

The Beatrice chapter of the ARC and others opposed to the lawsuit left the ranks of NebARC and helped form the Nebraska Chapter of the Mental Retardation Association of America (MRAA) (Frohboese & Sales, 1980). Although genuinely concerned with human rights, the MRAA Nebraska Chapter opposed the lawsuit on the basis that it would eliminate institutional care as an option, thereby diminishing parental choice in service decisions for their children with mental retardation (Frohboese & Sales, 1980). On August 27, 1975, the District Court granted the MRAA amicus status.

In 1975, the lawsuit was transferred from Lincoln to Omaha, and the trial commenced before District Judge Albert Schatz. Shortly after the trial had begun, the parties entered into negotiations that resulted in a formal agreement representing a consensus view about how mentally retarded citizens should be served in Nebraska. This agreement, or Consent Decree was approved by the Court on October 31, 1975. Some of the major features in the detailed agreement included a guarantee of the protection of constitutional rights for residents, the creation of a mental retardation panel to draft a plan of implementation for the terms of the agreement, and a guideline for reduction of the Beatrice State Developmental Center (BSDC, the name was changed July 1, 1975) population from 1,026 to 250 residents within three years. The Legislature, however, failed to fund the mental retardation panel before it could prepare the plan of implementation. Eventually, the parties agreed to a substitute panel consisting of three members. By November of 1978, the panel had prepared and presented a plan of implementation to Governor Exon. Charles Thone became governor, however, and drafted substitute plans. On November 10, 1980, the third draft of Thone's plan was submitted to the Court. Supporting the Thone's Plan were the plaintiff class, the defendants, the guardian ad litem who had been court-appointed to represent the interests of the

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residents, and the Nebraska chapter of MRAA. Opposed to the Thone Plan and urging the Court to adopt the Panel Plan were the plaintiff-intervenor United States Department of Justice, the Nebraska Association for Retarded Children, and the National Center for the Law and the Handicapped.

The Court adopted the Thone Plan on September 15, 1981. The Court reasoned that the Thone Plan was realistic and just and conformed to the terms of the initial agreement. The Court found that the Thone Plan possessed a number of advantages over the Panel Plan. First, the Panel Plan required the Nebraska Mental Retardation Panel to supervise the daily implementation of the plan and Consent Decree, thus intruding on state sovereignty. Second, the Court commended the Thone Plan for allowing parental participation in the placement process within the parameters of the Consent Decree. A third advantage of the Thone Plan concerned the ultimate reduction in population at BSDC; the Thone Plan envisioned a reduction in certifiable residential beds to 344 over a five year period, as opposed to 250 over a three year period as suggested in the Consent Decree. The Court concluded from expert testimony that a goal of 250 residents would be an unrealistic and arbitrary minimum that could result in "dumping" individuals, who could be more beneficially served at BSDC, into community programs inappropriate for the individual's needs or prior to the time that necessary community alternatives could be made available. The Court held that the Thone Plan provided a more realistic and feasible goal that would avoid a deleterious "dumping" effect.

The Court pointed out that the Consent Decree did not require a reduction to 250 residents within three years, but rather, if such condition was not met, the burden of persuasion would be on the defendants to show the alternative to

be in accordance with the agreement. In the Court's view, the Thone Plan met this burden.

The Plan specified a number of guidelines to direct specific implementation procedures. These included the following: 1) residents were not to be moved from BSDC or the regional centers until alternative services appropriate for the individual were available; 2) placement of each resident required individual evaluation; 3) any transfer of residents required input from parents or guardians; 4) a resident could move to a less restrictive alternative only if personal safety and proper habilitation and care could be guaranteed; 5) to the extent possible, a cross section of institutionalized persons were to be placed in community programs; 6) children should be placed with their natural families; 7) community programs should be designed to serve severely handicapped persons; 8) to the extent possible, each area should provide comprehensive services; and 9) the immediate emphasis should be placed on providing community options for persons without severe handicaps.

These goals were designed to assure the human rights of the individual through an effective system of services. The Plan purported to support the following principles:

- a. The right to have needs adequately met in the manner which least restricts liberty;
- b. The right to receive services necessary to meet basic human needs;
- c. The right to be protected from harm, including the harm caused by not receiving adequate services;

- d. The right to make grievances, if any, and have them resolved speedily and fairly;
  - e. The right to be in the mainstream of community life as much as possible consistent with harmonious living and personal health and safety;
  - f. The right to be treated according to one's age and needs;
  - g. A service system that has reasonable funding within the overall limitations imposed by funds available to operate all aspects of State government;
  - h. A service system that has all types of services regardless of severity of disability as close to the local level as reasonably possible and desirable;
  - i. A service system that places day-to-day decision-making authority closest to the citizen involved, subject, however, to overall coordination and oversight from the funding level; and
  - j. A service system that is open and accessible to public scrutiny.
- (p. 10).

In terms of implementation, the Plan provided for individual evaluation of each member of the class and placement in community programs if deemed the least restrictive treatment alternative. The Plan also called for supervision, evaluation, accreditation, and adequate funding of mental

retardation programs. The Plan delegated responsibility to OMR to prepare annual progress reports on the Plan of Implementation and to submit them to the Governor. Three of these progress reports have been prepared to date addressing, point by point, the progress the state has made in implementing the detailed recommendations found within the Plan. With regard to the lawsuit, the Plan provided that any party may petition the Court for dismissal of the action after June 30, 1982. On December 14, 1983, the defendants filed a motion to dismiss which the Court granted on January 31, 1984. The case of Horacek v. Exon is now history, but the implications for current services continue.

#### Other Institutions

The human rights and associated deinstitutionalization movement were also reflected in the activities of the church-run institutions, although less drastically than BSDC. At Martin Luther Home, a prototype cottage was constructed in the late 1960s with plans to build more. With the advent of the deinstitutionalization movement and the emphasis on community programming, further construction was halted.<sup>167</sup> Bethphage Mission served over 300 residents in the early 1970s. Over the next 10 to 15 years, Bethphage underwent its own deinstitutionalization drive and reduced its campus based clientele to 187.<sup>168</sup> Both corporations shifted their emphasis to community-based services.

The mental retardation services provided by the regional centers also felt the impact of the human rights movement. In the 1970's, accreditation and licensing standards were created to assure quality services. One of the primary objectives of these standards was the protection of human rights. To

receive Title XIX funds, facilities, including the regional centers, were required to meet ICF/MR licensing requirements.

In the early 1970s, the Norfolk Regional Center continued to provide services on its mental retardation ward. By 1975, the unit had failed to meet accreditation standards, and thus was not licensed as an ICF/MR.<sup>169</sup> Although improvements were attempted, the 1975 biennial report reflected little hope of meeting the standards without a major construction project. The mental retardation unit achieved licensure for a six month period in 1976 but, after this period, terminated their program. Some residents were reclassified and absorbed into other Norfolk Regional Center programs while others were picked up by community programs.<sup>170</sup>

At the Hastings Regional Center (HRC), the Developmental Unit for Children (DUC) was licensed as an ICF/MR in November 1977.<sup>171</sup> In an atmosphere of strong anti-institution sentiments, however, government officials and mental retardation advocates, in 1978, suggested eliminating the program.<sup>172</sup> In July 1978, a public hearing was conducted on the campus of HRC by state senators. Parents protested the proposed program termination so vehemently that the suggestion was dropped.<sup>173</sup>

In October 1977, the Comprehensive Care Service Mental Retardation Program (CCS/MR) (then called the Comprehensive Care Unit) at the Lincoln Regional Center received accreditation by the Joint Commission on Accreditation of Hospitals;<sup>174</sup> however, in February 1979, accreditation was revoked due to serious violations of the Accreditation Council for Mentally Retarded and other Developmentally Disabled Persons (ACMR/DD) standards, particularly regarding restraint and isolation of a resident. By October 1979, CCS/MR had



lost its certification as an ICF/MR by the State Department of Health. Staff changes were made shortly thereafter, and temporary certification was regained for three-month periods starting in late 1979. By 1981, improvements were substantial, and CCS/MR was fully certified for two years. In 1983, CCS/MR obtained certification for three years.<sup>175</sup>

Accreditation requirements made it difficult for some facilities to operate a profitable ICF/MR program. To be financially feasible, these facilities required a large number of clients, but with the mood of deinstitutionalization and the availability of community programs, the programs had difficulty filling their licensed beds. Keahaven in Neligh was licensed as an ICF/MR with a capacity of 24 beds in January of 1977. However, by November of that year it terminated its licensure. Rest Haven (eventually renamed Sandhills Manor) at Broken Bow was licensed for 24 beds in 1977, but could only attract a maximum of 12 to 15 residents. The facility discontinued the program in 1979.<sup>176</sup> Haven Home in Kenesaw obtained ICF/MR licensure for 12 beds in 1977 and an additional 12 beds in 1980. The program served a maximum of 18 residents and was discontinued in 1981.<sup>177</sup> Blue Valley Lutheran Home obtained ICF/MR licensure for 85 beds in December, 1977. The program was discontinued in 1982 because of difficulties in attracting eligible clients and qualified staff.<sup>178</sup> Beighley Care Home in Lincoln was licensed as an ICF/MR in 1976, but had problems meeting accreditation standards. In 1981, the administration of the program was assumed by Bethphage Mission, Inc.<sup>178</sup> Today, the only private ICF/MR not administered by Martin Luther Home or Bethphage Mission is the Omaha Developmental Center (ODC) which attained ICF/MR licensure in 1980. ODC had its license revoked later in 1980, but corrected the deficiencies and obtained relicensure.

The human rights model was the direct force behind deinstitutionalization and improvement of the conditions for those who remained institutionalized. The human rights model continues to be a basic theme today and provides a standard by which all services are judged.

### 9. Current Mental Retardation Services

Never measure the height of a mountain until you have reached the top. Then you will see how low it was.

-Dag Hammarskjold

From an historical analysis of the seven models, one can better understand the great variety of service options available to persons with mental retardation in Nebraska today. Reflecting the influence of all seven models, BSDC continues to be the largest residential facility in the state. As a result of the availability of community programs and the conclusion of civil rights litigation, the population at BSDC has been reduced to approximately 460 residents. BSDC operates by the philosophy that, for some individuals, an intermediate care facility is the least restrictive alternative that will satisfactorily meet their needs. These individuals tend to require greater intensity in care. The facility currently operates under the developmental and human rights models and offers a wide range of developmental services for its residents.

Although Bethphage Mission and Martin Luther Home both originated under an asylum model, both currently function under developmental/normalization and human rights models. Each facility is licensed as an ICF/MR and primarily serves residents with severe or profound mental retardation or with multiple handicaps. Bethphage currently reports serving 187 clients while 136 individuals reside at Martin Luther Home. The developmental services at both facilities are similar to those found at BSDC.

The Department of Public Institutions continues to provide specialized mental retardation services at two of the regional centers that have programs licensed as an ICF/MR. The Lincoln Regional Center's CCS/MR unit is licensed for 21 persons with mental retardation who also possess an additional mental or emotional disability. At the Hastings Regional Center, approximately 15 children reside in the DUC which is licensed for 21 persons with mental retardation and additional medical/physical problems.

Two other facilities are licensed as ICF/MR in Nebraska: Bethphage Mission operates an ICF/MR facility in Lincoln licensed for 38 residents, and Omaha Developmental Center, a nonprofit corporation, is licensed for 49 beds.

As previously discussed, community programs originated in the community model and were subsequently supported by the normalization/developmental and human rights models. Community-based programs continue to be organized into six regions and supervised by regional governing boards, consisting of an elected county commissioner or supervisor from each county within the region. Planning, supervision, and disbursing state funds for the community programs are the duties of OMR. In addition to publicly administered programs, six private community-based programs exist in Nebraska. Community programs reflect the concepts of normalization and human rights. Clients are served in a less restrictive environment allowing maximal interaction with the community. Services in community-based programs, as with all other mental retardation programs in Nebraska, reflect the developmental perspective. Private and public community-based programs serve over 2,000 mentally retarded citizens throughout the state.

10. Conclusion

We are like the trees.  
You are like the sun,  
The rain and the earth -  
You help us grow and stand  
Tall in the world.

- Ollie Rector

The two models that have the greatest impact upon the present system are the normalization/developmental and human rights models. The community perspective, while initially very influential, was a transitory model that has now been subsumed by the current guiding paradigms. Despite the consensual adoption of these models, diverse perspectives remain. In light of the historical analysis, a reexamination of the interested parties promises to be didactic.

As the analysis revealed, parents were the primary initiators of the community model and major participants in the development of the normalization/developmental and human rights models. Today, parent groups involved in mental retardation services advocate the protection of human rights for their children and in developmental services for persons with mental retardation. A major point of contention between the ARC and the MRAA concerns parental involvement in treatment decisions. The ARC holds the view that certain program settings fail to meet standards inherent in the developmental model and, therefore, should be precluded as treatment options. This was the motivation behind the Horacek lawsuit. In contrast, the MRAA maintains the position that the ultimate authority in treatment decisions

rests with parents or guardians and that no option should be precluded. These dichotomous perspectives raise the question of dominance of parental rights over the separate rights of their children. An additional issue concerns the conflict between parental authority and the *parens patriae* power of the state (i.e., when, if ever, the state should determine that parents are not acting in the best interests of their children and countermand parental decisions). This continuing debate has serious implications for the current system, particularly regarding the continued existence and relative emphasis of large institutional mental retardation facilities.

Professionals, as noted before, were instrumental in establishing the current system of mental retardation services in Nebraska. The large majority of professionals involved in mental retardation services today embrace the normalization and developmental concepts, yet how these concepts translate to service provision is still an issue. One issue is to what extent normalization is appropriate to all persons with mental retardation: Perhaps some individuals will not benefit from societal integration. Another issue is to what extent all persons with mental retardation should be expected to sacrifice their individuality to conform to preconceived societal norms as prescribed by the normalization principle. Other issues involve the most beneficial techniques for developmental training. These questions are for empirical investigation by the professionals. However, the feasibility, ethical, and implementation issues associated with these questions are matters of concern for all persons with interests in mental retardation services.

Advocates were the moving force behind the human rights movement. They had a monumental impact on current services through legal action. The effects of the Horacek case continue. The Department of Public Institutions and Office

of Mental Retardation continue to ensure the standards and fulfill the requirements contained in the Plan of Implementation. A current point of contention involves the question of whether for some individuals, the least restrictive alternative that will also insure their safety and treatment, can be found at the ICF/MR programs. This is the position taken in the Plan of Implementation. Yet, certain advocacy groups dispute this. Another issue is whether the benefits of risk taking outweigh the potential hazards. The parameters of many other constitutional and human rights await delineation and definition.

It is doubtlessly true that in society there are citizens adhering to each of the six models or combinations of these. Some may believe that mental retardation services should be limited to the education of children with mental retardation; others may believe that all persons with mental retardation should receive benevolent custodial care where they can be protected from society; some may still perceive of the mentally retarded as "different" and, therefore, threatening. Others may propose an extreme form of the community model believing that all persons with mental retardation can and should be served in the community. Still others will form concepts from the current community, normalization/developmental, and human rights models. It is difficult to evaluate the current consensus of the citizenry at this time. The civil rights concern does not appear to be as common as it was 10, 20, and 30 years ago. The developmental model associated with the rise of the humanist philosophy is no longer novel. The community model was a transitory paradigm designed to meet existing needs and has been incorporated into the current perspective. The educational model was a precursor of the developmental model and, hence, has also been incorporated into the new perspective. Although asylum and social control perspectives exist, it is

unpopular to express such notions.

The state bears the brunt of these conflicts, for it is the duty of the state to provide just and equitable resolutions.

