Approved 3-17-83
Date

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Marvin Littlejohn at
Chairperson

1:30 a.m./p.m. on March 14, 1983 in room 423-S of the Capitol.

All members were present except:

Committee staff present: Emalene Correll, Research Department
Bill Wolff, Research Department
Bruce Hurd, Revisor's Office
Sue Hill, Secretary to Committee

Conferees appearing before the committee:

Representative Gary Blumenthal
Representative Sandy Duncan
Ether May Miller, Kansas Association for Retarded Citizens
Dr. Robert C. Harder, Social Rehabilitation Services

Visitor's register, see (Attachment No. 1.)

Chairman called the meeting to order.

Chair recognized Rep. Blumenthal, and he spoke to committee about a request for an Interim study that would focus on recognizing the positive achievements of both state institutions and community facilities, and address gaps in the delivery of services to underserved mentally retarded population. (See Attachment No. 2.)

Rep. Blumenthal's remarks focused on eleven (11) points that could be addressed in an Interim study, and he stated that he had worked along with Dr. Don Horner, Kansas Director of Mental Retardation Services, Dr. Robert Harder, Secretary of SRS, Ethel May Miller and Brent Glazier of the KARC, in urging for this Interim study. Details of Rep. Blumenthal in attachment No. 2.

Rep. Duncan spoke in behalf of the request of an Interim study on Mental Retardation programs as well. As a result of some sub-committee work, he commented, many discussions took place, and he concurs with the suggestion of this Interim study request. The problems of the mentally retarded are not going to go away, and it is important that we as legislators continue to monitor what progress is being made in the areas of legislation requests he commented. This kind of broad base, cross-cutting study that an Interim study could be, is crucially needed. Some basic changes are needed. Some things need to be done. He urged the committee to propose this Interim study and indicate to the leadership that this is a very important request.

Ms. Ethel May Miller spoke from printed statement. Her comments touched on several points of study they felt were needed to fill gaps in areas of need for the mentally retarded. i.e., How to develop, implement, and fund state-community services. How to overcome some of the barriers and reach a balance, etc. (See Attachment No. 3) for details. Ms. Miller further commented that the Kansas Association for Retarded Citizens, Inc., submit these suggestions as being problem areas which an Interim study might address and make recommendations toward solutions to further the reaching of legislative goals and intent related to the mental retardation programs and services.

Ms. Miller noted an important Memorandum prepared by Emalene Correll of the Research Department on programs for the Mentally Retarded. (See Attachment No. 4.) for details of this memorandum.

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 423-S, Statehouse, at 1:30 a.m./p.m. on March 14, 1983.

Dr. Robert Harder distributed a printed statement from the Department of SRS, written by R. Don Horner, PhD, Dr. Harder, Al Nemec, and Gerald T. Hannah, PhD. This print-out states the Kansas Long Range Mental Retardation Plan. See (Attachment No. 5.), for details. Several specific areas are touched upon in this statement, showing there are areas of services that are needed to fill gaps. These specifics will be good examples for committee members to think about and help them to realize what needs are not being addressed currently, Dr. Harder commented. He stated he feels this Interim study being proposed is of critical importance.

Last year the Legislature passed HCR 5054 which laid out several mandates of the SRS. A comprehensive study has been done and a report to the Legislature has been made by their Department, Dr. Harder stated. This proposed Interim study is a logical follow-up to HCR 5054, plus long range plans. This will give the Legislature a chance to review with the SRS and the various community groups, what is going on with the mentally retarded throughout the state. It is an excellent opportunity to be sure the money previously spent in hearings and study will not be lost, and ideas not shelved. The SRS Department gives its full support to this proposed study.

Chairman adjourned meeting at 2:15 p.m.

Date: 3-14-83

GUEST REGISTER

HOUSE

PUBLIC HEALTH AND WELFARE

PLEASE PRINT

NAME	ORGANIZATION	ADDRESS
Janet Schalansky	KPCDD	Topeka
Ethel May Miller	Ks. Assn. for Retarded Citizens	"
AL Nemec	MH&RS — SRS	"
Pat Russell	Budget Division	"
Joan E. Krenkowski	Ks. Assn. for Retard. Inc	Newton
Brent B. Glazier	Kansas ARC	Shawnee
Don Cullen	KANSAS ARC	Hutchinson Ks
R. Don Horner	MH&RS — SRS	Topeka, KS
Gerald Hoeck	MH&RS	Topeka
Robert C. Hard	SRS	Topeka
KEITH R. LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS	"
Lynelle King	KSNA	"
Michele Hinds	Legislative Intern	Topeka
		(attachment No. 1.

2.

