Date

MINUTES OF THE HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES.

The meeting was called to order by Vice-Chairperson Jo Ann Flower at 3:30 p.m. on February 13, 1995 in Room 522-S of the Capitol.

All members were present except: Representative Pottorff, Excused

Committee staff present: Patricia Pierron, Legislative Research Department

Emalene Correll, Legislative Research Department

Gordon Self, Revisor of Statutes

Marian F. Holeman, Committee Secretary

Conferees appearing before the committee: Gordon Self, Revisor of Statutes

Jane Rhys, Exec.Dir., KS Developmental Disabilities Council

Mark Elmore, Exec. Dir. JoCo MRC

Others attending: See attached list

The meeting was opened for hearings on <u>HB-2458 an act enacting the developmental disabilities</u> reform act; prescribing certain powers, duties and functions for the secretary of social and rehabilitation services. Gordon Self, Revisor of Statutes, offered the bill briefing (Attachment 1).

Question was raised as to the need for this bill. Briefly, the answer is that as drafted, there are two aspects to the bill. One is to deal with services that are to be developed for persons with developmental disabilities. Two it lays out the service delivery mechanism. It spells out the direction the state would be going and provides specific delivery mechanism for provision of those services. It sets up a framework to close gaps, to provide uniformity in statewide services for persons coming out of institutions as well as all other services for the developmentally disabled in the State of Kansas. This bill deals with certain aspects of a total system relating to the developmentally disabled, but it does not deal with the front end which is prevention services/early intervention nor on the other end of the spectrum does it deal with services for the elderly. The bill is seen as a beginning framework which will evolve into a total system over a period of time. Speaker Tim Shallenburger believes this is an issue that should be addressed.

Jane Rhys, Executive Director, Kansas Developmental Disabilities Council (<u>Attachment 2</u>). She will provide balloons with specific language on suggested amendments.

Mark Elmore, Executive Director, Johnson County Mental Retardation Center (<u>Attachment 3</u>). Discussed community board memberships, local control, etc. Discussed problems involved with Tara-Mara closure and what needs to be done to prevent recurrence of such an event. Does this bill address that issue? Suggested changes to Section 6.

The next committee meeting will be February 15, 1995 at 3:30 p.m. in Room 522-S.

The meeting adjourned at 5:00 p.m.

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: February 13, 1995

NAME	REPRESENTING	
Sherry Diel	Kansas Advocacy & Protective Selvice	9
ROGER RAMSEYER	Hutchiuson HEIGHTS/Presbyterus	Marcor.
Tom Laina	Ks Assoc of Rehab Facilities	(KARF)
Mark Etmare	Jo. Co. M.R. Cartes	
Martha Holgesmill	KARF	
Larry Hinton	SRS	
The honninger Hosen	KS ASSOC OF SCHOOL BOARDS	
Dawin Hey il	SRS/MH4RS	
Robert S. Seew	The as & KAMSAS	
Josio Torrez	Families Together In	,
Jan Torrez	Consumer	
Sina Micharald	KACIL	
1 2me Rhan	KCDD	
Dong Bowman	Coordinating Council on Early Childhou	d Dev. Suc.
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NORMAN J. FURSE, ATTORNEY REVISOR OF STATUTES

ARDEN K. ENSLEY, ATTORNEY FIRST ASSISTANT REVISOR

JAMES A. WILSON III. ATTORNEY SENIOR ASSISTANT REVISOR

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GORDON L. SELF, ATTORNEY
JILL A. WOLTERS, ATTORNEY
ROBERT J. NUGENT, ATTORNEY

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SECRETARY—KANSAS COMMISSION ON INTERSTATE COOPERATION
KANSAS STATUTES ANNOTATED EDITING AND PUBLICATION
LEGISLATIVE INFORMATION SYSTEM

COMPUTER INFORMATION STAFF MARY O. CHENG, M.S. RICHARD M. CHAMPNEY, B.S.

To: Select Committee on Developmental Disabilities

From: Gordon Self, Assistant Revisor of Statutes

Date: February 13, 1995

Re: Explanation of House Bill No. 2458, The Developmental Disabilities Reform Act

House Bill No. 2458 enacts a developmental disabilities reform act and prescribes certain powers, duties and functions for the secretary of social and rehabilitation services related to the act. The bill contemplates a shift from the current service center model to an individual support model. The community developmental disability organization is charged with ensuring that the provisions of this act are carried out and persons with developmental disabilities are assisted in accessing services contemplated by the law.