The interests of a sixth group of individuals has not, to this point, been discussed. This group consists of individuals who are labeled as having mental retardation. We have only recently begun to listen to and consider the perspectives of this group (see Williams & Shoultz, 1982). Previously, their interests have been defined for them by parents, professionals, advocates, citizens, and state officials. When we see them as worthy of education, they are educated. When we see them as desiring protective custodial care, they receive custodial care. When we view them as threats, they are locked away. When we feel that community care is appropriate, they receive community care. When we see them as capable of growth and development, they will be given opportunities to grow and develop. Insert from p 81



When we see them as worthy of human rights, they are allowed to exercise their human rights. Our perspectives, models, theories and plans will determine the way persons we label as having mental retardation are able to live their lives.

Insert  
to  
p80

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## 1. Introduction

With time, the number who are restrained by memory must decline. The historian ... can hope that he provides a substitute for memory that slightly stays that decline.

- John Kenneth Galbraith

In preparation for the Mental Retardation System Plan, the Department of Public Institutions reviewed a variety of materials and talked with a number of individuals in an attempt to place the current configuration of mental retardation services in historical perspective. As a result of those investigations, the Department compiled a great deal of information regarding the history of mental retardation services in Nebraska. These materials have been organized into a history of Mental Retardation Services in Nebraska, which the Department is now providing to the general public. It is hoped that this history helps all those involved and interested in the field of mental retardation in Nebraska have a better understanding and appreciation of the growth and development of Nebraska's mental retardation service system.

The vast amount of material and its varied nature required some organizational framework for a readable presentation. One way to organize this information is to examine dominant philosophies for given time periods. At any given point in time there are a variety of views about social problems such as mental retardation and corresponding belief systems about the proper ways to respond to persons who experience those problems. Normally, however, there is one set of beliefs that dominate the social order and, therefore, greatly influence the actions of governments and others in their activities related to mental retardation. Thus, history can be divided according to the periods of time that certain ideas flourished and influenced the development of services and the treatment of persons with mental retardation.

The collections of ideas, beliefs, philosophies and ideologies that dominate different eras in the history of mental retardation services in Nebraska can be grouped into distinct categories. For the purposes of this history these categories will be referred to as models. As one scholar has stated, "Models are abstractions organized to place facts, events, and theories into an orderly framework for discussion ..." (Cockerham, 1981). Although there are certainly other ways of organizing and presenting this material, the Department has found this approach to be the most useful. While this historical account seeks to identify the dominant models in Nebraska's past response to mental retardation, there are, of course, transition periods where models compete with each other in terms of the dominant position; and as the dominance of models change with the emergence of new ideas and new challenges, parts of old models may be incorporated into new ones. Hence, while models may not always be readily identifiable or easily defined at any given point in time, they do provide a useful framework through which we can understand the issues and disabilities associated with mental retardation over a substantial historical period.

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The history of mental retardation services in Nebraska reflect trends found in the rest of the country. Discussion of national service responses to mental retardation, therefore, is included to provide context for Nebraska's history. The history of mental retardation services in Nebraska and the United States as a whole can be seen as reflecting the emergence, conflict, and dominance of seven models. First, the early responses did not distinguish mental retardation as a disability and, therefore, the same types of services were provided to all types of handicapped persons. Second, mental retardation came to be considered a distinct disability, and schools were established to provide specialized mental retardation services. Third, persons with mental retardation became viewed as requiring protection from society and services followed an asylum model. Fourth, society began to view persons with mental retardation as threats, and services were designed to protect society from them. Fifth, parents who found existing services too limited and inaccessible established their own services in their home communities. Sixth, professional ideologies such as normalization and the developmental model began to dictate the course of service delivery. Finally, concern with human rights significantly affected mental retardation services and led to the deinstitutionalization of Nebraska's institutions.

A word of caution is in order here. While these models dominated certain historical periods, they were not totally representative of all the thinking concerning mental retardation during that time. There has always been dissent from the dominant view and often that dissent becomes the next model of mental retardation services. Every attempt has been made to provide a balanced and objective analysis of the history of mental retardation services in Nebraska. Input and review has been sought from many individuals, and a diverse set of resources has been employed. This work seeks to record and understand the history of mental retardation services in Nebraska, not to judge, champion, or advocate particular models or groups. While some of the ideas presented may by today's models seem strange or even cruel, for the most part they reflected the good intentions of people, based upon the knowledge available, their experiences and the state of the art at the time.

Another word of caution is warranted. Much of the material here is taken from personal interviews, newspaper articles, and official reports. Every effort was made to obtain and verify all perspectives, but, as with all such historical interpretations, this product reflects the selective perspectives and memories of those individuals who were interviewed or whose ideas were previously documented in writing. It is hoped, however, that this analysis is, in the main, an accurate reflection of one part of Nebraska's history.

## 2. Early Thinking: Undifferentiated Treatment

With few exceptions (Woolfson, 1984), society did not distinguish between persons with mental retardation and persons with other handicaps prior to the late nineteenth century. Mentally retarded, mentally ill, deaf, blind, and physically handicapped persons were categorized as a group considered deviant. For the most part, treatment of these individuals was undifferentiated and often cruel. For example, the early spartans abandoned their handicapped children in the wilderness to die (Kott, 1971). It is reported that the ancient Romans would toss their deaf, blind, or mentally retarded children into the Tiber River to avoid the burden of caring for a defective child (Rosen, Clark, & Kivitz, 1976). In medieval Europe, persons with mental retardation and other handicaps often served as court jesters or fools, and in eighteenth century Europe, handicapped individuals, particularly those with mental retardation or mental illness, were condemned as being possessed by Satan (Kanner, 1964).

Before the middle 1800s, American society expressed little interest in providing systematic services for persons with handicaps. Influenced by the socio-historical perspective of the times, nineteenth century Americans viewed the mentally retarded as threats, embarrassments, or objects of ridicule (Deutsch, 1949; Wolfensberger, 1976). Often families would abandon their mentally retarded members or segregate them by confining them in attics or cellars to avoid the stigmatizing attitudes of society (Frohboese & Sales, 1980). Persons with mental retardation or mental illness in the United States were treated the same as criminals, paupers, and individuals with other types of handicaps. These persons eventually accumulated in jails, almshouses, or generic asylums (Dokecki & Mashburn, 1984). The first pleas for specialized services in this country did not distinguish between persons with mental retardation and persons with mental illness (Dix, 1976).

This model of undifferentiated treatment is evident in Nebraska's history. In 1855, the Counsel and House of Representatives of the Territory of Nebraska grouped idiots and noncompotes (terms used to describe persons with mental retardation), lunatics, and distracted persons into a class labeled insane persons.<sup>1</sup> The Nebraska lawmakers enacted the first service provision in 1858: persons afflicted with "idiocy, lunacy, or other unavoidable causes" were to be supported by their families or relatives; if familial support was not possible, the law required the county to provide support.<sup>2</sup> During this period, county care for Nebraskans with mental retardation often meant maintenance in county jails or poor houses (Allen, 1942). In 1865, two years prior to statehood,

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<sup>1</sup>Act of March 16, 1855, pt. 1, 1855 Neb. Terr. Laws (1st Sess.) 57 (Sherman & Strickland).

<sup>2</sup>Act of Nov. 4, 1858, pt. 2, 1858 Neb. Session Laws (5th Sess.) (Robert W. Furnas).

Nebraska lawmakers recognized the need for institutional care and provided for commitment of insane persons from Nebraska to the Iowa Hospital for the Insane.<sup>3</sup> Soon after statehood<sup>4</sup> in 1867, the Legislature established a State Lunatic Asylum in Lincoln<sup>4</sup> where insane persons, including persons with mental retardation, were institutionalized.

Recognizing the distinction between "idiots" and "insane" persons, the Legislature enacted a law in 1873 providing for the removal of persons with mental retardation from the asylum to their county of residence.<sup>5</sup> The legislation required the counties to provide services to mentally retarded individuals in the same manner as services provided the poor. Nebraskans with mental retardation, then, were transferred from inappropriate services to no services at all.

There is evidence that many former inmates of the early Nebraska penal system were mentally retarded and that feeble-minded and insane persons were incarcerated with the rest of the prison population. In fact, the death of a feeble-minded prisoner as the result of severe punishment sparked efforts for prison reform in the late 1800s. A legislative investigation criticized the co-mingling of insane and feeble-minded inmates with the general prison population (McKelvey, 1977). Hence, by the middle and late 1800s society began to differentiate and show concern for persons with mental retardation; nevertheless, to this point, little effort was made to establish any type of specialized mental retardation services.

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<sup>3</sup>Act of Feb. 13, 1865, pt. 1, 1865 Neb. Terr. Laws (10th Sess.) 8 (Taylor & McClure).

<sup>4</sup>Act of Feb. 15, 1869, 1869 Neb. Laws (4th Sess.) 253 (St. A.D. Balcombe).

<sup>5</sup>Act of March 3, 1873, ch. 31 §54, 1873 Neb. Gen. Stat. 424.

### 3. The Educational Approach

The immediate adoption of proper means of training and teaching idiots, may be urged upon higher grounds than that of expediency, or even of charity; it may be urged upon the ground of imperative duty.

-Samuel Gridley Howe

During the middle 1800s, a few progressive individuals spurned the prevailing attitude and argued that many persons with mental deficiencies were capable of growth and development. One such individual, Dr. Samuel Gridley Howe, conducted the first systematic study of persons with mental retardation in 1848 (President's Committee on Mental Retardation, 1976) and reported to the Massachusetts Legislature: "They [persons with mental retardation] can be taught to do some kinds of labor, to acquire some kinds of knowledge, to attend to their own persons and take care of themselves ... They must have schools, teachers, and apparatus peculiarly adapted to their capacities and powers" (p. 3). It was during this time that mental retardation became differentiated as a disability and separate facilities were proposed for the care of these individuals. After noting the unique qualities of mental retardation, one early author concluded:

- a. That idiots and imbeciles should be treated distinctively from all other classes.
- b. That they cannot with advantage be placed in ordinary schools with other children.
- c. That they ought not to be associated with the insane in asylums.
- d. That they should not be incarcerated in penal institutions.
- e. That they should not be congregated with the pauper inmates of alms-houses.
- f. That in the great majority of instances they are better and more successfully treated in well-organized institutions than is possible in their homes (Kerlin, 1877, p.21).

In light of this new perspective, states began establishing schools and institutions for persons, especially children, with mental retardation. These early advocates envisioned institutions as schools designed to educate persons with mental retardation rather than as custodial asylums. Once persons with mental retardation acquired self-sufficiency in adaptive social skills, they could return to their communities or families to become productive members of society. To facilitate the educational process, the early pioneers of these schools located the facilities in the centers of communities and cared for a relatively small number of residents (Wolfensberger, 1976).

In an 1883 senate address, Governor Nance of Nebraska emphasized the desirability for a separate institution to specifically serve mentally

retarded children.<sup>1</sup> In referring to the State Institute for the Deaf and Blind, Governor Nance stated:

Applications have been made to secure the admission of feebleminded children, and I earnestly endorse the opinion expressed by the principal that the time has arrived when an institution for this class of unfortunates should be organized either on an independent basis or in connection with some other state charitable institutions (p. 37).

Two years later, the same theme was echoed by the <sup>D.</sup>director of the Nebraska Institute for the Deaf and Dumb:

Admissions are constantly on file in this office for the admission of feebleminded children into this school. These children, though they have good hearing, are unable to speak ...; but the deficiency is not in the vocal apparatus. These are not fit subjects for a deaf mute school. These persons are growing up among us untaught, untrained, and unprovided for, to become a burden to society and an expense to the state. Considering the great benefits afforded this class by institutions for their instruction and development in other states, it would be a matter of justice to them, and of philanthropy on the part of Nebraska, to institute measures for the establishment of such a school that their condition may be improved (p. 9).<sup>2</sup>

That year, in 1885, a committee from the Nebraska House of Representatives journeyed to Iowa to inspect the Iowa Institution for Feebleminded Children and concluded, "In our judgement the feebleminded can, if taken at an early age, be guided in such a manner as to strengthen and make the unfortunate subject a useful citizen" (p. 688).<sup>3</sup> The committee went on to recommend that a similar facility be constructed in Nebraska.

Noting the benefits of institutionalization and absence of community care, the committee stated:

The condition of the children in this state who would become inmates of and derive benefits from such an institution is such as to warrant the assertion that they would be much better provided for, and instructed there in a manner which cannot be done by parents. In a large number of cases such children are inmates of county houses, which are in no wise calculated to protect them, and when suitable instruction or medical treatment cannot be had, such associations are calculated to leave their minds enshrouded forever in darkness that nature has unfortunately placed upon them (pp. 688-689).

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<sup>1</sup>Nance, A. Governor's Message. 1883 Neb. Senate J. 27.

<sup>2</sup>Gillespie, J.A. Fourth biennial report of the Nebraska Institute for the Deaf and Dumb for the years 1883 and 1884. Lincoln, NE: Journal Company State Printers, 1885.

<sup>3</sup>1885 Neb. House J. 687.

The Nebraska Legislature, following this recommendation, enacted legislation in 1885 establishing the Nebraska Institution for Feeble-minded Youth (NIFMY) at Beatrice; the Legislature appropriated an initial \$100,000, provided that the City of Beatrice or its citizens donate at least 40 acres for the site of the institution.<sup>4</sup> The original legislation also established "The Fund of the Institution for the Feeble-minded" and authorized "an annual tax levy on the taxable property of the state, not to exceed one-eighth (1/8) of one mill on the dollar." This was the basis of state fund support until the state changed from property tax to a sales and income tax base in 1966.

The Legislature originally envisioned the Nebraska Institution for Feeble-minded Youth as an educational facility. This educational ideology is expressed in the originating act:

Besides shelter and protection, the prime object of said institution shall be to provide special means of improvement for that unfortunate portion of the community who were born or by disease have become imbecile or feeble-minded, and by a wise and well adapted course of instruction reclaim them from their helpless condition, and, through the development of their intellectual faculties, fit them as far as possible for usefulness in society. To this end there shall be furnished them such agricultural and mechanical education as they may be capable of receiving.<sup>5</sup>

On May 25, 1887, the first three residents entered the facility. By December 28 of that year, the institution had admitted 65 children (Ray, 1980). The population continued to grow, and the educational philosophy continued to dominate through the late 1800s.

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<sup>4</sup>Act of March 5, 1885, ch. 52, 1885 Neb. Laws 255 [current version at NEB. REV. STAT. §83-217 et seq. (Reissue 1981)].

<sup>5</sup>Id. §2



#### 4. The Asylum

He who is born into this sad heritage leaves hope  
behind. We cannot cure what is not disease, but defect,  
and that which the cradle rocks the spade will cover.

-Martin W. Barr (1904)

#### Nebraska Institution for Feeble-minded Youth

During the inception of institutional care in Nebraska, a second treatment perspective was evolving. The early schools in the nation served only the "teachable class" (PCMR, 1977) while older persons with mental retardation and the more severely retarded did not receive care. Institutions soon began serving the dual role of teaching the "teachable" and providing custodial care for the "unteachable." Later in this evolution of perspectives, the custodial view came to predominate: Institutions were no longer considered schools but asylums that provided kind, safe, maternal care for the protection and happiness of their residents (Wolfensberger, 1976). As eloquently expressed by a contemporary writer of the time, "They [residents] must be kept quietly, safely, away from the world, living like angels in heaven ..." (Johnson, 1889, cited in Wolfensberger, 1976, p. 52); and as more crudely stated, "A well-fed, well-cared for idiot, is a happy creature." (Butler, 1898, cited in Wolfensberger, 1976, p. 52). As a result, institutions became larger, more isolated, and geared toward economic self-sufficiency. The same evolution of treatment perspectives is apparent in the early years of institutional care in Nebraska.