GARY H. BLUMENTHAL
REPRESENTATIVE, TWENTY-THIRD DISTRICT
JOHNSON COUNTY
6015 GRANDVIEW
MERRIAM, KANSAS 66202

STATE OF KANSAS

TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
MEMBER: ELECTIONS
INSURANCE
PUBLIC HEALTH AND WELFARE

To: House Public Health and Welfare Committee

Mr. Chairman and members of the committee. On behalf of the Association of Retarded Citizens (ARC) and myself, I am very grateful for this opportunity to address the House Public Health and Welfare Committee regarding continued improvement and refinement of services for the menatlly retarded. Our desire today is to initiate a summer interim study that will focus on recognizing the positive achievements of both state institutions and community facilities, yet also address gaps in the delivery of services to underserved mentally retarded populations.

Mental retardation seems to be one of the most misunderstood yet widespread disabilities. One out of every 10 Americans has a mentally retarded person in his family. According to national statistics, prepared by the ARC, approximately 3% of the population of the United States, or more than six million individuals will be identified as mentally retarded at some point in their lives. Mentally retarded individuals need not, as many believe, be destined to a life of complete and total dependency. The vast majority of mentally retarded may be classified as mildly retarded. These individuals differ from the non-retarded population only in the rate and degree of intellectual development. Their retardation may not be detected until they enter school. Through the support of services mandated by P.L. 94-142, they may receive support and assistance that may result, as adults, in their losing the designation of retarded, as they enter the job market and daily community life.

Moderately retarded persons may manifest developmental delay before they reach school age, yet through appropriate community based education throughout

(attachment No. 2.)

their developmental years, they too can be prepared to live a productive life in the community.

Severely and profoundly retarded persons show the most significant and pronounced developmental problems and may frequently have additional handicaps, such as physical disabilities in addition to mental retardation.

Historically Kansas has been a leader in recognizing and delivering appropriate support to the mentally retarded. Attached is a brief historical background of the Kansas Mental Retardation System, excerpted from the Kansas Long Range Mental Retardation Plan.

Other individuals today will share with you a more detailed description of Kansas State services for the mentally retarded. A past assumption of decision makers regarding mental retardation was that the majority of services to assist the mentally retarded should be focused exclusively upon the state level. Kansas, through the progressive direction of the Kansas Legislature, recognized the inequity of this model and provided direction through the enactment in the 60's of local mill levy authorization and the availability of state aid to supplement local funds for community MR programs. Thus through this direction state mental retardation hospitals saw a tremendous decrease in their average resident population from the late 60's through 1980. (Attachment) 1980-82, however, there has been a reversal in the trend of decreasing population in state MR facilities.

Much emphasis has been made on increasing the availability of the community MR programs. Parents of the mentally retarded have become more assertive in recognizing that their children need not fall into the two extremes of those who are profoundly retarded, thus served in a state institution away from the family unit and home community, or those who are easily served in a local community based program. Parents of retarded who might not have fit easily into either category have often become estranged from the state and local MR system because of their fear of the loss of their child, the distances of services

available, and the varied quality of services available. As a result many retarded have never been adequately served by MR programs, some are cared for by parents whose ability to care for them becomes less viable as the parents age and the retarded son or daughter faces an uncertain future.

It is my desire that an interim study focus on those individuals who may have fallen through the gap of services offered by the state. Examples range from the case of aging parents in their 70's who still care for their 40 year old retarded child, to the numerous formerly institutionalized MR clients who now are served by community programs who are jeopardized by increasing clientele and community expectations, without a similar increase in funding and support.

In consultation with SRS, the Division of Mental Retardation, the Kansas Association for Retarded Citizens and Community Living Opportunities, it is my sincere hope that the Legislature through an interim study will focus on the following areas:

1. Mentally retarded individuals not currently served by state or local MR programs, but in need of services.

2. Mentally retarded adults currently living at home with aging parents.

3. Mentally retarded adults whose aggressive behavior might threaten their community placement.

4. Mentally retarded children in special education programs who, while adjusting well in a day program, are creating difficulties with siblings, parents and neighbors.

5. Mentally retarded children succeeding in local special education programs, but whose family situation may require an out of home placement.

6. Mentally retarded adults whose degree of handicap is such that they cannot participate in programs of work adjustment or work activity.

7. The servicing of 16 years of age and younger developmentally disabled in local community living programs.

8. A system for placing and maintaining the placement of hard to place individuals or persons with a multiplicity of handicaps.

9. Development of community services for those who are mentally retarded and emotionally disturbed.

10. Standardization of admission and discharge criteria, to assure that persons are adequately served as program criteria indicates.

11. Follow-up procedures to monitor placement.

I am concerned that the focus of an interim study address the spirit of cooperation suggested by the 1982 Legislature in HCR 5054, which called upon state institutions and community based programs to develop positive cooperative programs to guarantee delivery of as full a range of needed services and programs as possible.