Section 1 (p. 1, lines 14 through 22):

This section contains statements of legislative policy or purpose related to the assistance to and access of persons who have a developmental disability related to specified services and supports and the same opportunities, dignity and respect as persons who do not have a developmental disability.

Section 2 (p. 1, lines 23-43, p. 2 lines 1-33):

This section contains definitions of terms used throughout the new act. The definition of developmental disability (p. 2, lines 4-19) is a modified version of the same term as defined in public law 130-230, the developmental disabilities assistance and bill 1994. of rights act of Community developmental disability organization (p. 1, lines 33-43, p. 2, line 1) is defined as an entity organized pursuant to K.S.A. 19-4001 et seq., related to community facilities for the mentally retarded and describes its duties as being a point of referral services and ensuring that persons with developmental disabilities have basic opportunities; provide services directly or by subcontract; and provide referral services to persons whose needs may be met in the community, directly or by subcontract.

House Select Committee on dilities Developmental Disabilities 2-13-93 Attachment

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Section 3 (p. 2, lines 34-43, p. 3, lines 1-42):

This section imposes duties upon the secretary of social and rehabilitation services relating to establishing, implementing, administering and maintaining the provisions of this act (p. 2, lines 34-37) in accordance with certain basic principles: Persons with developmental disabilities shall be assisted with obtaining services and support to enable them to determine their own needs (p. 2, lines 38-43, p. 3, lines 1-7).

Specifically, the secretary shall: (1) Propose and implement an annual plan to provide an organized network of community services to reduce reliance on institutions (p. 3, lines 8-16); (2) report to legislature on the number of persons with developmental disabilities, progress of implementation of annual plans and progress made to accomplish an organized network of community services (p. 3, lines 17-22); (3) prepare and submit budget estimates to division of budget and the legislature that provide an allocation of funds that approximate the ratio between the number of persons served in institutions and community services (p. 3, lines 23-34); (4) administer and disburse funds to community developmental disability organizations for the coordination and provision of community services (p. 3, lines 35-38); and (5) establish procedures and systems to evaluate the results of the implementation of this act (p. 3, lines 39-42).

Section 4 (p. 3, line 43, p. 4, lines 1-5):

This section provides that the community developmental disability organization shall be the primary supervisor to ensure that persons with developmental disabilities are provided assistance in accessing community services as provided in this act.

Section 5 (p. 4, lines 6-43 p. 5, lines 1-15):

This section provides requirements related to the full service community service system. The act provides for:

- (1) A system of adequate cost reimbursement for the delivery of community service that persons that move from the institutional setting into the community (p. 4, lines 10-16), consolidates federal and state funding into single rate structure (p. 4, lines 17-18), establishes a community services funding commission to develop, monitor and maintain rate structure for community services (p. 4, lines 19-24) and minimum qualifications of such rate structure (p. 4, lines 25-34);
- (2) a system of accountability that establishes community standards, requires providers to meet such standards and recognizes providers who meet such standards (p. 4, lines 35-43); and
- (3) a system of contracting as the primary implementation tool related to this act (p. 5, lines 1-15). Such system shall authorize open and equitable negotiation (p. 5, lines 3-4),

provide for independent arbitrator (p. 5, lines 5-6), require compliance with community standards established (p. 5, lines 7-8), provides for compensation for community services which meet the individualized needs of persons with developmental disabilities (p. 5, lines 9-12) and require community developmental disability organizations to contract with affiliates that the person with developmental disability chooses (p. 5, lines 13-15).

Section 6 (p. 5, lines 16-28):

This section provides for creation of enforcement and control provisions for the division of mental health and retardation services to utilize when the community developmental disability organizations do not meet the standards set out in law and administrative rules and regulations (p. 5, lines 16-19). Such enforcement and control provisions include inspection and review, issuance of correction orders, probation, suspension and receivership (p. 5, lines 19-28).

Section 7 (p. 5, lines 29-33):

This section provides that the secretary cannot require a community developmental disability organization to make any expenditure that the organization's board did not approve.