The admissions provision for the Nebraska Institution for Feeble-minded Youth (NIFMY), allowing the superintendent to determine whether an applicant was suitable<sup>1</sup> for care at the institution, reflected the educational perspective.<sup>1</sup> In elaborating on the admissions procedure, Dr. J.T. Armstrong, the first superintendent, stated, "the law provides that the most improvable cases and those between the ages of five and eighteen, shall be given preference in admission. The most helpless, and those over eighteen years of age, have been practically debarred by this clause."<sup>2</sup>

Thus, at the beginning of institutional care in Nebraska, a dual standard of services existed. For younger and higher functioning persons with mental retardation, Nebraska provided educational opportunities within an institutional setting. Others deemed unsuitable for state care, the older or lower-functioning persons, were left to be cared for by their families or local communities.

At the 14th annual meeting of the Association of Medical Officers of American Institutions of Idiotic and Feeble-minded Persons (later the American Association on Mental Deficiency) which was held at Beatrice in

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<sup>1</sup>Supra. Chapter 3, note 4, § 7

<sup>2</sup>Armstrong, J.T. Second biennial report of the Nebraska Institution for Feeble-minded Youth at Beatrice to the Board of Public Lands and Buildings, December 1, 1888. Lincoln, Nebraska: Journal Company, State Printers, 1888.

1889, the president of the Association stressed the need to provide services to persons who needed lifelong custody (Sloan & Stevens, 1976). Echoing this concern, Superintendent Armstrong repeatedly urged in his biennial reports the appropriation of funds for additional buildings to house those persons requiring primarily custodial care (Allen, 1942; Ray, 1980). An exact date for the emergence of custodial care at NIFMY is difficult to identify, but records show this transition occurring during the late 1800s and early 1900s.

In 1898, the fourth superintendent at NIFMY, Dr. Sprague, indicated that the facility was serving individuals with more severe handicaps: "We have [re]presented at the institution people suffering from all grades of mental defects - from the sunshine of almost normal intellects to the midnight gloom of idiocy ..." (p. 435).<sup>3</sup> By 1902, three types of care were provided:

school [those capable of benefitting from an academic curriculum],  
custodial - those who had passed through school but remained  
as permanent residents,  
asylum - those who had a 'low state of vitality, both  
mentally and physically' and required constant watch (Ray, 1980,  
p. 6).

In 1915, the legislature passed a law requiring the Beatrice facility to accept persons who were court-proclaimed "idiot, imbecile, or feeble-minded."<sup>4</sup> By 1921, the biennial report characterizes the institution as "a home and school for feeble-minded, regardless of age."<sup>5</sup>

At the turn of the century, then, the State Institution for Feeble-minded Youth began serving a dual purpose: to educate the "feeble-minded" who were capable of development and to provide a safe and happy environment for "idiots" whom Superintendent Sprague described as possessing:

a condition in which there could not be exercise of normal functions, either of the development of illusions or hallucination, as a complete arrest of all reasoning powers has occurred, or such powers have never existed. In this condition all life is a blank. The patient has no more power of reasoning than the lower animals; neither have they natural instincts to seek food to satisfy hunger and water to satisfy thirst (p. 436-437).<sup>6</sup>

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<sup>3</sup>Sprague, C.G. Seventh biennial report of the Nebraska Institution for Feeble Minded Youth at Beatrice to the Governor and the Board of Public Lands and Buildings, December 1, 1898. Lincoln, Nebraska: Jacob North & Co., Printers, 1898.

<sup>4</sup>Act of Apr. 14, 1915, ch. 131, §1, 1915 Neb. Laws 294 [current version at NEB. REV. STAT. §83-223 (Reissue 1981)].

<sup>5</sup>Stewart, S.J. Nebraska Institution for the Feeble-minded. Biennial Report of the Board of Control, 1921, 4.

<sup>6</sup>Supra, note 3.

Sprague believed these two groups of residents should be strictly segregated to avoid assumed detrimental effects.

Although the custodial function of the institution initially held a secondary role to the educational function, gradually evolving treatment philosophies brought about a role reversal. Authorities became less enthusiastic toward the educational function. In referring to this function, NIFMY Superintendent Frank E. Osborn reflected this attitude:

This part of our work [education] is essentially prominent but the results are not altogether satisfactory. There was a time when authorities on the subject considered that by proper training wonderful results could be accomplished and individuals classed as feebleminded could become practically normal. This theory is now exploited for it is only in cases where there is no impairment of the mental functions but rather an inability through environment to acquire knowledge where these marked results have been attained. It is now generally conceded that a feebleminded individual's training will result only in a relative improvement and that he will<sup>7</sup> never become advanced either as a student or an artisan (pp. 215-216).

The shift toward a more custodial philosophy gained momentum with the appointment of Dr. Dearing as superintendent in 1900. Noting that 47 inmates had been discharged under the former superintendent, Superintendent Dearing queried:

What can we say of those discharged? Nothing very favorable. They are not able to cope with the world in a business or social way, or are too restless and unmanageable to be kept at home. There are exceptions to this result, but they are so few and far-fetched as to hardly deserve a mention herein. These children will be children always. The state must sooner or later take up their guardianship and prepare a custodial home for them where they can have a permanent home and suitable care and control. The most highly trained and best educated of these children cannot compete in any way with the normal man or woman. Perpetual occupation in an industrial institution, where they can have the comforts<sup>8</sup> of a home and the protection of the law, is the only remedy (p. 514).

As the asylum model came to dominate the institution, the educational function remained important; however, the focus of that function shifted. The primary emphasis was no longer to prepare individuals with mental

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<sup>7</sup>Osborn, F.E. Twelfth biennial report of the superintendent of the Nebraska Institution for Feebleminded Youth at Beatrice to the Governor and Board of Public Lands and Buildings. Sixteenth Biennial Report of the Commissioner of Public Lands and Buildings, 1907-1908, 207-224. *pp.*

<sup>8</sup>Dearing, W.H. Eighth biennial report of the Nebraska Institution for Feebleminded Youth at Beatrice to the Governor and the Board of Public Lands and Buildings, December 1, 1900. Public Documents of Nebraska, 1899-1901, 1 (28), 509-536. *pp.*

retardation to function productively in society. Rather, residents at NIFMY were educated to function productively within the institutional setting, where they would most likely remain for life.

Life-long custody of residents also served to provide financial support for the institution by ensuring a stable pool of human resources. The original concept for funding or operating an institution was for it to be as self-sufficient as possible. Thus, much of the financial support for the institution was generated from within the institution, primarily from substantial farming and gardening activities. Most of the labor necessary to achieve the goal of self-sufficiency was performed by residents.

In 1921, the Legislature changed the name of NIFMY to the Nebraska Institution for the Feeble-Minded (NIFM), eliminating the reference to children. The new objective, as expressed in the statute, was to provide "custodial care and humane treatment for those who are feebleminded, to segregate them from society, to study to improve their condition, to classify them, and to furnish such training in industrial mechanics, agriculture, and academic subjects as it is severally fitted to require" (p. 843).

#### Private Institutional Facilities

During the evolution of the State-supported Beatrice facility, private institutional facilities for persons with mental retardation emerged. Two of these facilities, Bethphage Mission, Inc., and Martin Luther Home, were church-related.

Bethphage Mission was started by Reverend K. G. William Dahl, a Swedish immigrant. In the early 1910s, Dahl served as chaplain of the Immanuel Deaconess Institute in Omaha and during his tenure became interested in a person with behavioral/emotional disorders who had been confined to a county hospital. Viewing the poor conditions at the hospital, Reverend Dahl became inspired to establish a haven to provide care for "such afflicted human beings" (p. 3).<sup>10</sup> Dahl became a pastor of a tiny Lutheran parish in the hamlet of Axtell, and it was here that he would fulfill his dreams.

The Bethphage Inner Mission Association of Nebraska organized on February 19, 1913, and soon thereafter incorporated. The Association purchased forty acres of land in 1914. Until more funds could be raised and buildings erected, Dahl rented cottages in Axtell to shelter "unfortunates" (e.g., persons with mental retardation, behavioral/emotional disorders, physical handicaps, epilepsy, or problems in old age). Dahl admitted the first "guest" on June 29, 1914. On May 17, 1916 the first

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<sup>9</sup>Act of Apr. 25, 1921, ch. 241, §1, 1919-1921 Neb. Laws 842 [current version at NEB. REV. STAT. §83-218 (Reissue 1981)].

<sup>10</sup>Berquist, O.W. The beginning of Bethphage. Bethphage Messenger, March, 1963, pp. 3-4.

building on the institution's grounds was dedicated. By September 1916, Bethphage Mission served 40 guests with 20 staff members. Reverend Dahl died in 1917, but not before Bethphage was established as a beneficial treatment service for persons with mental retardation and other disabilities.

The genesis of the Martin Luther Home is not as easily chronologized. Lutheran clergy and parishioners founded the home in 1925, and, like Bethphage Mission, began serving persons with disabilities in a small rural village.<sup>12</sup> Before the institution opened its doors in Sterling, the first administrator's wife cared for three individuals in their home. The institution opened in buildings formerly used as a Lutheran academy.

The history of both facilities is similar. The major source of funding was charitable contributions donated primarily by Lutheran congregations and individual parishioners. Other support was derived from the profits of institutional activities, such as farming or sale of crafts, remuneration by families of residents for services provided (however, ability to pay was never an absolute admission criterion at either institution), and innumerable instances of community goodwill. For example, at Martin Luther, groups of women from various churches would donate and transport chickens and jars of fruit to the home.

One dissimilarity between the two private institutions is evident. While Bethphage Mission served a variety of physically and mentally handicapped residents, Martin Luther Home specialized in aiding persons with mental retardation from its inception. It was not until the middle 1940s that the Bethphage administration advocated specialization in mental retardation services.<sup>13</sup> In the early years of service, however, both facilities were similar in that they focused primarily on adult needs. Eventually, Martin Luther Home diverged from this practice. Because of the deterioration of the buildings at Sterling, the home relocated to Beatrice in 1956. Soon after this move the facility opened a residential vocational training program and changed its admissions policy; Martin Luther began admitting only children with mental retardation. One admission policy has endured for both institutions: The facilities have professed to accept individuals with mental retardation who could not receive services elsewhere.

At the time these institutions were beginning, the Nebraska Institution for the Feebleminded at Beatrice functioned mainly within the custodial model. And, so it was with the church-run institutions. Few residents were ever discharged from these homes. This philosophy of custodial care prevailed well into the 1950s. In 1946, the Division of Welfare of the National

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<sup>11</sup>Lonnquist, C.A. Glimpses of Bethphage: A reverie. In Glimpses of the Bethphage Mission. Minden, Nebraska: Warp Publishing Company, undated.

<sup>12</sup>Personal communication with H. Walt Fruehling, February 13, 1984.

<sup>13</sup>Christenson, A.A. Director's annual report. Bethphage Messenger, June, 1945, pp. 1-3.

Lutheran Council recommended that Bethphage limit its services to those requiring "life-time custodial care."<sup>14</sup> This sentiment was evident in the 1959 Bethphage annual report:

In a very few instances, some of the guests want to return to society and this desire has been granted. It is interesting to note, however, that in almost every instance, these have been returned to the shelter of Bethphage or some other institution in a comparatively short time.<sup>15</sup>

One can infer the same philosophy from the 1961 report of discharges: "Due to circumstances beyond our control, 11 were dismissed or removed from the Mission" (p. 1).<sup>16</sup> In a 1959 review of the history of Martin Luther Home it was stated: "From the beginning the institution tried to fill a twofold need, that of providing a home for those who need custodial care and a school for those who are capable of being trained."<sup>17</sup>

The motive behind this custodial philosophy derived from a desire to protect the disabled person from society, rather than to protect society from the disabled individual. The ubiquitous hostility society held against "deviant" individuals did not escape the notice of the institutions' directors.

Mentally and physically handicapped people, in the not too distant past, were frequently regarded with feelings of scorn and depreciation by the more fortunate persons, and were often the source of shame to their families. The culture in which we live even now is not congenial toward them. Many of these afflicted ones have known what it is to suffer rejection, name calling, and ugly and curious stares so that they have developed<sup>18</sup> a feeling of uselessness, frustration, fear and sometimes hostility.

Rather than placing residents into a hostile community environment, the institutions at this time provided a safe haven for those scorned by society. By the late 1950s, Martin Luther Home began specializing in child educational services and placed persons who graduated from the<sup>19</sup> program back into the community, primarily in their parent's homes. Bethphage

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<sup>14</sup>Ekerberg, H.R. Director's annual report. Bethphage Messenger, July 1960, pp. 1-4.

<sup>15</sup>Ekerberg, H.R. Director's annual report. Bethphage Messenger, August 1959, pp. 1-4.

<sup>16</sup>Ekerberg, H.R. The Director's annual report. Bethphage Messenger August, 1961, pp. 3-7.

<sup>17</sup>Bockelman, W. There's hope for the mentally retarded. Lutheran Standard, July 11, 1959, 117, 8-10.

<sup>18</sup>Ekerberg, H.R. The Director's annual report. Bethphage Messenger, June, 1962, pp. 1-4.

<sup>19</sup>Supra., note 12.

Mission began placing residents back into communities in the late 1960s when community programs became available.<sup>20</sup>

Treatment activities at these institutions were similar to those at the state institution. Many residents pursued academic subjects in accordance with their potentials. The institutions provided training in personal hygiene and self-help skills. At all three institutions, residents helped with the maintenance and functioning of the facilities. Residents also produced income by farming or constructing salable crafts. One area where the church-administered institutions differed from the state facility, not surprisingly, was the teaching of religious doctrine. Bethphage Mission and Martin Luther Home strongly stressed spiritual well-being of residents through Christian worship.

In the major institutions, then, education was provided for children who were thought capable of benefitting from such a program. For those persons who had completed the educational program but could not be integrated into the community and for persons who could not benefit from the existing training curriculum, custodial care was provided.

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<sup>20</sup>Personal communication with David Jacox, March 1, 1984.

## 5. Social Control

[The] effort to preserve a healthy race, cruel as it may seem in individual cases, is, after all, but a following of natural law; the buds unfit to mature, fall - the weaklings of the flock perish.

-Martin W. Barr

The dual institutional functions of education and custodial protection were well ingrained by the early 1900s. However, at this time a new motive for custodial care began emerging. Society began to view persons with mental retardation as threats. The common perception of mental retardation at this time was that such persons lacked moral restraint and possessed a propensity for crime and delinquency:

No amount of moral training during his school life can render him capable of judging points of morality for himself or make him proof against temptations to which his natural tendencies incline him to yield. The end will almost inevitably be that he will drift back into the care of the state, but through the gates of crime (Dunphy, 1908, cited in Wolfensberg, 1976, p. 55).

Even science reputedly supported this mentality:

The cumulative evidence furnished by surveys, community studies, and intensive group inquiries have now definitely proved that feeble-mindedness is an important factor as a cause of juvenile vice and delinquency, adult crime, sex immorality, the spread of venereal disease, prostitution, illegitimacy, vagrancy, pauperism, and other forms of social evil and social disease (Fernald, 1915, cited in Wolfenberger, 1976, p. 55).

✓ The purveyors of the "menace" perspective were adamant in their warnings: "the moron ... is a nuisance of society and civilization; ... he is responsible to a large degree for many, ~~if~~ not all, of our social problems" (Goddard, 1915, cited in Wolfensberger, 1976, p. 56). "When we view the number of the feeble-minded, their fecundity, their lack of control, the menace they are, the degradation they cause, the degeneracy they perpetuate, the suffering and misery and crime they spread - these are the burden we must bear" (Butler, 1915, p. 361, cited in Wolfensberger, 1976, p. 55). Coordinated efforts were made to confine mentally retarded persons and to segregate and sterilize them to prevent propagation of "feeble-mindedness." At an international level, this model culminated in Nazi Germany in the 1930s when an estimated 100,000 incurably handicapped persons were exterminated to preserve the homogeneity of the species (Rosen, Clark, & Kiritz, 1976).