I wholeheartedly concur with the suggested study proposed by the KARC, and have worked cooperatively with Dr. Don Horner, Kansas Director of Mental Retardation Services, Dr. Robert Harder, Secretary of SRS, Ethel Mae Miller and Brent Glazier of the KARC, in developing these study areas. I sincerely hope we will have your support in our call for an interim study.

SECTION II: The Kansas Mental Retardation System

Part A. Historical Background.

The state's first institution for the mentally retarded was established in Lawrence in 1881. Three years later, it was moved to Winfield and has been in continuous operation since that time. In 1899, the establishment of a state hospital in the southern part of the state to care for and treat the epileptic and insane epileptic of Kansas was authorized. The Parsons State Hospital was opened in 1903 and in 1909 the name was changed to the Parsons State Training School. In 1957, to more accurately connote the active treatment programs that had been developed at both Parsons and Winfield, the names were changed to Parsons and Winfield State Hospitals and Training Centers, respectively. In 1959, the Kansas Neurological Institute (KNI) was established in buildings formerly occupied by the Winter Veterans Administration Hospital in Topeka. Finally, in 1963 the legislature established a facility for the mentally retarded at the former Tuberculosis Hospital in Norton. This institution was officially named Norton State Hospital by the 1967 Legislature.

The state's system of community-based programs for the mentally retarded/developmentally disabled evolved following the formation of local associations for retarded citizens (ARCs) in the mid-1950's. With the realization that the state's institutions for the mentally retarded served but 3% or 4% of the state's mentally retarded citizens, the ARCs urged a joint assumption of responsibility for services on behalf of the remaining 96% to 97% of such persons. By the 1960's the statewide efforts of the Kansas Association for Retarded Citizens led to increased public and legislative recognition of the need for a new approach to the provision of services for mentally retarded persons.

The availability of state aid to supplement local funds was authorized by the legislature (for community day care centers for the mentally retarded and physically handicapped) in 1965. With the passage in 1974 of legislation authorizing state aid (popularly termed "649" funds) not to exceed 50% of the total eligible (local) income of mental retardation facilities receiving local mill levied support, the previously authorized state aid was discontinued and funds combined with the "649" appropriation.

Local mill levied funds in support of community mental retardation services were first authorized in 1969 at one-half mill, with an additional one-quarter mill for purchasing or constructing and equipping a facility. In 1977, the maximum mill levy for operating services was increased to three-quarter mill. The 1982 Legislature has made it possible to increase the levy to one mill.

Through local initiative, many of the agencies in non-metropolitan (or in less populated) areas merged together or contracted with each other to form a center. Ten counties formed centers for their county alone, twelve centers were formed to serve a two-to-four county catchment area, and five centers were established to serve a five to eighteen county catchment area. At the end of 1981, 98 of Kansas' 105 counties provided funds for a total of 29 community-based agencies for mentally retarded/developmentally disabled persons.

Part B. Descriptive Statistics Concerning the Population of Kansas, 1980.

Before an accurate picture can be drawn concerning the future of mental retardation services in Kansas, it is necessary to describe services as they exist. In order to access as complete a body of data as possible, 1980 was selected as the base year with more recent data provided when available. To provide an indication of the predominately rural nature of the state, it should be pointed out that in 1980, 809,135 Kansans or 34% of the total population of the state lived in three counties: Wyandotte, Johnson and Sedgwick. If counties with a population of around 50,000 or over are included (i.e., Leavenworth, Douglas, Shawnee, Riley, Reno and Saline) the total rises to 1,263,893 or 53% of the population.

The total population of Kansas in 1980 was 2,363,208. Of this number, it can be stated with a reasonable degree of certainty that at least 53,880 had some degree of mental retardation. Further, 28,566 of these individuals were residents of nine of the 105 counties. Of the 53,880 mentally retarded citizens in Kansas, 9% or 4,849 were pre-school age (birth through 5), 31% or 16,703 were school age (6 through 20), and 60% or 32,328 were adults (21 and over).