Section 8 (p. 5, lines 34-35):

This section provides that the effective date of the developmental disability reform act is July 1, 1995.

It should also be noted that there will need to be numerous technical amendments to the bill that amend existing statutory law to carry out the provision of this bill. The major components of such needed amendments include amendments to statutes related to changing references to community facilities for the mentally retarded to community developmental disability organizations and more specific language related to the enforcement and control provisions specified in section 6.

HOUSE BILL NO. 2452

By Select Committee on Developmental Disabilities

AN ACT enacting the developmental disabilities reform act; prescribing certain powers, duties and functions for the secretary of social and rehabilitation services.

Be it enacted by the Legislature of the State of Kansas:

Section 1. It is the purpose of this act to assist persons who have a developmental disability to have:

- (a) Services and supports which present opportunities to increase the independence and productivity of such persons and the integration and inclusion of such persons into the community;
- (b) access to an array of services and supports appropriate to such persons as individuals; and
- (c) the same opportunities, dignity and respect as persons who do not have a developmental disability.

Sec. 2. As used in this act:

- (a) "Adaptive behavior" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of that person's age, cultural group and community.
- (b) "Affiliate" means an entity or person who contracts with a community developmental disabilities organization.
- (c) "Community services" means services provided to meet the needs of persons with developmental disabilities concerning work, living in the community and individualized supports and services.
- (d) "Community developmental disability organizations" means an entity that is organized pursuant to K.S.A. 19-4001 through 19-4015 and amendments thereto and is organized to:
- (1) Directly or by subcontract serve as points of application or referral for services and to assist all persons with a developmental disability to have access to and an opportunity to participate in community services;

- (2) provide either directly or by subcontract, services to persons with a developmental disability. Contracts shall be with existing community services providers whenever appropriate; and
- (3) provide directly or by subcontract referral services to persons with a developmental disability whose particular needs can be met in the community or through other government agencies.
- (e) "Community services provider" means a community developmental disability organization or affiliate thereof.
 - (f) "Developmental disability" means:
 - (1) Mental retardation; or
- (2) a severe, chronic disability, other than mental retardation or mental illness, which:
- (A) Is attributable to a mental or physical impairment other than a mental or physical impairment caused solely by mental illness;
 - (B) is likely to continue indefinitely; and
- (C) results in: (i) In the case of a person under three years of age, at least one developmental delay; or (ii) in the case of a person three years of age or older, a substantial limitation in three or more of the following areas of major life activity, as appropriate for the person's age: Self-care, receptive and expressive language development and use, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; or
- (3) a condition which has received a dual diagnosis of mental retardation and mental illness.
- (g) "Institution" means state institutions for the mentally retarded as defined by subsection (c) of K.S.A. 76-12b01 and amendments thereto or intermediate care facility for the mentally retarded of 15 beds or more as defined by subsection (p) of K.A.R. 30-10-200 and amendments thereto.
- (h) "Mental retardation" means substantial limitations in present functioning that is manifested during the period from birth to age 18 and this is characterized by significantly subaverage intellectual functioning existing concurrently with

deficits in adaptive behavior including related limitations in two or more of the following applicable adaptive skill areas: Communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work; and

- (i) "Secretary" means the secretary of social and rehabilitation services.
- Sec. 3. (a) Except as otherwise specifically provided in this act, the secretary of social and rehabilitation services shall establish, implement, administer and maintain the provisions of the developmental disabilities reform act in accordance with the following:
- (1) That subject to appropriations of federal, state and local government funds, persons with a developmental disability shall be provided assistance to have food, housing, clothing and medical care, protection from abuse, neglect and exploitation and an array of services and supports which assist in the determination of individual needs; and
- (2) that persons with developmental disabilities will receive assistance in determining their needs, be provided information about all service options available to meet those needs, have coordination of services delivered, be assisted and supported in living with their families or independently, assisted in finding transportation to support access to the community, and individually planned habilitation, education, training, employment and recreation subject to supports and services available in the community of their choice.
- (b) To accomplish the policies set forth in subsection (a), the secretary of social and rehabilitation services shall, subject to the provisions of appropriation acts, annually propose and implement a plan including, but not limited to, financing thereof which will provide for an organized network of community services for persons with developmental disabilities, maximize the availability federal resources to supplement state and local funding for such systems and reduce reliance on separate,

segregated settings in institutions or the community for persons with developmental disabilities.