### Nebraska Institution for the Feeble-minded

During this period, the above philosophy came to dominate the orientation of the administration of NIFM. As the superintendent stated in the 1918 biennial report:



It must be remembered that our inmates are all irresponsible and must be watched and cared for. They must be continually guided from paths of temptation into paths of right living and thought. The feeble-minded, with very few exceptions, are the most contented, the most easily managed, and the happiest persons imaginable. They are easily led in the right path, but also just as easily led in the wrong. They cannot be reformed because they do not have the mentality to overcome temptation (p. 157).<sup>1</sup>

The biennial reports show that society considered persons with mental retardation as menaces<sup>2</sup> and the propagators of crime and insanity.<sup>3</sup> In urging lawmakers to provide expanded facilities for women with mental retardation, Superintendent Stewart expressed the prevailing attitude, "when we call to mind the fact that the feeble-minded woman out in the world is the great source of illegitimacy, delinquency, and mental defect, this urgency should<sup>4</sup> be especially recognized and additional room be made for them" (p. 21).

The national doctrine regarding mental retardation held that the immorality and criminality of mental retardation were hereditarily transmitted from generation to generation. This view led United States Supreme Court Justice Holmes to proclaim<sup>5</sup> in his often cited statement, "Three generations of imbeciles are enough." In the 1914 biennial report, Superintendent Fast expressed the current state of etiological knowledge: "Heredity is a tremendous factor in the causation of mental defects. Statistics show that at least sixty-five<sup>6</sup> percent of feeble-minded children come from mentally defective parents.

Because society considered persons with mental retardation as threats and menaces and mental retardation as hereditarily transmitted, families often disassociated themselves from their children with mental retardation to avoid stigmatization. A distant institution provided the means for this disassociation. For some parents, however, institutionalization and even death of the child with mental retardation were not enough to conceal the connection between mental retardation and the family name. In the 1930s,

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<sup>1</sup>Griffiths, D.G. Seventeenth biennial report of the superintendent of the Nebraska Institution for Feeble-minded Youth. Biennial Report of the Board of Commissioners of State Institutions, 1917-1918, 151-180.

<sup>2</sup>Fast, W.S. Fifteenth biennial report of the superintendent of the Nebraska Institution for Feeble-minded Youth. Biennial Report of the Board of Commissioners of State Institutions, 1914, 101-112.

<sup>3</sup>Supra., note 1.

<sup>4</sup>Stewart, S.J. Biennial report of the superintendent of the Nebraska Institution for Feeble-minded for the period ending June 30, 1923. Biennial Report of the Board of Control, 1923.

<sup>5</sup>Buckv. Bell, 274 U.S. 200 (1927).

<sup>6</sup>Supra., note 2, p. 107.

families of deceased residents objected to the NIFM practice of inscribing tombstones with the family name. Beginning in 1935, graves of deceased NIFM residents were identified only by number (Ray, 1980). The disassociation was then complete.

This view of mental retardation had a significant impact upon public policy. Society feared that if left to their own impulses, persons with mental retardation would procreate prolifically, unleashing a flood of mental defectives upon the world. The eugenics movement (advocation of improving the genetic composition of society through selective breeding) became widely accepted. In 1920, the Lincoln Star published an article imploring the state to impose more stringent marriage laws and the citizenry to selectively choose their spouses. The article stated:

The so-called high grade feeble-minded person or moron is regarded as a sort of inferior curiosity in most communities - and the matter dropped at that. But to see a whole community [referring to NIFM] of these sometimes mute, sometimes blubbering mistakes of someone's living is heartbreaking. A whole community of examples of the innocent suffering for the wrongdoing of some one else makes an indelible impression.

The article went on to quote the superintendent of NIFM:

All agree that a desirable population should be increased. And all must concede that the imbecile, the idiotic, the epileptic, and otherwise congenitally predisposed defectives must be eliminated ... There are circumstances when the propagation of human life may be as gravely criminal as the taking of a life already begun. Nothing can be more horrible than the thought of permitting the birth of children destined to be feeble-minded or criminal or insane, unnecessarily. Why not quarantine against the germs of human degeneracy?

One method of controlling the propagation of mental retardation was by segregation. This method was proposed by Superintendent Fast:

For the sake of future generations, I want to make a plea to the Governor and to the Board that adequate provisions be made for the segregation of the high grade feeble-minded child. My opinion is that, if for a period of two or three generations mentally defective men and women were absolutely prevented by segregation and otherwise from propagating their kind, feeble-mindedness and insanity would be very materially decreased and, if the mental defectives were segregated or otherwise made incapable of propagating their kind, in the period of a hundred years, feeble-mindedness and insanity would almost wholly be eliminated. We have no right to allow the defects of this generation to be stamped upon the children of coming generations.

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<sup>7</sup> Supra, note 2, p. 106.

<sup>8</sup> Lincoln Star, September 26, 1920. "Pitiful specimens of humanity at Beatrice Home for Feeble-minded cry out for stricter laws on marriage."

<sup>9</sup> Supra, note 2, pp. 106-107.

In response to this feeble-minded paranoia, the Legislature enacted Nebraska's first civil commitment law in 1915<sup>10</sup> allowing involuntary court commitment to NIFM. Another means of preventing reproduction by persons with mental retardation involved sterilization. The Nebraska Legislature passed the first sterilization law in the same year it enacted the civil commitment provision.<sup>11</sup> The statute created a Board of Examiners of Defectives and required the Board to examine institutionalized persons eligible for parole or discharge. If the Board found 1) the person capable of reproduction, 2) the likelihood that progeny would inherit mental retardation, and 3) the offspring would likely become "a social menace," sterilization would be a condition of discharge. The statute required informed and written consent from the resident before sterilization could occur. However, in 1929, new legislation replaced the 1915 statute and eliminated the consent requirement.<sup>12</sup> The first sterilization occurred in 1917. By 1966, the year of the last recorded sterilization,<sup>13</sup> 752 residents at the Beatrice facility had been sterilized.

In 1920, Superintendent Burford suggested additional measures: "In order to arrive at a proper solution for the feeble-minded problem, it will be necessary to have trained workers to recognize and classify the feeble-minded and defective persons outside of the institution."<sup>14</sup> Reflecting these sentiments, the Legislature established the State Commission for the Control of Feeble-minded Persons.<sup>15</sup> The purpose of the law and the Commission was to ensure "that all feeble-minded persons resident within this state shall become the wards of the state to the end that they shall not reproduce their kind."<sup>16</sup> The act required schools, hospitals, charitable organizations, and public agencies to identify and report those persons suspected of feeble-mindedness. Commissions were established by law in each county to "apprehend, examine, commit, establish guardianships, transport, and maintain the custody of any feeble-minded person within their respective counties."<sup>17</sup> The statute also required the submission of names of these individuals to all agencies in each county

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<sup>10</sup> Supra, Chapter 4, Note 4.

<sup>11</sup> Act of April 8, 1915, ch. 237, 1915 Neb. Laws 554 (repealed 1929).

<sup>12</sup> Act of Apr. 30, 1929, ch. 163, §5, 1929 Neb. Laws 563, 564 (amended, Act of May 9, 1957, ch. 391, §5, 1957 Neb. Laws 1351, 1353; Act of June 5, 1963, Neb. Laws 1661, 1662; repealed 1969).

<sup>13</sup> Central Records. Beatrice State Developmental Center.

<sup>14</sup> Supra, note 8.

<sup>15</sup> Act of May 27, 1935, ch. 143, 1935 Neb. Laws 533 (repealed 1951).

<sup>16</sup> Id., pp. 533-534.

<sup>17</sup> Id., p. 535.

that issued marriage licenses. No agency could issue a marriage license to anyone on the list unless one of the parties seeking to marry could provide proof of sterilization.

A combination of the three perspectives (education, asylum, and social control) characterized the functioning of the Beatrice State Home (the name was changed in the 1940s) until the late 1960s. Caretakers of persons with mental retardation expressed little optimism about returning these individuals to society. The institution served to provide a safe habitat for the resident while at the same time protecting society from the "feble-minded menace." The institution focused its educational role on providing residents the skills necessary to function within the institution. In a 1942 evaluation of the Beatrice facility, Allen concluded:

The Institution is conducted almost entirely on a custodial basis. Social services, including individualized planning for the patient, are lacking. His training is limited mainly to those occupations which will contribute to the maintenance of the Institution (p. 74).

### Regional Centers

In the late 1800s, Nebraska established three regional centers located at Lincoln, Hastings, and Norfolk for the care of persons with mental illness. Although these facilities were designed for treatment of persons with behavioral/emotional disorders, persons with mental retardation were also confined within their walls. Through the 1950s and 1960s, approximately eight percent to 12 percent of the regional center populations were diagnosed mentally deficient.<sup>18</sup> One can conjecture a number of reasons for inclusion of persons with mental retardation into the regional center population. First, little differentiation existed in treatment for different disorders at this time. Like the Beatrice facility, the institutions for behavioral/emotional disorders provided a method of segregating threatening persons from society. The predominant method of treatment applied to all residents regardless of diagnosis was custodial maintenance. Second, during this time, the Beatrice facility was overcrowded. Persons requiring institutional services were placed wherever there was room.<sup>19</sup> Finally, the Beatrice State Home was not as well equipped as the regional centers to tend persons with behavioral problems. These types of residents were often transferred from Beatrice to the regional centers.<sup>20</sup>

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<sup>18</sup>Derived from biennial reports 1953 - 1969.

<sup>19</sup>Personal communication with George J. Lytton, April 10, 1984.

<sup>20</sup>Personal communication with Jai Sookram, April 18, 1984.

Eventually special wards developed at the centers for treatment of persons with mental retardation. The first such ward emerged at the Norfolk Regional Center, then called the Norfolk State Hospital. For relief of overcrowding, the Beatrice State Home (BSH) transferred 30 female and 60 male residents to Norfolk in 1963.<sup>21</sup> These residents were primarily persons with Downs Syndrome. Although BSH initially listed these residents as under "temporary" care at Norfolk,<sup>22</sup> a ward was established for permanent placement. Since the existing staff at Norfolk were unfamiliar with mental retardation treatment techniques, new staff for the ward were required. These new staff members were selected from inmates at the state penitentiary and reformatory who had not committed violent crimes. This choice of staff elicited concern from the parents of the residents. However, the parents eventually became satisfied about the character of the new staff. The inmates were trained for three months at the Beatrice facility and then transferred to Norfolk, where their training made them an asset to the original Norfolk staff.<sup>23</sup>

During the 1960s, the Beatrice State Home maintained responsibility for approximately 40 children with mental retardation who had been transferred to the Nebraska Hospital for the Tuberculous at Kearney. These children were listed as being among the population of Beatrice State Home but receiving custodial care at Kearney.<sup>24</sup> Because of the decline of tuberculosis, the hospital began phasing out its programs in the early 1970s. By 1972, the facilities were purchased for use by Kearney State College.<sup>25</sup> Since the children had to be moved and Beatrice was facing litigation regarding its overcrowded conditions (infra), a special ward was created at the Hastings Regional Center.<sup>26</sup> On September 8, 1971, 42 children with mental retardation were transferred to the Children's Developmental Unit (eventually renamed the Developmental Unit for Children) at Hastings.<sup>27</sup> In addition to a diagnosis of severe or profound mental retardation, most of these children were physically handicapped.

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<sup>21</sup>Wyant, M.E. Beatrice State Home. First Biennial Report: Department of Public Institutions, 1963, 77-95.

<sup>22</sup>Id., p. 90.

<sup>23</sup>Personal communication with Allen McElravy, April 10, 1984.

<sup>24</sup>E.g., Program for the mentally retarded. Fourth Biennial Report: Department of Public Institutions, 1969, 175-195.

<sup>25</sup>Nebraska Hospital for the Tuberculous. Sixth Biennial Report: Department of Public Institutions, 1973, 245.

<sup>26</sup>Supra, note 19.

<sup>27</sup>Supra, note 25.

In 1958, the Lincoln Regional Center (then entitled the Lincoln State Hospital) provided a building for mental patients from all the state mental institutions who had tuberculosis.<sup>28</sup> By 1963, this building also housed tubercular residents from the Beatrice State Home.<sup>29</sup> Despite this early housing of a distinct population with mental retardation at the regional center, a special unit for persons with mental retardation did not evolve until 1975. The Extended Care Unit (later renamed Comprehensive Care Service) began serving persons with multiple mental handicaps on June 30, 1975. A substantial number of the residents had mental retardation and exhibited behavioral problems and poor social skills. Many of the persons with mental retardation were also diagnosed as having a severe behavioral/emotional disorder. The unit was divided into two sections: one for persons diagnosed primarily as mentally ill and the other for persons diagnosed primarily as mentally retarded.<sup>30</sup>

The regional centers initially served a social control purpose and functioned as a custodial home for residents including persons with mental retardation. However, as will be discussed later, by the 1970s, the functions of regional centers had changed significantly reflecting an active treatment philosophy. The care of mentally retarded citizens was substantially affected by this changing philosophy and the emerging community, developmental, and human rights models.

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<sup>28</sup>Spradling, F.L., Biennial Report: Lincoln State Hospital. Twenty-Third Biennial Report: Board of Control, 1959, 73-103.

<sup>29</sup>Gray, R.W. Lincoln State Hospital. First Biennial Report: Board of Control, 1963, 35-45.

<sup>30</sup>Lincoln Regional Center. Seventh Biennial Report of the Department of Public Institutions, 1975, 52-62.

## 6. The Community-Based Movement: The Parent's Crusade

Any caring relative of a chronically handicapped person, either from birth or traumatic accident or disease, suffers as does the person.

-Mary Hepburn O'Shea

Before the 1950s, few alternatives to institutional care existed. Parents had the choice of committing their mentally retarded children to large, overcrowded institutions or expending tremendous time and effort in providing care themselves. By the 1930s, one can identify the first semblance of parent organizational efforts across the nation to advocate and provide for the welfare of their mentally retarded children. In 1933, five mothers from Cuyahoga County, Ohio, formed the Council for the Retarded and established a special education class to serve youngsters with mental retardation who were excluded from the public schools (Segal, 1970). Parents in Washington founded a statewide organization in 1936 called the Children's Benevolent League. The League provided gifts to institutionalized children and a support network for parents (Lippman, 1976). To provide community-assistance for persons with mental retardation, in 1939, parents in New York formed the Welfare League for Retarded Children, and mothers in Boston established the Greater Betterment Association of Massachusetts in 1945 (Segal, 1970). In September 1950, representatives of parent groups across the country met in Minneapolis and created the National Association of Parents and Friends of Mentally Retarded Children which later became the present day National Association for Retarded Citizens (Segal, 1970; for a discussion of analogous parental concern in Canada, see Simmons, 1982).

Through the 1950s, state-supported community programs for persons with mental retardation were lacking in Nebraska. The Legislature took an important step in 1949 for providing community educational services to children with mental retardation.<sup>1</sup> The Legislation required local school districts to provide special education classes for the "educable mentally retarded" who were defined as:

"children of school age who, because of retarded intellectual development as determined by individual psychological examination, are incapable of being educated profitably and efficiently through the use of ordinary classroom facilities and procedures, but who may be expected to benefit from special educational facilities and methods designed to make them socially adjusted and economically useful."<sup>2</sup>

However, in response to an inquiry from the Nebraska Commissioner of Education, the Attorney General rendered an opinion<sup>3</sup> in 1958, that public schools were not responsible for educating trainable mentally retarded

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<sup>1</sup>Act of March 16, 1949, ch. 131, 1949 Neb. Laws 341 [current version at NEB. REV. STAT. §43-604 et seq. (Reissue 1978)].

<sup>2</sup>Id. at p. 342.

<sup>3</sup>Op. Att'y Gen. 349-50 (1957-58).

children, i.e., those with IQs between 30 and 50.<sup>4</sup> The Attorney General expressed his opinion that the legislature intended this class of children to be served at the Beatrice State Home. This opinion excluded a large number of persons with mental retardation from eligibility for local special education services.