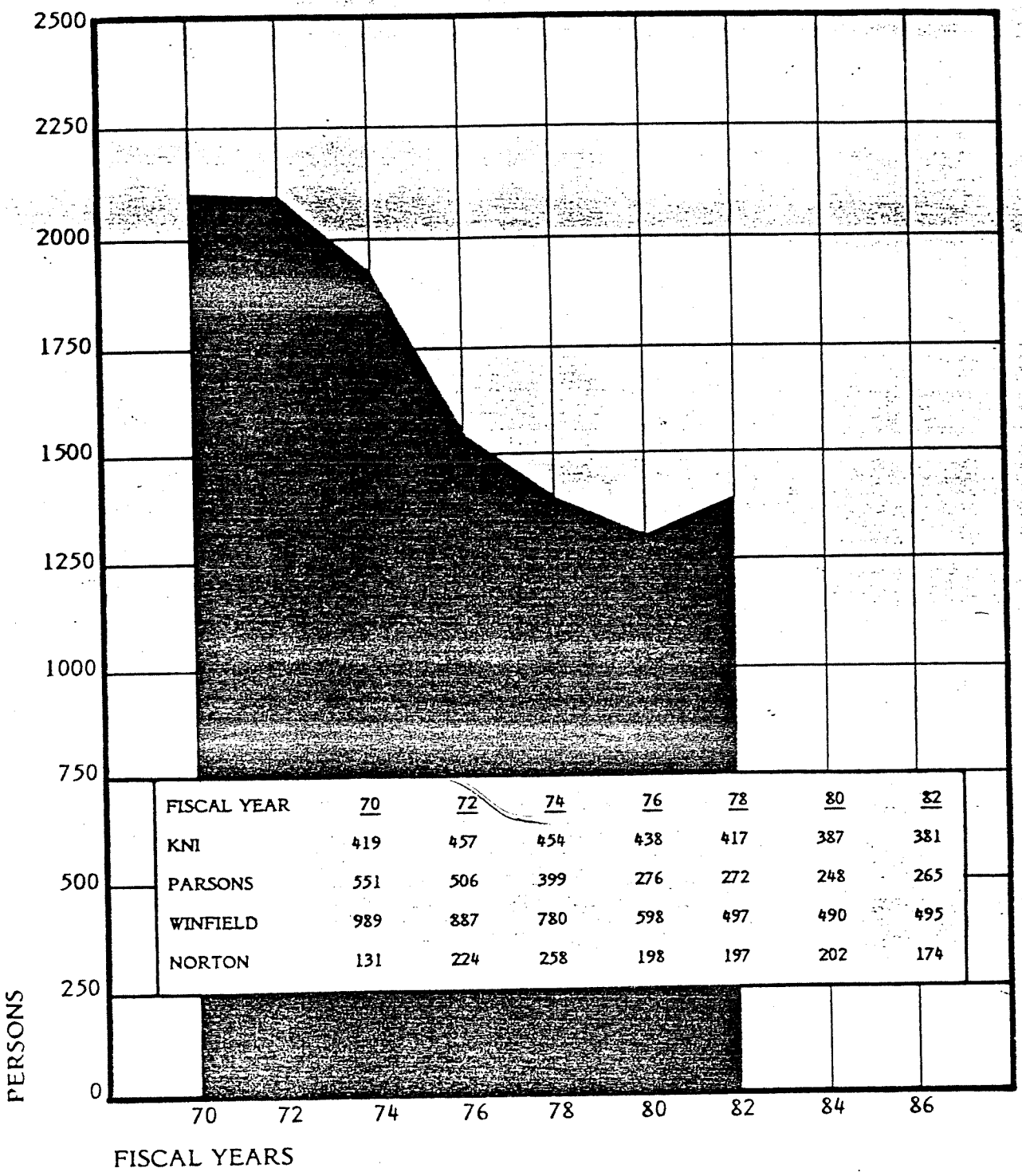
Part C. Descriptive Statistics on Services to Mentally Retarded in Kansas, 1980.

In Kansas, services for the mentally retarded operate through two major paralleled systems: state institutions and community-based programs. The four institutions for the mentally retarded in Kansas are viewed primarily as offering inpatient care to the severely and profoundly mentally retarded whereas the twenty-nine community mental retardation agencies are viewed as offering a variety of services in the community as an alternative to institutionalization.

The following indicates some overall statistics on services to mentally retarded citizens. In 1980 through both public and private state and community mental retardation facilities and programs, 14,629 individuals received services as follow:

- 102 - foster care
- 154 - private institutions
- 627 - intermediate care facilities
- 1,385 - state mental retardation facilities
  - 205 - Norton
  - 283 - Parsons
  - 393 - KNI
  - 504 - Winfield
- 1,724 - rehabilitation services
- 3,265 - community MR/DD facilities
- 7,372 - special education programs.

AVERAGE RESIDENT POPULATION STATE MENTAL RETARDATION HOSPITALS



FISCAL YEAR	70	72	74	76	78	80	82
KNI	419	457	454	438	417	387	381
PARSONS	551	506	399	276	272	248	265
WINFIELD	989	887	780	598	497	490	495
NORTON	131	224	258	198	197	202	174

KANSAS
ASSOCIATION FOR RETARDED CITIZENS, INC.
11111 WEST 59th TERRACE
SHAWNEE, KANSAS 66203
(913) 268-8200

To: House of Representatives March 14th, 1983
Public Health & Welfare Comm.
Marvin Littlejohn, Chairperson

Re: Possible Study - Mental Retardation Programs

Brief background of involvement of Kansas Assn. for Retarded Citizens relating to state institutions, and the development of community-based services. (From Kansas Long Range Mental Retardation Plan, July, 1982, Page 7.)