- (c) The secretary shall report to the legislature the number of persons with developmental disabilities and the number of families eligible to receive community services and shall make a progress report on the implementation of the annual plans and the progress made to accomplish a full service community services system for person with developmental disabilities.
- (d) The secretary shall prepare and submit budget estimates for the department of social and rehabilitation services to the division of the budget and the legislature and shall establish and implement policies and procedures within the programs and activities of the department so that funds for state-level programs and activities for persons who are developmental disabled are allocated between services delivered in institutions and community services in percentages that approximate the percentages of persons served in those respective settings. If there is a deviation from such percentages the secretary shall submit a report to the legislature that contains an explanation on why such deviation from such percentages occurred and what is to be done to eliminate such deviation in such percentages in the future.
- (e) Subject to the provisions of this act and appropriations acts, the secretary shall administer and disburse funds to each community developmental disability organization for the coordination and provision of community services.
- (f) The secretary shall establish procedures and systems to evaluate the results and outcomes of the implementation of this act to ensure the attainment of maximum quality and efficient delivery of community services.
- Sec. 4. In the administration of the developmental disabilities reform act and implementing plans, persons with developmental disabilities shall have access to an array of community services through the provision of services in local communities whenever possible, with primary supervision for the

provision of such services with community developmental disability organizations.

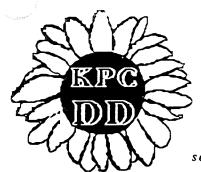
- Sec. 5. To accomplish a full service community services system there shall be:
- (a) A system of adequate and reasonable cost reimbursement for the delivery of community services that:
- (1) For persons moving from institutions into community services, directs funding to follow in an amount not less than that which is required to reimburse community services providers for services as set forth in such person's essential lifestyle plan, for a period not less than two years from the date of that person's departure from the institution, after which time funding for such person will be provided through the reimbursement system for other persons with developmental disabilities;
- (2) consolidates federal and state funding sources into a single rate structure;
- (3) (A) establishes a community services funding commission that will develop, monitor and maintain rate structures for community services and services delivered by institutions; or
- (B) requires an independent, professional review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments; and
 - (4) such system shall be adequate to support:
- (A) A system of employee compensation and benefits comparable to state employment;
- (B) training and technical support to attract and retain qualified employees;
- (C) a quality assurance process which is responsive to consumers' needs and which maintains the standards of quality service;
- (D) coverage under K.S.A. 75-6101 through 75-6119 and amendments thereto; and
 - (E) program management and coordination responsibilities;
 - (b) a system of accountability that:
 - (1) Establishes community services standards which insure

effective service delivery, fiscal accountability and networking cooperation;

- (2) provides for a recognition of achievement and maintenance of community services standards and acknowledgment of the accomplishment of national accreditation as equivalent to achievement of community services standards; and
- (3) conditions participation as a community services provider upon the achievement and maintenance of such standards; and
- (c) a system of contracting that is the primary method for implementing the provisions of this act that:
- (1) Authorizes open and equitable negotiation between contracting parties or their designated agent or agents;
- (2) authorizes arbitration by an independent entity in the event of contract disputes;
- (3) requires achievement and maintenance of community services standards by community services providers;
- (4) includes compensation for community services which meet the individualized needs of persons with developmental disabilities for community services in the areas of: (A) Work; (B) living in the community; and (C) individualized supports and services; and
- (5) requires community developmental disability organizations to contract with those qualified affiliates from whom a person with a developmental disability chooses services.
- Sec. 6. Whenever the secretary of social and rehabilitation services finds a community developmental disability organization to have failed to comply with the requirements, standards or rules and regulations established pursuant to this act or any other provision of law, the secretary shall have the power to inspect and review the operations of the community developmental disability organization; issue correction orders that subjects the community developmental disability organization to a probationary period of enhanced review by the secretary to assure compliance with the order; and suspend the community

developmental disability organization and removal of the organization's board of directors and the power to file an application with the district court for an order appointing the secretary as receiver to operate the community developmental disability organization.