To remedy the absence of community services at this time, parents and private organizations established local schools across the state to satisfy the educational needs of children with mental retardation. In the early 1950s, parents established local branches of the National Association for Retarded Children at Lincoln, Omaha, and Norfolk (Frohboese & Sales, 1980). In 1955, the local organizations created a state organization called the Nebraska State Association for Retarded Children (NebARC) which held its first convention in Norfolk.<sup>5</sup> One of the primary objectives of the new organization was to establish and operate community-based services (Frohboese & Sales, 1980). Initially, parents organized community programs there were no alternatives; eventually, however, parents, advocates, professionals, and public officials came to recognize the community model as a preferred service option. One can best conceptualize this model as a transition between the asylum and social control models and the normalization/development and human rights models. The three local organizations at Lincoln, Omaha, and Norfolk started schools before NebARC came into existence.

In Omaha, children with cerebral palsy and mild mental retardation were served at Dr. J.P. Lord's School, an educational facility for the physically disabled.<sup>6</sup> For a brief time, in the late 1940s, the school admitted children with physical disabilities and more severe mental retardation. This practice was soon suspended, however.

Parents in Omaha first banded together in 1951 and established classes for their children that same year in a church. In 1952, the parents incorporated as the Omaha Opportunity Center, Inc., which became a member of the National Association for Retarded Children a year later.<sup>8</sup> In 1953, parents solicited donations via a television fund-raiser and purchased a three-story brick house at 5016 California Street. Initially, the school served about six children; however, this number had grown to 11 or 12 students by 1953.<sup>10</sup> Students were taught by retired

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<sup>4</sup>DeMarais, J. Summary of Nebraska law related to the education of handicapped children. Unpublished report to the Director of Special Education, Nebraska State Department of Education, 1974.

<sup>5</sup>Personal communication with Eleanore Enersen, January 24, 1984.

<sup>6</sup>Personal communication with Richard Gulisha, May 25, 1984.

<sup>7</sup>Personal communication with Margaret Devore, May 24, 1984.

<sup>8</sup>Overview: The History of GOARC. Information supplied by ENCOR, February 17, 1984.

<sup>9</sup>Personal communication with Margaret Devore, February 10, 1984.

<sup>10</sup>Personal communication with Gretchen Long, February 10, 1984.



teachers who were paid very little and by volunteer parents. Subjects at the school included academics, personal hygiene, cooking, and ceramics. Although parents paid tuition, much of the funding came from proceeds of garage sales and private donations. In 1963, the Douglas-Larry County Association for Retarded Children established preschool services at HELP (Helping Exceptional Little People) Nursery School. This school provided educational opportunities for children who were too young for the Opportunity Center. Participation at the Omaha Opportunity Center reached its peak in 1964 and 1965 when 75 children were enrolled. By 1968, all the children were absorbed into local school districts, and state-run programs, and the Omaha Opportunity Center was discontinued.<sup>11</sup>

In Lincoln, parents organized in 1953, establishing the Lancaster Association for Retarded Children (LARC) (Brown, 1971). The children first came together at a Christmas party in 1953, held at the home of Eleanor and Larry Enersen, and in January 1954, the school began in this home.<sup>12</sup> In June 1954, the parents rented the back of an old restaurant at 21st and J Streets for the school. By the next year, parents had raised enough money to rent the entire building. At this time, approximately 30 children were enrolled. In 1958, the school moved to the first two floors of a state-owned building at 34th and Adams Streets. Through tuition payments and private donations, parents were able to obtain a barracks building from the University of Nebraska and move it to 84th and Adams. By 1968, program changes included the establishment of occupational training services and educational classes for adolescents (Brown, 1971). The program moved to the General Arnold School in 1968 and received public funds for the first time.

Parents in Norfolk organized in July 1953.<sup>13</sup> The organization formed classes for the children soon thereafter which were held in a park during the summer.<sup>14</sup> In the autumn, the school moved into a third floor room above a commercial building on the corner of 4th and Norfolk Avenue. Soon after its inception, the school served approximately 20 students ranging from 3 to 20 years of age. Students came from at least six nearby counties. Subjects included academics, social skills, and personal hygiene. Parents provided funds through fund drives and charitable dances until 1967 when the local school system began providing special education services.

A number of other local parent groups established community services in the late 1950s. In 1955, parents in North Platte established the North Platte Opportunity Center.<sup>15</sup> Students between the ages of 5 and 17 met in a

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<sup>11</sup> Supra, note 8.

<sup>12</sup> Supra, note 5.

<sup>13</sup> Three-year plan: 1979-1982, Region IV Office of Developmental Disabilities.

<sup>14</sup> Personal communication with Ruth Sorensen, February 21, 1981.

<sup>15</sup> Personal communication with Ernest Rutledge, May 23, 1981.

former bar and pool hall.<sup>16</sup> Later, the school moved to a new building designed for educating handicapped children.<sup>17</sup> The students were children the school system termed "uneducable" and, therefore, ineligible for the small special education class in the public school. The children were instructed by volunteers in academics, social adaptability, and vocational skills. Somewhat surprising was that most volunteers were not parents,<sup>18</sup> but rather altruistic community members from all walks of life.<sup>18</sup> Eventually, the state provided funding for the school.

A parent organization was initiated in Columbus in 1956 as a result of a letter written by Mrs. Leonard Keith that was printed in the local newspaper.<sup>19</sup> In the letter, she urged parents of children with mental retardation to organize, and subsequently parents formed the Columbus Chapter of the Nebraska Association for Retarded Children. The group organized lectures and educational meetings and created the first school in the Columbus area for children with mental retardation. Lennie Keith, the son of Mrs. Leonard Keith, was the first pupil and was tutored in the den of the home of Mrs. Otte, the teacher.<sup>20</sup> Beginning June 16, 1958, classes for ten students were held above a studio. In 1960, a new school building, The Columbus Opportunity Center, was built with funds raised by a host of charitable community organizations and equipped with equipment contributed ~~from~~<sup>by</sup> private donors.<sup>21</sup> In 1965, the public school system began providing special education services, diminishing the enrollment at the Opportunity Center. The school's function then shifted to adult services.

On April 8, 1957, a small school for children with mental retardation opened its doors in the old Elks Club at Broken Bow.<sup>22</sup> Students ranged in age from approximately 5 to 21 and were taught academics, personal hygiene and ceramics.<sup>23</sup> Parents eventually raised enough money by soliciting donations, serving soft drinks at social occasions, and selling honey to buy a building for the school. Recognizing the need for adult day services, parents established a workshop in 1969.

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<sup>16</sup>Personal communication with Andy Larson, February 7, 1984.

<sup>17</sup>Personal communication with Marge Layman, February 7, 1984.

<sup>18</sup>Personal communication with Phyllis Lambert, February 26, 1984.

<sup>19</sup>The Columbus Daily Telegram, Tuesday, October 2, 1956.

<sup>20</sup>Omaha World-Herald, Thursday, February 14, 1957.

<sup>21</sup>Supra, note 13; Personal Communication with Carl Rafferty, February 10, 1984.

<sup>22</sup>Personal communication with Mrs. Charles Land, February 7, 1984.

<sup>23</sup>Personal communication with Lyle Foster, February 3, 1984.

Parents organized in Nebraska City during the summer of 1957 through the efforts of Mrs. Al Schmitz.<sup>24</sup> Although special education classes existed in the Nebraska City Public Schools at this time, the school system required students to possess a minimum IQ to participate in the classes. To provide educational opportunities for children with mental retardation who did not qualify for the public school program, parents formed a school, the Arbor Training Center, in the spring of 1958. June Liesemeyer taught the first classes in the basement of Nebraska City's Memorial Building.<sup>25</sup> Seven or eight students, ranging in age from about five to the late teens enrolled in the school when it opened its doors. Initially, classes were held only on Saturday afternoons, but by the spring of 1959, the school held regular classes five days a week.<sup>26</sup> In the summer of 1961, it had expanded to two classrooms in a rented commercial building. A few months later, the parent organization purchased a house that provided space for three classrooms.<sup>27</sup> Initially, the curriculum included classes in academics and basic living skills, but later expanded to include workshop activities.<sup>28</sup> The school continued to be supported by community and private sources of funding until 1971 when public fund sources became available.<sup>29</sup>

The Cass County Association for Retarded Children established a school at Weeping Water around 1957. Helping Hand School met in a little country schoolhouse, and classes in personal hygiene, academics, and independent living were taught by Fay Morton. Parents purchased an old panel van to transport the pupils to and from school.<sup>30</sup> Funds were obtained through home sales, benefit bingo parties, and charitable contributions. By 1963, the school served 13 students with a staff of two teachers and a director.<sup>31</sup> In about 1966, the school moved to a Baptist Church in Plattsmouth where it remained until the school district began providing special education services.<sup>32</sup>

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<sup>24</sup>Honoring the Otoe County Association for Retarded Children: Supplement to Syracuse Journal - Democrat, Monday, April 23, 1979. Article entitled, Long history of caring highlights ARC, pp. 2-3.

<sup>25</sup>Personal communication with June Liesemeyer, February 21, 1984.

<sup>26</sup>Supra, note 24; id.

<sup>27</sup>Supra, note 25.

<sup>28</sup>Personal communication with Roberta Rivett, February 21, 1984.

<sup>29</sup>Supra, note 25.

<sup>30</sup>Personal communication with Vernon Waterman, May 25, 1984.

<sup>31</sup>The Communicator, No. 8, 1963 (Publication of Nebraska Association for Retarded Children).

<sup>32</sup>Supra, note 22.

In Fremont, parents established the Opportunity Center around 1958.<sup>33</sup> The school began above a grocery store and initially served three or four students. In 1962, parents recognized the need for expanded school facilities and attempted to purchase a home. However, community opposition prevented the purchase. Instead, the school moved to an older building that had served as an orphanage. In about 1966, the local Association for Retarded Citizens began a preschool program that served eight to ten children with mental retardation between the ages of 2 and 6. Classes were designed to provide educational experiences, rather than just day care.<sup>34</sup> The Fremont Opportunity Center continued until the public school system began providing special education classes in the late 1960s.

Hope School in Hastings opened<sup>35</sup> in the living quarters of a former federal ammunitions facility in 1959. The first six to eight<sup>36</sup> students were primarily children the local school refused to serve. In the beginning, one full-time teacher and one part-time teacher taught the children crafts and household skills. The school was funded through tuition, donations, and fund-raising activities.

Grand Island parents also initiated services in the late 1950s by forming a preschool program. The program met for two-hour sessions, two days a week, and offered<sup>37</sup> parents some temporary relief from the continuous care they provided. Parents started a school in Trinity Lutheran Church in the early 1960s. A primary source of funding for the Grand Island school, as well as for many of the other schools, was Honey Sunday, a coordinated statewide honey sale organized by NebARC.

By 1960, Omaha could boast another school for children with mental retardation. Madonna School began as an orphanage school. When the local school system began assuming responsibility for the education of the orphans, two children from the orphanage did not fit into the school system because of their mental retardation. Two other youths with mental retardation joined the two orphans in attending classes initiated by Sister Evangeline at St. James Orphanage. The students, ranging in age from 5 to 11, were taught the usual subjects in elementary education, including reading, writing and mathematics. In 1970, the school moved to a former Lutheran church and began accepting higher-need individuals with mental retardation. The school continues today<sup>38</sup> educating approximately 50 students in academics and vocational training.

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<sup>33</sup>Personal communication with Ione Norenberg, February 24, 1984.

<sup>34</sup>Personal communication with Linda Pfeifer, February 10, 1984.

<sup>35</sup>Personal communication with Vergail Jensen, February 4, 1984.

<sup>36</sup>Personal communication with Mrs. Vernon Fleharty, February 7, 1984.

<sup>37</sup>Personal communication with Irwin Peterson, February 3, 1984.

<sup>38</sup>Personal communication with Sister Evangeline, February 14, 1984.

Although by the early 1960s many parent groups had formed schools in the eastern portion of the state, the western portion was virtually without parent-sponsored schools for children with mental retardation. In<sup>39</sup> 1964, however, parents in Scottsbluff developed a preschool program. In 1966, the school began serving older children and provided a workshop for adults. The school and workshop were housed in a building locally referred to as "the Pest House." It had been<sup>40</sup> formerly used by the city to quarantine people with communicable diseases. In 1969, the<sup>41</sup> school received public funds and moved to the former Kiwanis Club building.

Two schools developed in the Bellevue area at about the same time. CHAP (Children Have A Potential) School began around 1964 at Offut Air Force Base.<sup>42</sup> The wives of military personnel started the school in the chapel to educate their children with mental retardation. Classes met three days a week<sup>43</sup> in the mornings, and the children learned educational and self-help skills. Although initially funded by parents, the Air Force eventually provided funds for staff and equipment. At its inception, CHAP School served only children of military personnel. However,<sup>44</sup> in the late 1960s, the school opened its doors to civilian children. Two or three years before civilians gained access to CHAP School, Bellevue parents established the Bellevue Developmental Center. The center began in a little old red school house<sup>45</sup> and initially served three children with mental or physical handicaps. The center eventually served nine children ranging in age from 2 to 12. By the late 1960s, the children were absorbed into public-funded programs.

Parents established a program in Sutherland for a brief period of time. In 1965, Sutherland parents obtained funds through donations, dances, dinners, and auctions to purchase a home. This residential and school program served 8 to 9 students, ranging from 6 to 21 years of age. The program lasted only two years, however,<sup>46</sup> and children transferred to facilities in Scottsbluff and Ogallala.

By 1967, Omaha had yet another school for children with mental retardation. The initiators of Project CHANCE (Children Have A Need Cooperative Enterprise) originated the program in August 1967, and designed

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<sup>39</sup> Personal communication with William Howe, February 3, 1984.

<sup>40</sup> Personal communication with George Sommers, February 3, 1984.

<sup>41</sup> Personal communication with Glenda Lacy, February 4, 1984.

<sup>42</sup> Personal communication with George Armstrong, February 10, 1984.

<sup>43</sup> Personal communication with Mrs. James Glover, February 10, 1984.

<sup>44</sup> Supra, note 42.

<sup>45</sup> Supra, note 42.

<sup>46</sup> Personal communication with Odith Dykes, February 7, 1984.

it to reach children from low-income, northside neighborhoods.<sup>47</sup> Initial funding was provided through a Federal Office of Educational Opportunity-Headstart grant. Originally supervised by Greater Omaha Community Action, in 1969 it became a program under the Greater Omaha Association for Retarded Citizens. The program sought to serve youngsters with handicaps who were between the ages of 3 and 8 and ineligible for local school programs. By 1970, the school served over 100 children.

South Central Association for Retarded Citizens established a school in Ragan in March 1968. The City of Ragan<sup>48</sup> allowed the school to locate in the vacant public school facility. The association also purchased a home one block from the school. This house served as a<sup>49</sup> residence for five children whose homes were too far away to commute. Approximately 12 children from the towns of Alma, Hildreth, Holdrege, Orleans, and Wood River attended the classes.<sup>50</sup> In 1969, the State provided funds to support the school while the local association maintained the residential facility.<sup>51</sup> By 1971, the State assumed responsibility for both programs.<sup>52</sup> In 1974, the program moved to Oxford where it is located today.

Two other programs started in 1969 and existed briefly before public funds became available. In Wahoo,<sup>53</sup> parents began a preschool program supported by tuition and donations. In Hay Springs, parents and volunteers established the Day of Recreation for children with mental retardation. Bible classes, therapeutic games, and recreation were the major part of the curriculum. In 1971, before the program received public funds, the Methodist church in Hay Springs<sup>54</sup> allowed the children to meet three days a week in the Sunday school classroom.

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<sup>47</sup>Personal communication with Shirley Dean, February 10, 1984.

<sup>48</sup>New View School. Pamphlet issued by Educational Service Unit No. 11, P.O. Box 485, Holdrege, Nebraska.

<sup>49</sup>Personal communication with Virgil Peterson, February 3, 1984.

<sup>50</sup>"Ragan School News," Franklin County Sentinel, September 17, 1969.