We agree with the description in the Kansas State MR Plan of the four major problems encountered by the movement to establish a coordinated continuum of services delivery rather than relying on state institutions as the primary treatment and residential service option. (page 15.)

1. Inappropriate community placements that result in exploitation of the client and, in some instances his or her return to an institution.

2. Anxiety among parents and families of mentally retarded persons who reside in institutions because they fear that the state may abdicate responsibility for their family member.

3. Continued competition for funds between institutions and community programs.

4. Inadequate fiscal and other incentives to encourage the full array of resources required in the community to meet the needs of the mentally retarded.

Another problem, we might add, is that the pressures in the community for services come not only from the state to serve those in order to reduce institution populations, but from those who recognize both the need and the right of their son or daughter to be served within or very near their home community, the latter accounting for about 97% of the state's population of retarded citizens.

These continuing problems, plus the following which do relate to the above, are problems we suggest might best be addressed thru an interim study in order that recommendations might be made toward solution:

1. How to develop, implement, and fund services in priority or gap areas of need, ~~not only~~ for those unserved, or on waiting lists, or inappropriately, or

(Attachment No. 3.

underserved, or in services either too restrictive, or not restrictive enough to aid the individuals in their growth and development. What incentives, or requirements to do so?

a. Hard to place individuals, or persons with a multiplicity of handicaps. The dual diagnosed persons, those both emotionally disturbed and mentally retarded, those both severely physically handicapped and mentally retarded, etc.

b. Community residential services for severely retarded and multi-handicapped children under age 16.

c. Community residential programs in sufficient number to be able to serve as needed those adult retarded who have always lived within the family home, but whose parents are

2. How to develop, implement, and fund into the state-community service a system of linkages or follow-along to assure that individuals get from "here to there", and are not simply dropped, or terminated, or lost in the shuffle, or worse still, end in jail awaiting emergency admission to an institution.

3. How to overcome some of the barriers in achieving such suggested solutions as "regionalization", "balance"in accountability in programming and budgeting, and funding etc. in view of the combination of boards, authorities, and funding sources involved in community center services operations.

4. How to clarify the various criteria or boundaries for enrollment or admission into community services. One concern is that as public school special education services and/or vocational rehabilitation services refer more and more of their students or clients into the more restrictive work adjustment-work training programs of community centers , those the community center services were originally designed and funded to serve are left on waiting lists. (Those ineligible by reason of age, or level of functioning for existing education and rehabilitation services.)

   What is more, these are the persons the additional tax monies (to education and rehabilitation dollars) such as county mill levy and state aid "649" monies were originally appropriated to serve.

We concur with the reminders issued thru the division of mental retardation that:

1. ". . .the community-based services program is still very much in in its infancy and is still in need of expansion and development.

2. "The wide variation in the ages, functional capacities and types of disabilities represented by those in need of services requires that a comprehensive range of living and program settings be available."

3. "As the state continues to reduce its reliance on state institutions as the single living and program setting for those who happen to be mentally retarded or otherwise developmentally disabled, state policy should continue to be aimed at stimulating a balanced continuum of residential and programming alternatives."

4. "The overall goal of state policy should be to create a community-based service system that:

   (a) Uses finite tax resources in the most efficient and economical manner.

   (b) Facilitates providing services to clients in the setting that is most appropriate for maximum growth and development."

We submit our suggestions as being problem areas which an interim study might address and make recommendations toward solutions to further the reaching of legislative goals and intent related to mental retardation programs and services.

Respectfully submitted,

Ethel May Miller

Ethel May Miller, Chr.
State Legislative Affairs

Brent Glazier, Exec. Dir.
Kansas Association for
Retarded Citizens, Inc.

4

MEMORANDUM

February 18, 1983

TO: Representative Jessie Branson

FROM: Kansas Legislative Research Department

RE: Programs for the Mentally Retarded

Significant Dates - State Institutions

1. The first residential care facility for the mentally retarded was established by the Legislature in 1881 when, what is now known as Winfield State Hospital and Training Center was authorized. The 1881 Legislature was acting under the assumption that there were 49 mentally retarded children under 15 years of age in Kansas when it voted to create Winfield as a facility for the mentally retarded.

2. Norton State Hospital and Training Center was primarily an institution for the diagnosis, treatment, care and disposition of tuberculosis from its opening in 1915 to 1963. From June 1963 to June 1970, the hospital served a dual role, caring for both tuberculosis and mentally retarded cases. In-patient tuberculosis care was terminated in April of 1968 and outpatient care in June of 1970. Since that time the hospital has provided evaluation, diagnosis, care, and training exclusively for a mentally retarded population.