- Sec. 7. Nothing in this act shall authorize the secretary or the department of social and rehabilitation services to require that community developmental disability organizations make expenditures other than expenditures approved for the community developmental disability organization by the governing board of the organization.
- Sec. 8. This act shall take effect and be in force from and after its publication in the statute book.



Kansas Council on Developmental Disabilities

BILL GRAVES, Governor WENDELL LEWIS, Chairperson JANE PHYS, Executive Director Docking State Off. Bldg., Room 141, 915 Harrison Topeka, KS 66612-1570 Phone (913) 296-2608, FAX (913) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES FEBRUARY 13, 1995

Testimony in Regard to <u>H.B. 2458</u>, AN ACT CONCERNING DEVELOPMENTAL DISABILITIES REFORM; PRESCRIBING CERTAIN POWERS, DUTIES AND FUNCTIONS FOR THE SECRETARY OF SRS.

To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities.

Madame Chairwoman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities regarding H.B. 2458, an act concerning developmental disabilities reform.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. We also have representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities, to see that they have choices in life.

General Comments: We applaud the attempt to reform services for individuals with developmental disabilities because we believe that the system is in need of reform. However, since we advocate for choice, we question having the same entity as the gatekeeper for services, the provider of case management services, and a service provider. It is our belief that this will not foster additional services since it will tend to discourage competition, thus eliminating choice. If the State is going to the efforts of setting up the system in Section 5, why not set up a system of vouchers so that individuals with developmental disabilities and their families can chose the service provider they wish? Accountability shall be covered under Page 3 Lines 39 - 42. This appears to give all authority to the Community Developmental Disabilities Organizations and none to individuals with developmental disabilities and their

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families. The responsibilities of these organizations are not delineated, nor is there an appeal process for individuals and families if the organization does not concur with what they are seeking.

Specific Comments: On Page 1, Line 37 does all persons mean that individuals may not be turned away because of the severity of their disability or their age? In Lines 39 and 42 would this eliminate the Parent Assistance Network, which has been funded under contract to Families Together, since this would have each Community Developmental Disabilities Organization either contracting on its own or providing the service themselves? The Parent Assistance Network is a family run program which provides counseling and referral services to parents of children with developmental disabilities.

Page 2 Line 22 we would consider an "institution" to be one in which there are beds for eight or more individuals. (Most homes do not have over eight individuals in residence.) Line 4 through 19 does not totally coincide with the State's definition of developmental disability (attached, items 5 and 6 are omitted). We support the more lenient definition since more people will be served. However, we assume that there will be adequate funding to support the additional individuals.

Page 3 Lines 4 through 7 Are the Community Developmental Disabilities Organizations knowledgeable of the laws governing education and transportation? Additionally, how would this impact KSA 39-1701 et seq. (The Interagency Provision of Services for Children, Adolescents, and Families Act).

Page 4 Line 8 Who determines what is reasonable and who audits the system? Line 17 Why are county funds omitted? Line 19 Who is on this Commission? Where is the accountability for the Commission? Line 22 Who staffs this review process? Lines 36 through 41 Is this a licensure or national accreditation?

Page 5 Lines 7 and 8 Who determines that this has been met and how is it determined, through monitoring, on-site visitations? Lines 16 through 28 Do all levels have to been gone through or can the Secretary go immediately to suspension if the organization has put individuals in danger? Lines 29 through 33 If Social and Rehabilitation Services cannot require certain expenditures, what happens again, if a client needs something and the Community Developmental Disabilities Organization refuses to provide or contract for the item?

We do appreciate the efforts that this Committee has expended and would be willing to work with the Committee in answering some of the questions we raised. I would be happy to respond to questions.

Jane Rhys Kansas Council on Developmental Disabilities

WHO IS ELIGIBLE?

In order to assure that limited resources are used as efficiently as possible MR/DD Services has developed specific eligibility criteria. These criteria are not intended to define mental retardation or other developmental disabilities, but to define the group of persons with MR/DD who can be served with funds we administer.