<sup>51</sup>"Service unit to begin programs for retarded" Holdrege Citizen, December 13, 1968.

<sup>52</sup>"New school nearing completion," Oxford Furnas County, Thursday, April 25, 1974.

<sup>53</sup>Personal communication with Marilyn Calhoun, February 14, 1984.

<sup>54</sup>Personal communication with Lola Fincker, February 21, 1984.

The community model was not based upon lofty ideals or intellectual philosophies. Instead, purveyors of the model were motivated by a deep concern for the welfare of mentally retarded citizens. The absence of formal ideology, however, does not detract from the significance and impact of the model. The community model was the first step in replacing the previous institution-oriented models. The commitment of parents to their mentally retarded children, their dedication to a better quality of life for all persons with mental retardation, and their refusal to accept the more pessimistic models of mental retardation led to one of the more dramatic shifts in how society responded to disabled individuals. Parent-initiated programs became the foundation for Nebraska's system of community-based mental retardation programs.

## 7. Normalization and the Developmental Model

We have a powerful new ideology, and we believe it is good, conscious, and harmonious with facts. We aim to be the state that will set a model to other states in the implementation of this ideology.

-Wolf Wolfensberger

In contrast to the parentally-instigated community model, the normalization principle and the developmental model evolved primarily as professional concepts. Prior to the 1950s, lay persons and professionals focused on the hereditary aspects of mental retardation. During this time, the eugenics movement was an important force in mental retardation services advocating segregation and sterilization. In the 1950s, however, a new perspective arrived. Intelligence came to be viewed as an interaction between heredity and environment and, therefore potentially malleable by enriched or deprived surroundings. It logically followed that mental retardation could be ameliorated, if not eliminated, through appropriate treatment. With the emergence of behavioral technologies derived from the behaviorist learning theories, persons with severe and profound mental retardation made great strides in caring for themselves and accomplishing tasks (Maloney & Ward, 1979). The belief evolved that persons with mental retardation had potential that could be developed through proper learning.

Belief in the potential for persons with mental retardation to grow and develop throughout life became known as the developmental model. The major principles of the developmental model are the following:

1. Development begins at conception and continues throughout the life span of every human being.
2. Normally, human development progresses in a sequential, orderly, and predictable manner. Consequently, developmental sequences can be identified and used in planning programs and assessing progress.
3. The rate and direction of development may be significantly modified by utilizing and controlling certain physical, psychological, and social aspects of the individual's environment. (Accreditation Council, 1978, p. 14)

✓✓ Normalization was first conceptualized in Europe in the 1950s. However, the concept did not gain prevalent professional acceptance until almost 1970 (Wolfensberger, 1972). In 1968, Nirje (the Executive Director of the Swedish Association for Retarded Children) presented this view in English for the first time. As defined by Nirje, "the normalization principle means making available to all mentally retarded People [sic] patterns of life and conditions of every day living which are as close as possible to the regular circumstances and ways of life of society" (1976,



p. 231). Normalization, translated to habilitation, involves integration of the person into society and individualized programs to fulfill the person's growth potential (Wolfensberger & Glenn, 1973). Normalization does not refer to making all persons "normal."

### Nebraska Psychiatric Institute

The normalization and developmental treatment concepts were manifested professionally in the areas of mental health and mental retardation, in part, through the activities of staff of the Nebraska Psychiatric Institute (NPI). NPI was established in 1947 as the Nebraska Psychiatric Unit to provide treatment for 130 persons with behavioral/emotional disorders receiving custodial care at the Douglas County Hospital in Omaha. The unit was located within the hospital and administered jointly by the State Board of Control and the University of Nebraska School of Medicine. In 1952, the University of Nebraska College of Medicine, the State Board of Health, and the State Board of Control provided funds for a new NPI building. The new NPI was built on the campus of the College of Medicine and provided teaching and research opportunities in addition to a 100-bed psychiatric hospital.

In the early 1960s, NPI established a research center for the study of mental retardation (Centennial History Committee, 1980). In January 1963, this ward consisted of ten beds for children involved in research concerning the detection, prevention, and treatment of mental retardation.<sup>1</sup> In addition, NPI created a research program at the Beatrice State Home.<sup>2</sup> In 1968, the Meyer Children's Rehabilitation Institute (MCRI) was formed at the University of Nebraska Medical Center. The MCRI provided "interdisciplinary education for personnel in health, education, and vocational fields needed in services to children with handicaps; ... exemplary interdisciplinary service programs; and ... basic and clinical research on the prevention and treatment of handicapping conditions in children" (Centennial History Committee, 1980, p. 92).

This research setting was to become the context within which normalization and development were applied as theoretical models for treatment in Nebraska. For example, Wolf Wolfensberger, a research scientist at NPI from 1964 to 1971, became one of the leading proponents of the normalization concept in this country (see Wolfensberger, 1972). Professionals from NPI, along with professionals administering the community programs, initiated a zealous advocacy of this new ideology.

This emerging professional paradigm was not the primary force behind the establishment of community programs in Nebraska. The major initiators were parents seeking alternative services and advocates pursuing human rights. However, the professional concurrence did lend an additional sense of

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<sup>1</sup>Wittson, C.L. Nebraska Psychiatric Institute. First Biennial Report: Department of Public Institutions, 1963, 59-76.

<sup>2</sup>Wyant, M.E. Beatrice State Home. First Biennial Report: Department of Public Institutions, 1963, 77-95.

Currently University Psychiatric Services

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legitimacy to the decentralized, community treatment movement. The model of normalization and development also had a tremendous influence on the course of habilitative efforts within community programs. The system of state-supported community programs in Nebraska served as an experimental setting for application of the model; normalization and the developmental model became the basic foundation for services in these programs (Casey et al., 1985; Lensink, 1976).

### Community-Based Programs

In addition to special education programs for higher-functioning children with mental retardation and the institutional care provided at BSH, the State of Nebraska began providing public funds to community services for persons with mental retardation in the late 1960s. While concerted and effective state funding of community-based programs did not occur until this time, one can identify the first semblance of state concern for systematic mental retardation services in the early 1960s. In March 1961, Governor Frank B. Morrison created the Interagency Committee on Mental Retardation.<sup>3</sup> This committee was primarily advisory, but engaged in some lobbying for legislation pertaining to persons with mental retardation. In 1965, the committee divided into two separate committees, the Governor's Interagency Committee on Mental Retardation and the Governor's Citizen Committee on Mental Retardation. The Interagency Committee coordinated agency programs and advised the governor. The Citizens Committee studied the needs of persons with mental retardation and proposed legislation and administrative action to meet those needs. Both committees assisted in the development of the Nebraska Plan to Combat Mental Retardation.

This Plan was developed by the Community Services Division of NPI in 1964 and 1965. Interested citizens, parents, and professionals from across the state contributed to the planning process. In addition, each state agency involved in mental retardation services submitted an outline of their activities and future expectations. Three experts were then asked to review the data and make recommendations. From these procedures, the Plan recommended, in part, that the State develop six mental retardation service regions to administer diversified and specialized community programs. Recognizing that the Beatrice State Home continued to operate under the custodial model, the Plan recommended that the population be reduced to 1,000 residents and the function of the institution be clarified.<sup>4</sup> Perhaps this Plan was ahead of its time since, as Wolfensberger and Menolascino (1970) note, it lacked enthusiastic support and was never implemented (see also Casey et al; 1985).

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<sup>3</sup>Second annual report of the Governor's Inter-Agency Committee on Mental Retardation to his excellency, Frank B. Morrison, Governor of Nebraska, June, 1963.

<sup>4</sup>Blueprint for action: The Nebraska plan to combat mental retardation. Community Services Division, Nebraska Psychiatric Institute in cooperation with the Nebraska Department of Health, 1966. See also: Nebraska State Plan for Construction of Facilities for the Mentally Retarded. Nebraska State Department of Health, 1969.

Significant state action with implications for mental retardation services occurred in 1967 when the Legislature created the Office of Mental Retardation (OMR) within the State Department of Health.<sup>5</sup> Initially, the Office operated with two staff members, the Coordinator/Director and a research assistant. The duties of the Office consisted of studying the existing community programs and establishing new programs where needed. OMR was limited in creating needed programs, however, since the Legislature appropriated a maximum of only \$50,000 from the General Fund for the creation and operation of both the Office and the programs.<sup>6</sup>

An even more significant event occurred in 1967 with the creation of the Citizens' Study Committee on Mental Retardation. The following sequence of events led to the formation of the Committee. In the spring of 1967, a NebARC committee proposed that a study be conducted of the residential facilities in Nebraska. This proposal, which was supported by the Director of the Department of Public Institutions, was then presented to the Governor's Citizen Committee on Mental Retardation along with eight NebARC nominees to constitute a study committee. The Governor's Committee accepted the proposal and suggested four additional nominees to the study committee. These twelve members were officially appointed by Governor Tiemann as the Citizens' Study Committee on Mental Retardation which was to function as a sub-committee of the Governor's Citizen Committee on Mental Retardation. For a discussion of the dynamics of the Study Committee, see Casey et al. (1985).

The Committee was forthright in specifying its ideological perspective listing five evaluative assumptions: 1) a person with mental retardation is a human being deserving of legal, human, and social rights and should be treated as other human beings; 2) intimate interaction should exist between services and communities; 3) maximal contact should exist between persons being served and their families; 4) services should provide an optimal environment for the development and well-being of the individual; and 5) each person being served should have access to an advocate who will safeguard her or his interest. These values mirrored the essence of normalization and the developmental model.

As a result of extensive investigation of existing services, the Committee issued scathing criticisms of the current system.<sup>8</sup> Stated the Committee:

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<sup>5</sup>Act of July 19, 1967, ch 433, 1967 Neb. Laws 1321 (repealed 1969).

<sup>6</sup>Act of July 19, 1967, ch 433 §3, 1967 Neb. Laws 1323 (repealed 1969).

<sup>7</sup>Nebraska Citizen's Study Committee on Mental Retardation. The Report of the Nebraska Citizen's Study Committee on Mental Retardation (Vol. 1), July 1968.

<sup>8</sup>Id.

Nebraska today has an archaic and fruitless program for the mentally retarded ... The existing condition is one of the blackest pages in our state's book ... Public zoos traditionally spend more to care for their large animals than is spent to care for the mentally retarded ... Dehumanization of retardates is a result of our present Nebraska condition. Retardates who could be trained to use the bathroom, to wash and clean themselves, are often sentenced to living in their untrained condition and to waste away without attention (pp. 11-13).

The Committee proffered explicit and detailed recommendations. Several of the recommendations concerned the provision of more resources and authority to state agencies administering mental retardation programs. The Committee also urged the development of community services and protection of specific rights for persons with mental retardation. For example, the Committee advocated the repeal of sterilization laws discriminating against persons with mental retardation.

Responding to the Committee's report, the Nebraska Unicameral enacted significant legislation in 1969. One of the most important laws provided for the creation, funding, and coordination of community-based programs in the state. The legislation also moved the Office of Mental Retardation (OMR) under the Department of Public Institutions and created an advisory committee to OMR consisting of professionals and lay persons. The act defined the purposes of OMR, delineated the duties of the director, and enabled OMR to direct state funds to community mental retardation services. OMR could provide state monies on a grant basis to fund up to 60 percent of the community programs. The initial state appropriation for the community-based service component for FY69-70 was \$209,705. State funding increased dramatically thereafter.

In 1973, the Legislature enacted new legislation that established taxing authority and increased state funding to 75 percent of the community programs' costs. The law also completed the framework for the current system of community mental retardation services in Nebraska<sup>10</sup> by establishing six mental retardation service regions in the state. Under this structure, parent-initiated services became primarily state funded and new programs emerged.

In 1977, the Office of Mental Retardation began disbursing funds to regions on an aid payment basis. This method of funding regions was the result of a letter from the State Attorney General's Office advising the Department of Public Institutions that the funding relationship with regions was one of disbursing funds to the regions within the fund amounts appropriated by the Legislature.<sup>11</sup> The opinion also indicated that such a relationship

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<sup>9</sup>Act of July 28, 1969, ch. 580, 1969 Neb. Laws 2332 [current version at NEB. REV. STAT. §83-1,141 et seq. (Reissue 1981)].

<sup>10</sup>Act of May 17, 1973, LB311, §8, 1973 Neb. Laws 843 [current version at NEB. REV. STAT. §83-1,143.06 (Reissue 1981)].

<sup>11</sup>Letter from Paul L. Douglas to Jack Cleavenger (September 5, 1975).

did not require a contractual agreement or the Department to reimburse regions based on services provided, such as reimbursing on a unit of service basis. This funding procedure, aid disbursement, is the current system used for state funding of regions.

In conjunction with this new-found state support came increased support from counties and the federal government. Community-based program funding from a county governmental body appears to have originally occurred in 1968 when Douglas County appropriated \$110,000 to the Greater Omaha Association for Retarded Citizens (GOARC) program.<sup>12</sup> With the formation of mental retardation regions through the Interlocal Cooperation Act, counties began to provide direct fund support to community-based programs. In 1969, the Legislature set the local/county contributions at 40 percent of the total funding with up to three-fourths of the local contribution allowed to be in the form of "soft match," i.e., facilities, fixtures, etc.<sup>13</sup> In 1973, legislation changed the local rate to one local/county dollar for every three dollars from the state. The local match could include "in-kind services, and income from workshops and room and board payments."<sup>14</sup>

A surge of federal support occurred in the 1960s and early 1970s. President Kennedy created the President's Panel on Mental Retardation in 1961. This tremendously influential panel published a report in 1962 containing a number of recommendations pertaining to improvement in society's treatment of persons with mental retardation. One of these recommendations urged the development of community-centered programs (Maloney & Ward, 1979). In 1963, Congress enacted the Mental Retardation Facilities and Community Mental Health Centers Construction Act which provided funds for treatment and research.<sup>15</sup> In October 1970, Congress passed the Developmental Disabilities Service and Facilities Construction Act.<sup>16</sup> The legislation is notable for its developmental perspective. The amendments replaced the term mental retardation with the term developmental disabilities which referred to:

disabilities attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual ... closely related to mental retardation or to require treatment similar

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<sup>12</sup>Touche Ross & Co. "State of Nebraska: Review of the community-based mental retardation program." January 20, 1975. Copy on file with the Office of Mental Retardation.

<sup>13</sup>Supra, note 9.

<sup>14</sup>Act of May 17, 1973, LB311, §5, 1973 Neb. Laws 842 [current version at NEB. REV. STAT. §83-1,143.03 (Reissue 1981)].

<sup>15</sup>Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, Pub. L. No. 88-164, 77 Stat. 282 (codified in scattered sections of 42 U.S.C.).

<sup>16</sup>Developmental Disabilities Service and Facilities Construction Amendments of 1970, Pub. L. No. 91-517, 84 Stat. 1316 (codified in scattered sections of 42 U.S.C.).

to that required for a mentally retarded individual, which disability originates before such individual attains age 18, which has continued or can be expected to continue indefinitely, and constitutes a substantial handicap to the individual.

✓ In addition, the new legislation replaced references to clinical training with the term "interdisciplinary training".<sup>17</sup> This legislation was intended to: 1) assist states in developing plans to meet the needs of persons with developmental disabilities; 2) provide funds to construct facilities for the provision of developmental disability services; 3) provide funding for the implementation of services for the developmentally disabled; 4) support local planning and assistance applied to developmental disability services; 5) support training of personnel required to provide services for the developmentally disabled and encourage research regarding staff and personnel needs; and 6) support research regarding the effective provision of developmental disability services.<sup>18</sup>

Federal support also became available directly to community programs. In 1968, Douglas County received a Facility Establishment Grant from the Federal Rehabilitation Services for increasing staffing and purchasing additional facility equipment.<sup>19</sup>

✓ In 1970, community-based programs received a source of federal funds which quickly became the second largest source of funding for community-based programs: Title XX of the Social Security Act.<sup>20</sup> Originally, Title XX was limited to non-medical social services for persons categorically related to federal entitlement programs. Title XX allowed the state to purchase social services from approved service providers and receive 75 percent federal funds for the expenditures. Community-based programs (after 1973, the mental retardation regions) were approved by the state's Department of Social Services as service providers under Title XX regulations.