3. Parsons State Hospital and Training Center, known as Parsons State Training School when it was established in 1953 in buildings that dated back to 1900 when they were used as a hospital for epileptic patients, began providing treatment, care and training for the ambulatory mentally retarded in 1953.

4. The Kansas Neurological Institute (KNI) was estalbished by the Legislature on July 10, 1959, and the first resident was admitted in January 1960.

5. For current capacity of the mental retardation institutions by program see Table I attached. For budget and appropriation information see Attachment No. 1.

Significant Dates - Community Programs

1. K.S.A. 19-4001 et seq., was enacted in 1961 to authorize the board of county commissioners of any county to establish and operate or join with other counties to establish and operate community mental health centers, including the authority to make a property tax levy for such mental health centers and programs. The act was amended by the 1970 Legislature to add authority for community facilities for the mentally retarded and to authorize a separate tax levy therefor.

2. In 1961, the Legislature enacted K.S.A. 76-170 which authorizes outpatient evaluation, care and treatment for persons who are not admitted as regular in-patients to state mental hospitals, state hospitals and training centers and KNI, including authorization to charge a fee for such outpatient services.

(Attachment No. 4.)

3. In 1965, K.S.A. 39-1001 through 39-1008 were enacted. These statutes authorize a grant-in-aid program, administered by the Secretary of Social and Rehabilitation Services, whereby federal funds made available to the state and any other funds may be made available to local community organizations for day care programs for mentally retarded or other handicapped children. (Currently, there is no funding for this program.)

4. In 1973, the Kansas Legislature enacted K.S.A. 39-3901 et seq. (sometimes known as the 577 grant program) under which grant funds are made available through the Department of Social and Rehabilitation Services to assist with the start-up costs of community-based group boarding homes or community-based services for children and youth. K.S.A. 39-1305 defines eligible community-based group boarding homes as those that provide 24-hour-a-day care and shelter, evaluation, diagnosis, treatment, education, and rehabilitation to adjudicated delinquent, emotionally disturbed, mildly retarded, developmentally disabled and dependent and neglected youth.

5. In 1974, the Kansas Legislature enacted K.S.A. 65-4401 et seq., the act which provides for state financial assistance for community mental health programs and community facilities for the mentally retarded.

6. In 1975, the federal agency that administers the federal portion of Title XIX (Medicaid or Medical Assistance) developed rules and regulations that prohibited persons whose primary diagnosis is mental retardation from placement in a nursing home setting that is primarily for geriatric or medical residents. The rules and regulations set a deadline of July 1, 1980 by which full compliance with the regulations was required to be met. See Table No. II for data on bed size and number of licensed and certified ICF/MR facilities.

7. Kansas initiated Project Reintegration in 1974-75 under which persons who were residents of state mental health and mental retardation facilities were evaluated as to the level of care needed by such persons and as to their ability to function in less restrictive environments. During 1975 and succeeding years, residents found to be appropriate for less restrictive placement were discharged from state institutions and placed in community programs or facilities.

Significant Dates - Education of the Developmentally Disabled (Kansas)

1. Kansas has recognized a commitment to exceptional children in Kansas schools since 1949 when a special education division was created within the State Department of Education.

2. The first state appropriation for reimbursement of school district special education programs was distributed in FY 1952 ($80,000) for 19 classes for the mentally retarded and 60 homebound instruction programs. In FY 1983, the state categorical aid for special education is $58.5 million.

3. Until 1969, legislation regulating the establishment of special education was permissive. In 1969, the Legislature required school districts to provide educational services for mentally retarded children by July 1, 1974. In 1971, the mandate was extended to include cerebral palsied and epileptic children and to define the term, developmentally disabled, to describe all the mandated categories.

4. In 1972, the Legislature authorized the State Board of Education to determine the exceptional conditions included within the term, developmentally disabled, and thus within mandated special education, by rule and regulation.

5. The 1974 Legislature revised the special education laws and established a July 1, 1979 mandate for the provision of special education services to all exceptional children (handicapped and gifted). (The July 1, 1947 mandate implementation date for services for the developmentally disabled was not changed by the 1974 legislation.)

6. A 1979 amendment delayed the mandate for gifted pupils by one year — from July 1, 1979 to July 1, 1980. Thus, the 1980-81 school year was the first in which mandated services for all exceptional children were required to be in effect.

Significant Dates - Education of the Developmentally Disabled (Federal)

1. The federal Elementary and Secondary Education Act of 1965 established a federal commitment to the development of programs for educationally deprived children.

2. In 1966, the 1965 act was expanded by the addition of a new Title VI under which assistance was made available to the states for the initiation, expansion, and improvement of programs for handicapped children.