To be eligible for services funded by MH&RS persons must meet the following criteria:

Mental retardation means significantly sub-average intellectual functioning as evidenced by an IQ score of 70 or below on a standardized measure of intelligence. Other developmental disability means a condition such as autism, cerebral palsy, epilepsy, or other similar physical or mental impairment. In addition, mental retardation and otherwise developmentally disabled is evidenced by a severe, chronic disability which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments, AND
- 2. is manifest before the age of 22, AND
- 3. is likely to continue indefinitely, AND
- results in substantial functional limitations in any three or more of the following areas of life functioning:
 - a. self-care.
 - b. understanding and the use of language,
 - c. learning and adapting,
 - d. mobility,
 - e. self-direction in setting goals and undertaking activities to accomplish those goals,
 - f. living independently,
 - g. economic self-sufficiency, AND
- reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and are individually planned and coordinated, AND
- does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill or have disabilities solely as a result of infirmities of aging.

When an assessment of "substantial functional limitations" is needed the **Eligibility Determination Instrument** is available from MR/DD Services.

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February 13, 1995

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES

TESTIMONY ON HOUSE BILL 2008

Representative JoAnn Pottorff, Chairperson

Presented by Mark Elmore, Executive Director JCMRC

Chairperson Pottorff and Members of the Committee:

Thank you for allowing me time to present comments to your select committee. I am Mark Elmore, executive director of Johnson County Mental Retardation Center, an agency presently providing service coordination to more than 600 persons with mental retardation and their families. In addition I serve as President of the Kansas chapter of the American Association on Mental Retardation, active member of Kansas Association of Rehabilation Facilities and parent of a grown daughter with a developmental disability.

JCMRC provides a comprehensive array of services and supports to individuals through employment options, various living services and ongoing service coordination. We have led the effort to affiliate other organizations in our area to help provide a comprehensive service system to the many citizens that turn to us for help. Presently we have affiliate contracts with six other service organizations and 175 individuals. We have been offering direct services since 1972 and have literally helped thousands of individuals with disabilities in employment and living opportunities.

As a representative of the many consumers and parents that we deal with daily we appreciate the select committee's leadership in offering this bill. We believe it is a positive step in acknowledging and enhancing the partnership between the state and local community organizations that support persons with disabilities. An effort that has been undertaken with a sense of urgency and dedication to the thousands of parents and friends of persons with disabilities that yearn for some acknowledgement that our most vulnerable citizens need our assurance of ongoing support and if necessary assistance. We have often supported such efforts.

Before I address specifics of this bill please let me briefly share from my unique role as something of a participant historian on the development of community service to persons with mental retardation in Kansas over the last 28 years. When I entered this profession back in 1967 as a worker at Winfield State Hospital and Training Center the institutions were involved in tremendous change. Change in moving from old buildings to new ones; change in serving only 25 persons per ward; change from serving over 1100 persons at WSHTC with a few hundred staff by moving individuals into various community options; change in seeing small parent-run community schools develop to serve their adult children; change in personally helping start what is today a comprehensive community network of services. The change has not always been easy. With the crisis of

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moving hundreds of persons in the 1950's and 1960's out of the institutions passed we then faced and conquered the need to establish community services in all areas of the state. As I worked in both small and large community programs in rural and urban settings during the 1970's I participated in the most exciting time in the history of service to persons with mental retardation in Kansas. During the 1980's as community services in Kansas were maturing, institutions again came under fire for inadequate care. During his time period I visited several states that had closed institutions, downsized them and developed viable new alternatives. I borrowed ideas, implementing them and other new concepts at JCMRC and participated in networking throughout Kansas on how to improve our service system.

I have been most fortunate to be an active participant in all of this change process. I believe that a historical prospective is vital to a vision for the future. That brings me to your Developmental Disabilities Reform Act. A concept of establishing a state community service policy that will provide a vision of the service system of the future.

In Section 1, the purposes given in this act highlight the goals of many organizations like JCMRC. The emphasis on services and supports, increasing independence and productivity, integration and inclusion of persons into the community all match the changes taking place in the community service sectors today.

You open a door that has many challenges attached when we shift current service efforts from mental retardation to developmental disabilities. A shift that our organization could support if issues of increased funding seemed likely. Without increased funding to reach the additional disabilities included in this change we fear that waiting problems will only increase. Our organization has taken steps to reverse our trends of serving persons with disabilities other than mental retardation simply because we do not have the fiscal resources to meet all the present requests for services and supports. Parents who have worked long and hard to see services for their sons and daughters worry that increased service populations will add greatly to the already burdened funding available.