Other forms of federal funding also became available. Medicaid became an important funding source for persons in the community-based component of the state's mental retardation system. For eligible persons served in community-based programs, Medicaid provides 58 percent of the funding for medical services. Each person's eligibility is determined by her or his income, resources, and disability. A person's categorical eligibility for Medicaid is through the Aid to the Disabled Program.

Persons with mental retardation also became eligible to receive Supplemental Security Income (SSI) benefits and/or State Supplemental Assistance (SSA) to SSI.<sup>21</sup> As with Medicaid, eligibility for SSI or SSA is determined by income, resource guidelines, and disability.

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<sup>17</sup> Id.

<sup>18</sup> Id.

<sup>19</sup> Supra, note 12.

<sup>20</sup> 42 U.S.C. §§1397-1397f (1983).

<sup>21</sup> 42 U.S.C. §1381 et seq (1983).

✓ Funding from SSI and SSA is received directly or on behalf of individuals. Such funds became perhaps the single most important source of payment from persons to community-based programs for payment of room and board ~~for operation of community-based facilities~~. In addition, persons in the community-based service component, as well as those in the ICF/MR component, became eligible for Social Security benefits through the parent's Social Security account as a disabled dependent. 11

With this support from county, state, and federal resources, community-based mental retardation programs flourished. In Region I, consisting of 11 panhandle counties, all programs regionalized by mutual agreement on July 1, 1976. These parent-initiated programs continued to offer quality mental retardation service, but with the assistance of public funds.<sup>22</sup> By 1977, Region I served 139 clients.<sup>23</sup>

Region II consisted of 17 counties in the southwest part of the state and had its regional office in McCook. With public funding, new programs and program expansions occurred in North Platte, McCook, Ogallala, Cozad, Imperial, and Elwood.<sup>24</sup> One hundred sixty-eight clients were receiving community-based services in Region II by 1977.<sup>25</sup>

✓ By 1971, the 22 counties in Region III had signed agreements under the Interlocal Cooperation Act. By 1975, the Region had<sup>26</sup> seven community programs<sup>27</sup> that two years later, were serving 375 clients.

✓ ✓ In Region IV, serving 22 counties in the northern part of the state, the regional Office of Developmental Disabilities was incorporated in December ~~of~~ 1971. The ~~Office~~ reorganized in 1974 as a governmental inter-local cooperative. In addition to parent-initiated programs in Norfolk and Columbus, services emerged in Wayne, South Sioux City, Bloomfield, Valentine, O'Neill and Lyons. On May 24, 1979, Keya Paha and Cherry counties withdrew from the Region IV interlocal agreement and, through a separate interlocal agreement, administered services through the Keya Paha-Cherry County Mental [Retardation] Service. By 1979, approximately 350 clients were receiving services under the supervision of the Region IV office.<sup>28</sup> ~~handicapped children. In 1978, Nebraska extended the school~~

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<sup>22</sup> Supra, Chapter 6, note 52.

<sup>23</sup> Information supplied by the Nebraska Office of Mental Retardation, May 2, 1984.

<sup>24</sup> Region II Services for the Handicapped, Three Year Plan; 1979-1982 (1979).

<sup>25</sup> Supra, note 23.

<sup>26</sup> Region III Mid-Nebraska Mental Retardation Services. Three Year Plan: 1979-1982 (1979).

<sup>27</sup> Supra, note 23.

<sup>28</sup> Region IV Office of Developmental Disabilities. Three Year Plan: 1979-1982, (1979); personal communication with John Corcoran, May 18, 1984.

In the southeastern portion of Nebraska, Region V initially consisted of 14 counties. Two more counties were added in 1974. By October 1974, the 16 counties had signed interlocal agreements. By 1976, five community programs were being funded through the regional office<sup>29</sup> in Lincoln and by 1977 were serving 479 persons with mental retardation.<sup>30</sup>

In 1970, the five counties in Region VI formed the Eastern Nebraska Community Office of Retardation (ENCOR)<sup>31</sup> which became a model service delivery system providing residential, vocational, educational, social, and support services to all five counties (see Casey et al., 1985; Lensink, 1976).<sup>32</sup> By 1977, 639 clients received mental retardation services in Region VI.

This growth was not unadulterated, however. In 1975, Congress placed a national expenditure ceiling on Title XX funds. For Nebraska, this action reduced Title XX funds to community-based mental retardation services by more than \$1.6 million between FY74-75 and FY75-76. This funding reduction had pernicious effects on community services: Many services were entirely eliminated.<sup>33</sup> However, through continued state support, the regional programs soon resumed their growth.

In the middle 1970s the responsibility for serving school-aged children shifted to the public schools, and community programs began to specialize in adult services. This shift in emphasis started in 1973 when the Nebraska Legislature, anticipating federal legislation, enacted a law requiring the State Board of Education to provide appropriate educational programs for all handicapped children, ages 5-18 by October 1, 1976.<sup>34</sup> The upper age limit was extended to 21 in 1976.<sup>35</sup> The anticipated federal legislation was the Education for all Handicapped Children Act<sup>36</sup> which Congress passed in 1975 (effective by 1978) to require a "free appropriate" education for all *handicapped children*. In 1978 Nebraska extended the school

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<sup>29</sup>Region V Mental Retardation Services. Three Year Plan: 1979-1982, (1979).

<sup>30</sup>Supra, note 23.

<sup>31</sup>Eastern Nebraska Community Office of Retardation. Three Year Plan: 1979-1982, (1979).

<sup>32</sup>Supra, note 23.

<sup>33</sup>Supra, note 31.

<sup>34</sup>Act of May 30, 1973, LB403, 1973 Neb. Laws 982 (codified in scattered sections of NEB. REV. STAT. §43, §79).

<sup>35</sup>Act of April 7, 1976, LB761, 1976 Neb. Laws 519 (codified in scattered sections of NEB. REV. STAT. §43).

<sup>36</sup>Education for all Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 [codified at 20 U.S.C. §§1401 et seq. (1978)].



system's <sup>37</sup>responsibility to the education of preschool handicapped children.

In the early 1980s, a number of private community-based mental retardation programs emerged. Martin Luther Home developed community programs at Beatrice, Omaha, and York. Bethphage Mission established programs in Holdrege and a group home in Lincoln. Other community programs that evolved included Youth Care, Inc. in Omaha and Developmental Services Corporation in Hastings.

Community-based programs continued their growth and evolution through the early 1980s. By 1984, 2,290 clients were being served by private and public community mental retardation programs. These programs established a standard of excellence that was widely recognized. The national and international recognition became particularly noticeable for Region VI mental retardation services, ENCOR. Region VI was frequently identified by the President's Committee on Mental Retardation (1972, 1978) as an exemplary program. In addition, persons from around the world who were interested in mental retardation services came to view the ENCOR experience first hand, and a great demand arose around the country for professionals associated with ENCOR to consult and lecture (Casey et al., 1985).

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<sup>37</sup>Act of April 17, 1978, LB889, 1978 Neb. Laws 913 [current version at NEB. REV. STAT. §§43-646 to 43-646.01 (1978)].

## 8. Human Rights: The Deinstitutionalization Movement

Ward T1 [Beatrice State Home]

Twenty-five small boys and girls and 2 staff on ... the day room noise level is tremendously high ... no place for privacy ... TV blaring away but nobody watching it ... urine on the floor.

- Robert Perske

The human rights model has been expressed most conspicuously in litigation. However, state legislative action and private social activism have also been prompted by this perspective. The modern human rights movement originated in civil rights activity in the 1950s. At this time, black Americans sought equal opportunity and treatment through social activism, litigation, and legislative change. Although initially associated with racial equality, the human rights model eventually became a banner for other oppressed groups. By the 1960s, groups identified by religion, gender, national origin, and age actively pursued their constitutionally protected rights. It was not until the 1970s, however, that advocates made substantial progress in safeguarding the human rights of persons with developmental disabilities (including persons with mental retardation) and mental health problems. Litigation involving mental institutions established and defined a right to treatment,<sup>1</sup> a right to refuse intrusive treatments,<sup>2</sup> and procedural rights in commitment proceedings.<sup>3</sup> As the reigning president of the American Association on Mental Deficiency observed:

While other times have also observed progress in the field, I think we are truly in an era that marks itself distinctly from all others. The distinction is rooted in a recognition and a campaign for human rights. (Rosen, 1974, p. 61)

Society had long singled out persons with mental retardation for disparate treatment in such areas as marriage, child-bearing, adoption, child-rearing, voting, and obtaining a drivers' license. Representatives of persons with mental disabilities began questioning the rationality of

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<sup>1</sup>E.g., O'Connor v. Donaldson, 442 U.S. 563 (1975); Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971), 334 F. Supp. 1341 (M.D. Ala. 1971), 344 F. Supp. 373 (M.D. Ala. 1972), aff'd sub. nom. Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974).

<sup>2</sup>E.g., Mills v. Rogers, 457 U.S. 291 (1982).

<sup>3</sup>E.g., Lessard v. Schmitt, 349 F. Supp. 1078 (E.D. Wisc. 1972); Parham v. J.R., 431 U.S. 494 (1977).

a person should not be hospitalized, with drastic curtailment of liberty involved, if he can be treated in a community ... The right to be treated in a setting less restrictive than an institution [is] required by the constitutional principle of the least drastic means [a term synonymous with least restrictive alternative]. (Mental Health Law Project, 1973, pp. 27-28).

Another popular concept, derived more from a human rights as opposed to a legal perspective, was dignity of risk. This theory proposed that overprotection of persons with disabilities robs those persons of individuality and potential for growth. Custodial care of people with mental retardation in a safe, protective environment is dehumanizing. Only through encountering normal risks can persons exhibit such attributes as courage and dignity. Although interaction with the real world may be dangerous, it is the right of all persons and necessary to achieve self-respect (Persky, 1972). The dignity of risk concept became an additional rationale for deinstitutionalization.

By the 1960s and 1970s, journalistic exposes portrayed institutions as deathtraps and snakepits. Stories of mistreatment, financial exploitation, deteriorating facilities, and dehumanizing effects abounded (Blatt & Kaplan, 1966; National Institute of Mental Health, 1976). This picture of institutions, combined with the professional concept of normalization, the legal concept of the least restrictive alternative, the human rights concept of dignity of risk, and the availability of community options created the atmosphere for the deinstitutionalization movement.

#### The Beatrice State Home

Since the inception of institutional care for persons with mental retardation in Nebraska, the institutional population grew unabated to a high of over 2,300 residents by the late 1960s. One can identify sporadic references concerning dissatisfaction with the large institutional model<sup>5</sup> before this period. For example, in the 1939 biennial report, Superintendent Burford noted:

There is a belief among some psychologists that a person's ability to adjust into normal society will lose effectiveness upon confinement in an institution for the feeble-minded. This is because the background of the individual is such that he does not have to meet the challenge of higher levels of performance. So that it is better for those who are subnormal mentally, especially on the upper levels, to attempt to make an adjustment in society rather than to thrust them into an institution where they may lose what little social experience they have had. After all, by far the biggest percentage of those who are subnormal mentally are not confined in state institutions, but are making some kind of adjustment in society. (p. 268)

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<sup>5</sup>Nebraska Institution for the Feeble-minded. Thirteenth Biennial Report of the Board of Control of Nebraska, 1939, 265-277.

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Despite this admonition, the institution as a mental retardation service option continued to dominate in Nebraska and the rest of the nation. By 1961 the Director of the Beatrice State Home (BSH) expressed concern about the overcrowded conditions: "At the time of <sup>1</sup>the writing the Beatrice State Home is responsible for 2,399 people, with 78 <sup>2</sup>on the waiting list. We have reached the saturation point, whereby we are overcrowded and facilities are badly needed in all areas ..."<sup>6</sup>

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An impetus toward deinstitutionalization occurred with the formation of the Citizens' Study Committee on Mental Retardation in 1967. The Committee made detailed recommendations concerning BSH. It suggested a reduction in the number of residents from approximately <sup>3</sup>2300 to 850 in six years. The committee also advocated improved conditions for residents remaining institutionalized. For example, the committee recommended an improvement in staff/resident ratios and creation of developmental training programs for residents.

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In the succeeding years, the population at BSH decreased dramatically. However, this reduction resulted, in large part, from a federal funding scheme rather than recommendations by the Committee. Title XIX of the Social Security Act (Medicaid) allowed eligible certified medical facilities to receive payment for medical services provided to eligible persons. In 1969, BSH was certified as an Intermediate Care Facility (ICF) which allowed the institution to be paid as a licensed medical facility for services provided to eligible persons. This provision allowed as much as ~~fifty-eight~~ <sup>5</sup>percent of care costs to be reimbursed with federal funds. The impact to the state was to obtain over ~~fifty~~ <sup>6</sup>percent federal funding for the total operating costs of BSH and eventually other state-operated ICF/MR units. Title XIX, however, required that an Independent Professional Review team determine whether long-term institutional care was appropriate for each resident. For each person found ineligible for Title XIX funds, the facility administration had a duty to locate an appropriate placement (Scheerenberger, 1976, p. 79). Many persons at BSH in 1969 were found not to be eligible for Title XIX funds and were transferred out of <sup>9</sup>BSH and into community-based programs, nursing homes, and other services. From June 30, 1969 to June 30, 1971, the resident population decreased from 1,945 to 1,485.<sup>10</sup> By the following

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<sup>6</sup>Wyant, E.M. (1961). Report on the Beatrice State Home. In "Preliminary Report of the Governor's Inter-Agency Committee on Mental Retardation to His excellency, Frank B. Morrison, Governor of Nebraska.

<sup>7</sup>Supra, Note Chapter 7, note 7.

<sup>8</sup>42 U.S.C.A. §§1396-1396P (1983).

<sup>9</sup>Personal communication with Jim Hanlon, May 3, 1984.

<sup>10</sup>Program for the mentally retarded. Fifth biennial report: Department of Public Institutions, 1971, 93-112.

year, however, this institutional exodus had slowed considerably.<sup>11</sup>

When the State became involved in providing community services, parent groups such as NebARC shifted their function from providing services to advocating the rights of persons with mental retardation. On March 24, 1972, NebARC created the Committee on the Human and Legal Rights of the Mentally Retarded. The purpose of the Committee was to examine state mental retardation facilities and<sup>12</sup> to report violations of the rights of persons with mental retardation. The Committee reported its findings on July 8, 1972. After a detailed examination of the BSH, the Committee concluded, "... even at<sup>13</sup> its best, Beatrice presents a panorama of warehousing and storage."<sup>13</sup> The Committee criticized the perceived lack of privacy, absence of sanitary conditions, and disregard for resident rights and freedoms. The existing treatment philosophy was readily identifiable: "Custody,<sup>14</sup> instead of development, illustrates the life of a resident at Beatrice."<sup>14</sup> The Committee recommended that the Governor be given 30 days to respond to the allegations. Should the Governor fail to do so, the Committee suggested court action. The determination of the Committee was evident from the report's concluding phrase -- "cooperation yes, compromise no!"<sup>15</sup>

When the Governor did not respond as the Committee wished, NebARC filed a class action lawsuit on September 28, 1972, in the United States District Court for the District of Nebraska. Thus began protracted litigation in the case of *Horacek v. Exon*.<sup>16</sup> The complaint alleged violation of federal civil rights statutes and seven constitutional amendments and sought declaratory and injunctive relief. The defendants, Governor J. James Exon; Director of DPI, Michael LaMontia; Director of Medical Services, Jack Anderson; Director of OMR, William Falls; and Superintendent of BSH, M.E. Wyant, filed a motion to dismiss which Judge Urbom denied on March 23, 1973.