3. In 1970 the Education for the Handicapped Act was passed to replace the 1965 and 1966 legislation. The major thrust of the 1970 act was the development of educational resources and personnel training for the handicapped.

4. Amendments added to the Education for the Handicapped Act in 1974 provided for basic due process, educational services in the least restrictive environment, and state plans.

5. In 1975, additional amendments, among other things, articulated a national goal of providing handicapped children with a free, appropriate public education.

Programs Directed Toward Preventing Handicapping Conditions

1. One of the earliest of the programs aimed at preventing handicapping conditions was the statutory mandate that certain children be immunized prior to entering school or on entering school. In the early 1960's, the mandatory immunization requirements were extended to include measles, a childhood disease which may result in brain or nerve damage and other handicapping conditions.

2. An early predecessor of the WIC (Women, Infants and Childrens Supplemental Nutrition) Program, known as just the Supplemental Food Program was initiated on a limited basis in Kansas in the early 1960s. In 1973, federal funds became available for the WIC Program which has been expanded over the years to include additional areas in Kansas. The WIC Program is aimed at assuring proper nutrition for pregnant females and their children in order to prevent nutrition-deficient conditions, low birthweight, and resultant handicapping conditions.

3. Migrant health programs were initiated as early as 1963 in one area of Kansas. There are now several programs in the state that provide health care and nutrition assistance to migrants and their children. The programs are aimed at the early detection, and treatment or prevention of health and nutrition problems that may have long-term health effects.

4. Family planning programs, including counseling and genetic counseling were first initiated on a limited scale with all state funding in 1965. In 1968 some OEO funds were allocated to family planning and, in the early 1970s Title X federal funds became available for assistance for family planning services. Among other services, family planning programs attempt to provide counseling about the higher risks associated with very young pregnancies and resultant low-birthweight, high-risk infants.

5. In 1965, the Kansas Legislature enacted legislation mandating PKU testing of newborns to identify PKU infants in order that treatment might be initiated to prevent the damage that may result from untreated PKU conditions. Those statutes were amended in the 1970s to include congenital hypothyroidism and other conditions that may be identified from the same testing procedures as mandated tests for newborns.

6. In 1966 or 1967, several low-income children and youth projects were initiated in Kansas. These projects were aimed at providing health screening, health care and multi-disciplinary outpatient services for children and youth ages 0 to 21.

7. In 1974, the first of the teen-age pregnancy maternal and child health projects were initiated. These projects now are available in additional counties in the state and are specifically aimed at preventing low-birthweight pregnancies, providing special services for high-risk teen-age pregnant females, and preventing abuse or neglect of newborns and infants who have teen-age mothers or parents.

8. Other preventive programs include poison control programs, and child passenger safety restraint programs.

Adoption Support

In 1972, the Kansas Legislature enacted the Adoption Support Act of 1972, K.S.A. 38-319 et seq. under which the state provides financial assistance to the adoptive parents of hard to place children. To be eligible for such support the child must be hard to place in adoption because of society's attitudes about his age; racial or ethnic background; mental, emotional or physical handicap; or membership in a sibling group and have resided in a foster home or child care institution or be likely to be placed in such facilities.

5

STATE OF KANSAS
JOHN CARLIN, *Governor*

STATE DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

MENTAL HEALTH AND
RETARDATION SERVICES

ROBERT C. HARDER, *Secretary*

STATE OFFICE BUILDING
TOPEKA, KANSAS 66612
(913) 296-3774
KANS-A-N 561-3774

24 February 1983

DR ROBERT C HARDER, SECRETARY
SOCIAL AND REHABILITATION SERVICES

R Don Horner, PhD
Al Nemec
Gerald T Hannah, PhD

EXAMPLES OF SERVICES THROUGH COMMUNITY-BASED PROGRAMS, NEEDED BY SELECTED SUBCATEGORIES OF INDIVIDUALS WHO HAPPEN TO BE MENTALLY RETARDED OR OTHERWISE DEVELOPMENTALLY DISABLED, THAT SHOULD BE ADDRESSED BY AN INTERIM STUDY

As pointed out in the Kansas Long Range Mental Retardation Plan, the community-based service program "is still very much in its infancy" and "is in need of expansion and development." The wide variation in the ages, functional capacities and types of disabilities represented by those in need of services requires that a comprehensive range of living and program settings be available. Therefore, as the state continues to reduce its reliance on state institutions as the single living and program setting for those who happen to be mentally retarded or otherwise developmetally disabled, state policy should continue to be aimed at stimulating a balanced continuum of residential and programming alternatives (eg group homes, apartment units, specialized foster family homes, in-home support services; respite care, etc). Similarly, in the area of daytime habilitative services, the emphasis should be on providing a broad range of programming options (infant stimulation and early intervention services, school-based programs, adult activities services, sheltered workshops, on-the-job training, etc). The overall goal of state policy should be to create a community-based service system that : (a) uses finite tax resources in the most efficient and economical manner, and (b) facilitates providing services to clients in the setting that is most appropriate for maximum growth and development.