We support the concepts covered in this act that emphasize contracts shall be with existing community service providers whenever appropriate. We share that this concept is presently working, and does not set in place a non-competitive service system. Given the numerous affiliate organizations that JCMRC contracts with and our mandate by Mental Health and Retardation to sign on all willing organizations we see many choices for service and supports to be provided in our community.

In your Section 3, we see many of the issues that families so often talk to us about covered. Parents are extremely concerned that their child will receive help when the parent is gone. Family members worry about protection from harm. Service providers need to individualize services throughout the service system. We support the concept of financing for an organized network of community services that maximizes available funds. We noted the requirement of providing data on the number of persons with developmental disabilities and families eligible to receive services and support such efforts to eliminate duplication and confusion from present efforts. We are concerned that the submission of budget estimates

will not lead to full funding of the needs as presented. Parents and family members often speak to us wondering why there are no guarantees for services like they have when their children are in schools. The committee may want to debate the issue of including in this act any form of a bill of rights to service concept or guarantee of basic service provisions like food, shelter and service coordination. In item (d) of this section your new concept of reporting percentages of persons served by setting with comparisons on funding deviation is most interesting. We have often heard from state officials the why of increased funding for institutions while persons served decreases. We have marveled at the philosophy that the state is only really responsible for fully funding those in institutions and letting community services rely on local funding to pick up subsidy needed for the provision of services. We question if a modern interpretation of the state constitutional charge to foster and support benevolent institutions for the benefit of mentally handicapped persons, or clarifications of the funding policies of the state in this act would be appropriate.

Moving on to some specifics on Section 5, we fully support the concepts outlined in moving to a full service community services system. We believe Kansas can join other states in not only providing a full service system but we believe we could move over time to only a community service system. Our organization has pushed for a system of adequate and reasonable cost reimbursement. We believe there are variables in the cost of services across the state and feel a one price fits all philosophy does not allow for truly individualized services. We also applaud a move to a single rate structure. We have argued in the past that the cost of moving individuals from large state facilities to small three person living settings is at least equal in cost. We believe a single rate structure that would include state institutions would allow for more appropriate cost comparisons, service comparisons and a mechanism for eventually closing one or more state facilities. If the state would move to a single rate structure that covers all persons served, the many steps necessary to determine a rate for the individual to return to their home communities would be eliminated. Then we could go about moving the people rather than fighting over what the appropriate rate should be. This would also do much to eliminate the disparity in the wage scales of the state paid staff at institutions and the community paid staff in community services. Presently the wage difference does not encourage staff from the institutions to move with the individuals to the community. Maybe a single rate structure would equalize this effort and solve the relocation of state staff problems.

Our organization welcomes the concept of establishing a community services funding commission if it is a separate body outside of the present Department of Social and Rehabilation Services or Mental Health and Retardation Services Division. If not, then the present problems related to appeal procedures being insider based would not be solved. As the present system has been developed seldom have we used independent professional reviews of the rate structures. The requirement in this act to do so would do much to eliminate the friction that does appear to be developing in the mental retardation services system.

The many points covered in this section under (4) related to system support, would do much to move our state back towards appropriate levels of services. I would be glad to speak to each of the points if you have questions.

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One last point today. The issue of allowing the state to remove the board of directors of an organization as covered in Section 6 does little to project a partnership image that we have all worked so long to develop. There will be many community leaders who will see this as another in a long effort by the state to control any and all community type boards. If the vision is that the state wishes to move toward a state-run system, then this is probably best left in the act. If not then it should be deleted.

In summarizing my comments today I am reminded of the many times during these committees hearings that I have been encouraged when you ask for participants to share their dreams for the future. Throughout my career in this field my role has been to help parents and consumers realize their dreams. The organizations that I have led were built on the dreams of parents. The services provided were driven by the consumers and their families. The changes in the system over the past thirty plus years have generally been pushed to new heights by parents. As a parent my dream is that Kansas will guarantee basic assistance, if unavailable from the family, so that persons with a disability who need support in being in and of the community will have such opportunities.

Thank you for your efforts as a committee and your attention today.

Mark Elmore
JCMRC Executive Director