In the succeeding years, the composition of the plaintiffs changed. Initially, the plaintiffs included the Nebraska Association for Retarded Citizens and the parents of five institutionalized youths representing the class of others similarly situated. Because of organized parental opposition to deinstitutionalization and the lawsuit, 69 residents opted

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<sup>11</sup>Nebraska Association for Retarded Children. Report to the Board of Directors by the Human and Legal Rights Committee, July 8, 1972.

<sup>12</sup>Id.

<sup>13</sup>Id., p. 5.

<sup>14</sup>Id., p. 8.

<sup>15</sup>Id., p. 17.

<sup>16</sup>Horacek v. Exon, No. 72-L-299 (D. Neb., filed September 28, 1972).

out of the plaintiff class by July 18, 1975. On June 5, 1974, the Court dismissed the Nebraska Association for Retarded Citizens as a plaintiff for lack of standing (absence of sufficient interest or injury). The Association subsequently joined with the National Center for Law and the Handicapped as amicus curiae (a group with special interest or expertise that the Court allows to file a brief on behalf of one of the parties). On March 28, 1975, the Court allowed the United States Department of Justice to become a plaintiff-intervenor or a party to the action.

The Beatrice chapter of the ARC and others opposed to the lawsuit left the ranks of NebARC and helped form the Nebraska Chapter of the Mental Retardation Association of America (MRAA) (Frohboese & Sales, 1980). Although concerned with human rights, the MRAA Nebraska Chapter opposed the lawsuit on the basis that it would eliminate institutional care as an option, thereby diminishing parental choice in service decisions for their children with mental retardation (Frohboese & Sales, 1980). On August 27, 1975, the District Court granted the MRAA amicus status.

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In 1975, the lawsuit was transferred from Lincoln to Omaha, and the trial commenced before District Judge Albert Schatz. Shortly after the trial had begun, the parties entered into negotiations that resulted in a formal agreement representing a consensus view about how mentally retarded citizens should be served in Nebraska. This agreement, or Consent Decree, was approved by the Court on October 31, 1975. Some of the major features in the detailed agreement included a guarantee of the protection of constitutional rights for residents, the creation of a ~~Mental Retardation~~ Panel to draft a plan of implementation for the terms of the agreement, and a guideline for reduction of the Beatrice State Developmental Center (BSDC) the name was changed July 1, 1975) population from 1,026 to 250 residents within three years.

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The Legislature, however, failed to fund the ~~Mental Retardation~~ Panel before it could prepare the plan of implementation. Eventually, the parties agreed to a substitute panel consisting of three members. By November of 1978, the panel had prepared and presented a plan of implementation to Governor Exon. Charles Thone became governor, however, and drafted substitute plans. On November 10, 1980, the third draft of Thone's plan was submitted to the Court. Supporting the Thone Plan were the plaintiff class, the defendants, the guardian ad litem who had been court-appointed to represent the interests of the residents, and the Nebraska chapter of MRAA. Opposed to the Thone Plan and urging the Court to adopt the Panel Plan were the plaintiff-intervenor United States Department of Justice, the Nebraska Association for Retarded Children, and the National Center for the Law and the Handicapped.

The Court adopted the Thone Plan on September 15, 1981. The Court reasoned that the Thone Plan was realistic and just and conformed to the terms of the initial agreement. The Court found that the Thone Plan possessed a number of advantages over the Panel Plan. First, the Panel Plan required the Nebraska Mental Retardation Panel to supervise the daily implementation of the plan and Consent Decree, thus intruding on state sovereignty. Second, the Court commended the Thone Plan for allowing parental participation in the placement process within the parameters of

the Consent Decree. A third advantage of the Thone Plan concerned the ultimate reduction in population at BSDC; the Thone Plan envisioned a reduction in certifiable residential beds to 344 over a five-year period, as opposed to 250 over a three-year period as suggested in the Consent Decree. The Court concluded from expert testimony that a goal of 250 residents would be an unrealistic and arbitrary minimum that could result in "dumping" individuals, who could be more beneficially served at BSDC, into community programs inappropriate for the individual's needs or prior to the time that necessary community alternatives could be made available. The Court held that the Thone Plan provided a more realistic and feasible goal that would avoid a deleterious "dumping" effect.

The Court pointed out that the Consent Decree did not require a reduction to 250 residents within three years, but rather, if such condition was not met, the burden of persuasion would be on the defendants to show the alternative to be in accordance with the agreement. In the Court's view, the Thone Plan met this burden.

The Plan specified a number of guidelines to direct specific implementation procedures. These included the following: 1) residents were not to be moved from BSDC or the regional centers until alternative services appropriate for the individual were available; 2) placement of each resident required individual evaluation; 3) any transfer of residents required input from parents or guardians; 4) a resident could move to a less restrictive alternative only if personal safety and proper habilitation and care could be guaranteed; 5) to the extent possible, a cross section of institutionalized persons were to be placed in community programs; 6) children should be placed with their natural families; 7) community programs should be designed to serve severely handicapped persons; 8) to the extent possible, each area should provide comprehensive services; and 9) the immediate emphasis should be placed on providing community options for persons without severe handicaps.

These goals were designed to assure the human rights of the individual through an effective system of services. The Plan purported to support the following principles:

- a. The right to have needs adequately met in the manner which least restricts liberty;
- b. The right to receive services necessary to meet basic human needs;
- c. The right to be protected from harm, including the harm caused by not receiving adequate services;
- d. The right to make grievances, if any, and have them resolved speedily and fairly;
- e. The right to be in the mainstream of community life as much as possible consistent with harmonious living and personal health and safety;
- f. The right to be treated according to one's age and needs;

- g. A service system that has reasonable funding within the overall limitations imposed by funds available to operate all aspects of State government;
- h. A service system that has all types of services regardless of severity of disability as close to the local level as reasonably possible and desirable;
- i. A service system that places day-to-day decision-making authority closest to the citizen involved, subject, however, to overall coordination and oversight from the funding level; and
- j. A service system that is open and accessible to public scrutiny.  
(p. 10).

In terms of implementation, the Plan provided for individual evaluation of each member of the class and placement in community programs if deemed the least restrictive treatment alternative. The Plan also called for supervision, evaluation, accreditation, and adequate funding of mental retardation programs. The Plan delegated responsibility to OMR to prepare annual progress reports on the Plan of Implementation and to submit them to the Governor. Five of these progress reports were prepared addressing, point by point, the progress the State had made in implementing the detailed recommendations found within the Plan (Nebraska Department of Public Institutions, 1982, 1983, 1984, 1985a, 1985b). With regard to the lawsuit, the Plan provided that any party may petition the Court for dismissal of the action after June 30, 1982. On December 14, 1983, the defendants filed a motion to dismiss which the Court granted on January 31, 1984.

#### Other Institutions

The human rights and associated deinstitutionalization movement were also reflected in the activities of the church-administered institutions, although less drastically than BSDC. At Martin Luther Home, a prototype cottage was constructed in the late 1960s with plans to build more. With the advent of the deinstitutionalization movement and the emphasis on community programming, further construction was halted.<sup>17</sup> Bethphage Mission served over 300 residents in the early 1970s. Over the next 10 to 15 years, Bethphage underwent its own deinstitutionalization drive and reduced its campus-based clientele to 187.<sup>18</sup> Both entities shifted their emphasis to community-based services.

✓ The mental retardation services provided by the regional centers also felt the impact of the human rights movement. In the 1970's, accreditation and licensing standards were created to assure quality services. One of the primary objectives of these standards was the protection of human rights. To receive Title XIX funds, facilities, including the regional centers, were required to meet ICF/MR licensing requirements.

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<sup>17</sup> Supra, chapter 4, note 12.

<sup>18</sup> Supra, chapter 4, note 20.



In the early 1970s, the Norfolk Regional Center continued to provide services on its mental retardation ward. By 1975, the unit had failed to meet accreditation standards, and thus was not licensed as an ICF/MR.<sup>19</sup> Although improvements were attempted, the 1975 biennial report reflected little hope of meeting the standards without a major construction project. The mental retardation unit achieved licensure for a six-month period in 1976 but, after this period, terminated their program. Some residents were reclassified and absorbed into other Norfolk Regional Center programs while others were picked up by community programs.<sup>20</sup>

At the Hastings Regional Center (HRC), the Developmental Unit for Children (DUC) was licensed as an ICF/MR in November 1977.<sup>21</sup> In an atmosphere of strong anti-institution sentiments, however, government officials and mental retardation advocates, in 1978, suggested eliminating the program.<sup>22</sup> In July 1978, a public hearing was conducted on the campus of HRC by state senators. Parents protested the proposed program termination so vehemently that the suggestion was dropped.<sup>23</sup> However, in 1985, the ~~DUC Unit~~ failed to meet certification from the Department of Health. By November 18, 1985, the ~~Unit~~<sup>DUC</sup> was closed and its 14 residents transferred to the Beatrice State Developmental Center.

In October 1977, the Comprehensive Care Service Mental Retardation Program (CCS/MR) (then called the Comprehensive Care Unit) at the Lincoln Regional Center received accreditation by the Joint Commission on Accreditation of Hospitals;<sup>24</sup> however, in February 1979, accreditation was revoked due to serious violations of the Accreditation Council for Mentally Retarded and other Developmentally Disabled Persons (ACMR/DD) standards, particularly regarding restraint and isolation of a resident. By October 1979, CCS/MR had lost its certification as an ICF/MR by the State Department of Health. Staff changes were made shortly thereafter, and temporary certification was regained for three-month periods starting in late 1979. By 1981, improvements were substantial, and CCS/MR was fully certified for two years. In 1983, CCS/MR obtained certification for three years.<sup>25</sup> On December 20, 1984, the Director of the Department

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<sup>19</sup>Norfolk Regional Center. Seventh Biennial Report: Department of Public Institutions, 1975, 77-84.

<sup>20</sup>Personal communication with Allen McElravy, April 10, 1984.

<sup>21</sup>Hastings Regional Center Biennial Report. Ninth Biennial Report: Department of Public Institutions, 1979, 55-98.

<sup>22</sup>Personal communication with George J. Lytton, April 10, 1984.

<sup>23</sup>Supra, note 21.

<sup>24</sup>Lincoln Regional Center Biennial Report. Ninth Biennial Report: Department of Public Institutions, 1979, 99-112.

<sup>25</sup>Personal communication with Jai Sookram and Terry McElroy, April 10, 1984.

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of Public Institutions, in response to periodic public controversy, low staff morale, and complaints made to the Office of the State Ombudsman, appointed a task force to study CCS/MR. The Director charged the task force with determining how the needs of the 21 persons on the unit could best be met.<sup>26</sup> As a result of funding cuts the CCS/MR program was closed on August 30, 1985, and following the recommendations of the task force the residents were transferred to alternate placements including the Beatrice State Developmental Center, the Nebraska Psychiatric Institute, and community-based programs.

Accreditation requirements made it difficult for some facilities to operate a profitable ICF/MR program. To be financially feasible, these facilities required a large number of clients, but with the mood of deinstitutionalization and the availability of community programs, the programs had difficulty filling their licensed beds. Keahaven in Neligh was licensed as an ICF/MR with a capacity of 24 beds in January of 1977. However, by November of that year it terminated its license. Rest Haven (eventually renamed Sandhills Manor) at Broken Bow was licensed for 24 beds in 1977, but could only attract a maximum of 12 to 15 residents. The facility discontinued the program in 1979.<sup>27</sup> Haven Home in Kenesaw obtained ICF/MR licensure for 12 beds in 1977 and an additional 12 beds in 1980.<sup>28</sup> The program served a maximum of 18 residents and was discontinued in 1981. Blue Valley Lutheran Home obtained ICF/MR licensure for 85 beds in December 1977. The program was discontinued in 1982 because of difficulties in attracting eligible clients and qualified staff.<sup>29</sup> Beighley Care Home in Lincoln was licensed as an ICF/MR in 1976, but had problems meeting accreditation standards. In 1981, the administration of the program was assumed by Bethphage Mission, Inc. Today, the only private ICF/MR not administered by Martin Luther Home or Bethphage Mission is the Omaha Developmental Center (ODC) which attained ICF/MR licensure in 1980. ODC had its license revoked later in 1980, but corrected the deficiencies and obtained relicensure.

The human rights model was the direct force behind deinstitutionalization and improvement of the conditions for those who remained institutionalized. The human rights model continues to be a basic theme today and provides standards by which all services are judged.

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<sup>26</sup>Report of the Task Force on the Comprehensive Care Services - Mental Retardation Unit, Lincoln Regional Center. Lincoln, Nebraska: Department of Public Institutions.

<sup>27</sup>Personal communication with Clarine Dickinson, June 14, 1984.

<sup>28</sup>Personal communication with Bob Williams, June 15, 1984.

<sup>29</sup>Personal communication with Laverne Poppe, June 15, 1984.

## 9. Conclusion

The two models that have the greatest impact upon the present system are the normalization/developmental and human rights models. The community perspective, while initially very influential, was a transitory model that has now been subsumed by the current guiding paradigms. Despite the consensual adoption of these models, diverse perspectives remain.

It is doubtlessly true that in society there are citizens adhering to each of the six models or combinations of these. Some may believe that mental retardation services should be limited to the education of children with mental retardation; others may believe that all persons with mental retardation should receive benevolent custodial care where they can be protected from society; some may still perceive of mentally retarded persons as "different" and, therefore, threatening. Others may propose an extreme form of the community model believing that all persons with mental retardation can and should be served in the community. Still others will form concepts from the current community, normalization/developmental, and human rights models. It is difficult to evaluate the current consensus of the citizenry at this time. The civil rights concern does not appear to be as common as it was 10, 20, and 30 years ago. The developmental model associated with the rise of the humanist philosophy is no longer novel. The community model was a transitory paradigm designed to meet existing needs and has been incorporated into the current perspective. The educational model was a precursor of the developmental model and, hence, has also been incorporated into the new perspective. Although asylum and social control perspectives exist, it is unpopular to express such notions.

The previous guiding philosophies for Nebraska's mental retardation services arose by historical accident. Service designs can be traced to the influence of a general public attitude toward persons with mental retardation or to dedicated groups of individuals that bucked the dominant philosophies with new ideals. From this evolution of historical models, Nebraska has arrived at a service structure that is renowned for the excellence of some of its programs.

It is often easier to identify the models of the past than it is to characterize the dominance of certain thinking in the present. It is clear today in the field of mental retardation that there continues to be strong influence of the ideas of human rights, normalization, and the developmental model. On the other hand, however, there are signs of change and new challenges. Nebraska is embarking on an era where educational models of mental retardation will have guided the response for children with mental retardation, and the adult service system is now currently receiving new clients, the majority of whom have never been institutionalized. On the other end of the spectrum is the aging of the mental retardation population, many of whom in past decades would have never lived to be elderly. New technologies are allowing for innovations in independent living and vocational options. New approaches to services delivery, such as support<sup>ed</sup> employment, offer more opportunities for integration within the main stream of community life. There are still vestiges of community versus institution orientations, but there are also signs that those divisive distinctions are waning and attention is being turned to other challenging problems such as the waiting list, better →

community integration, and more innovative services. A significant characteristic of today is that mentally retarded persons themselves are beginning to have a voice in the construction of societal models regarding mental retardation services. Through self advocacy efforts (Williams & Shoultz, 1982) Nebraska's mentally retarded citizens are putting forth their own models of how one should view the disabilities associated with mental retardation and the way in which those disabilities should be addressed.

Nebraskans have good reason to be proud of the history of commitment that the State has made to its citizens with mental retardation. The problems facing the field of mental retardation today are not insurmountable. As shown by our history, Nebraskans have responded to past challenges of establishing and providing quality mental retardation services. The citizens of this State are at a crossroad. Now ~~is~~<sup>is</sup> the time to take action and plan in a systematic way an effective response to the challenges confronting us.

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