(attachment no. 5.)

There are several subcategories of mentally retarded and other developmentally disabled individuals who do not fit easily into the current range of community-based services yet are generally not considered as appropriately placed in an institutional program. The subcategories of individuals can be described as follows:

1 Mentally retarded children in local special education programs who, while adjusting well in their day program, are creating difficulties with siblings, parents and neighbors.

A typical case involves a child who disrupts the family setting by making excessive demands of parents, damages property, embarrasses siblings, and is viewed negatively by relatives, friends and neighbors. This and similar situations could be helped through family support services such as parent counseling, training and respite care. Such support could prevent or at least delay the necessity for an out-of-home placement.

2 Mentally retarded children in local special education programs who, while adjusting well in their day program, are in a family situation that requires an out-of-home placement.

A dramatic case involves a severely-multiply handicapped child who is making progress in a special education program but is one of four children of a divorced mother who works ten hours a day, six days a week in a laundry. The mother must arrange before and after school day care for her children as well as meet the caregiving required by her severely handicapped child (medication administration, bathing, range of motion exercises, positioning, etc). In addition, she must attend to her normal children--all after having worked hard, long hours at the laundry. The only available out-of-home placement is a state institution. While the mother does not want to take her child out of the special education program and believes strongly that her child's personal needs will not be met in a state institution, exhaustion and her inability to meet the needs of her three normal children may force her to seek institutional placement. This and similar situations could be eased if small community residential facilities for severely handicapped children were available in at least such urban areas as Kansas City, Topeka, and Wichita.

3 Mentally retarded adults who are in community-based programs of work activity but live at home with aging parents.

A typical case invovles a man and woman both in their early seventies and retired. Their mentally retarded adult offspring, in his late forties, is doing well in the workshop program and with the exception of brief hospital stays and summer camps has spent his entire life at home. The mother has terminal cancer and the father has a serious heart condition. There are only 24

residential placements available in the catchment area served by the center and their son has been repeatedly passed over for placement due to the fact that (a) he requires insulin injections for diabetes and (b) there is a waiting list of applicants who do not require the availability of medically trained staff. The parents are extremely concerned about their son's future once they are no longer around or reach the point where they themselves will require considerable assistance. This and similar situations could be helped through the increased availability of group homes and increased availability of group home staff certified to administer medications.

4 Mentally retarded adults whose degree of handicap is such that they cannot participate in programs of work adjustment or work activity.

A typical case involves a severely retarded adult who was never accepted in any program of training outside the home. The parents, in their mid fifties, inquired about the availability of training through the local community-based agency. The results of a vocational evaluation indicates that the young woman's degree of retardation requires a program focusing on learning activities of daily living such as table manners, proper grooming, social interaction, etc. Since the agency does not have such a program, the family was referred to a private ICF/MR program in another part of the state. The family was told that their daughter did not require the level of care provided by that type of facility. They continue to make inquiries as to when an appropriate placement might be available. This and similar situations could be helped through the increased availability of adult day - training programs focusing on activities of daily living.

5 Mentally retarded adults whose behavior is erratic, eccentric disruptive, and/or aggressive and is judged to be potentially dangerous to themselves, other residents and/or staff.

A typical case involves a large, moderately retarded adult female who performed well in the work setting but in the residential program occasionally wandered off and had to be found, verbally abused other residents and staff, insisted on wearing several layers of clothing, pounded on windows when asked to do something she didn't want to do, pushed other residents and staff out of the way to be first on and first off the bus, and stole food from other residents' lunch boxes. Over time, several members of the staff came to fear that she might harm herself; other residents; or smaller older female staff members and asked that she be removed from the program. Efforts were made to convince the staff that they could cope with her until, after being reprimanded, she broke a number of windows in the home. The client was terminated from the residential program and was taken in by her sister and brother-in-law. This and similar situations could

be helped through the increased availability of small group homes with intensive training programs, implemented through well trained staff and appropriate staff to resident ratios, as well as the availability of professional support staff for consultation on specific problems.

These are the major subcategories of individuals who are often unserved or underserved through community-based services, yet do not necessarily require placement in a state institution. There are other groups such as the nonambulatory that are difficult to accomodate due to rigorous fire and safety standards, but individuals such as those in the examples provided above represent the greatest need for expansion and development. The programs at the state institutions for the mentally retarded are designed to serve those whose medical and behavioral deficits require twenty-four hour a day availability of and supervision by highly-trained professional and paraprofessional: (a) medical personnel, and (b) developmental specialists.

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