

Approved: 2-16-98
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Chair Sandy Praeger at 10:00 a.m. on February 10, 1998 in Room 526-S of the Capitol.

All members were present except:

Committee staff present: Emalene Correll, Legislative Research Department
Robin Kempf, Legislative Research Department
Norman Furse, Revisor of Statutes
Jo Ann Bunten, Committee Secretary

Conferees appearing before the committee:

Michael Byington, Envision
Vicki Vermillion, Stillwell
Roxanne Brewer, Wichita
Cynthia Thomas, Topeka
Sherry Diel, Deputy Director, Kansas Advocacy and Protective Services, Inc.
Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities

Others attending: See attached list

Approval of Minutes

Senator Steineger made a motion to approve the Committee minutes of February 2, 3, 4 and 5, 1998, seconded by Senator Hardenburger. The motion carried.

Hearing on SB 284 - Communications accommodations under the developmental disabilities reform act

Michael Byington, representing Envision, a state-wide not-for-profit organization which serves persons who are blind, low vision, deafblind and multiply disabled blind, expressed his support for **SB 284** which would expand the Developmental Disabilities Reform Act and allow for successful communications for certain individuals with disabilities. He pointed out that the bill started out strictly as a deafblind bill, but after meeting with other advocacy groups, Mr. Byington offered an amendment to the bill that would include, not only deafblind individuals, but those individuals with special needs such as individuals with cerebral palsy, persons who are developmentally disabled blind, or developmentally disabled deaf as outlined in his written testimony. (Attachment 1)

Former State Representative and member of the National Federation of the Blind, Dick Edlund, spoke briefly in support of **SB 284** and urged the Committee's consideration of the bill.

Vicki Vermillion, parent of a deafblind and developmentally disabled young woman, expressed her support for **SB 284** and noted that communication accommodations are not addressed under the current Medicaid waivers. She pointed out that presently, service providers are difficult to find, train and keep because of the low hourly wage paid by the waivers, and that the proposed amendments to the bill would allow for communication assistants in the waiver support system. She also noted that by using communication assistants who are trained and certified in communicating with deafblind individuals, the deafblind population will be able to utilize the supports necessary for living in the community. (Attachment 2) During Committee discussion it was noted that there are approximately 500 deafblind individuals in Kansas.

Roxanne Brewer, mother of a deafblind daughter, testified before the Committee in support of **SB 284**. Ms. Brewer noted that an intervener is important to someone who is deafblind, because information which normally is absorbed through the eyes and ears must be introduced through sign by the intervener which can be very expensive. (Attachment 3)

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE, Room 526-S
Statehouse, at 10:00 a.m. on February 10, 1998.

Cynthia Thomas, parent of a deafblind child, addressed the Committee in support of **SB 284**, (Attachment 4), as well as written testimony supporting the bill from Steve and Jacque Clifton, (Attachment 5).

Sherry C. Diel, Kansas Advocacy and Protective Services, Inc., addressed the Committee in opposition to the original version of **SB 284** and noted that she had not seen the proposed amendments offered by Mr. Byington and would support striking language in the bill relating to the definition of deafblind. (Attachment 6) Testimony was also offered by Jane Rhys, Kansas Council on Developmental Disabilities, in opposition to the original bill without the proposed amendments. (Attachment 7) During Committee discussion the Chair suggested that Ms. Diel and Ms. Rhys confer with Mr. Byington and SRS on the proposed changes to **SB 284** as well as what funding would be involved and bring recommendations back to the Committee.

Adjournment

The meeting was adjourned at 11:00 a.m.

The next meeting is scheduled for February 11, 1998.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE GUEST LIST

DATE: 2-10-98

NAME	REPRESENTING
J. Rhy Stephanie Wilson	KS Council on D/D MH & DD
Donna J. J...	
Roxann Brewer	DB Task Force
Shelle Barnes	Sec of PDB
RUTH R. Lowrie	CHRISTIAN SCIENCES COMM ON PUBLICATION FOR KS
Michael Broughton	Environ
Jay L. Hollen II	DB Task Force
Sherry C. Auld	KS Advocacy & Protective Services
Aaron Briggs	TILRC
Tessa Goupil	TILRC
Merle Vera Furry	Brent Furry
Gary Cobbin	KS Optometric Assn
Mary Margaret Rowen	KII
ELIZABETH KAPPELMAN	KIT - Ec. Minut
Mel Dwyer	UNCS
Michelle Peterson	Peterson Public Affairs Group
Lyndee Y. Thomas	Parent of a deaf blind child

Choices & resources for people who are blind or low vision



EnvisionSM

**PLEASE REPLY TO: Michael Byington, Director
Envision Governmental Affairs Office
P. O. Box 1063
Topeka, Kansas 66601
(785) 575-7477 (local office and voice mail)
(785) 233-2539 (FAX)
mbyington@delphi.com or mbyingto@ink.org**

February 10, 1998

TO THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE:

REGARDING SENATE BILL 284

I want to thank the Committee for taking the time to hear this Bill. There is a balloon. The document attached to this testimony contains three columns. The left column represents the existing statutes which are known as the DD Reform Act. The center column shows Senate Bill 284 as originally requested. The right hand column shows the balloon.

I want to tell you how this bill came to exist, and how the balloon evolved as well. This is a story of a number of families of deafblind individuals, deafblind consumers, and professionals in the field of deafblindness working together to attempt to improve the lives of a very specialized population, those persons who are developmentally disabled by current functional definition, but who also have a dual sensory impairment such as deafblindness, or a sensory impairment such as deafness or blindness in combination with their developmental disability.

The Deafblind Task Force was created through recommendations in an

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Senate Public Health & Welfare
Date: 2-10-98
Attachment No. 1

Appropriations Sub Committee Report generated during the 1995 session of the Kansas Legislature. It is a working group comprised of parents and family members of deafblind citizens, deafblind consumers themselves, and professionals who work with the deafblind. The group's emphasis has always been consumer driven. In fact the Committee's rules offer families of deafblind citizens and deafblind consumers two votes for any one cast by a professional in matters where decisions must be made. The Task Force was created because the Committee which recommended it saw a great need for coordination between persons who are involved with deafblind individuals to insure that services are made available in a coordinated, logical manner.

I am employed as the Director of Governmental Affairs with Envision, a State-wide not-for-profit organization which serves persons who are blind, low vision, deafblind, and multiply disabled blind. I have been honored to be asked to provide the Deafblind Taskforce with some technical consultation concerning legislative and systems advocacy matters.

From its early days through the present, the information which has been given to me by the Taskforce is that the greatest barrier to deafblind or sensory impaired individuals who are also developmentally disabled living at their maximum potential for productivity and participation in life is the barrier of communications. The DD Reform Act created a system where there is a single point of entry gate-keeper for all services available to the developmentally disabled. Resources are distributed more evenly, and many argue that they go further. The fact that we have virtually eliminated waiting lists for community based services to the developmentally disabled is considered a major milestone, not just within our State, but throughout the nation. The fact is, however, that while many day to day maintenance and habilitation services are available through the DD Reform Act, the Act never states that the type of communications the developmentally disabled individual uses should be considered in selecting those agencies and persons who are going to provide services. There is no emphasis in the law requiring that services be provided using the communications which work best for the individual. Now many of you may think that such a conclusion would be a no-brainer. It simply makes sense to provide the communications accommodations which are going to insure that the services lead to the maximum possible benefit. The fact is, however, many of the single point of access gate-keepers, the Community Developmental

Disabilities Organizations (CDDOs) have by history worked largely with the mentally retarded population subset within the developmental disabilities arena, and have not worked extensively with persons who are sensory impaired, and certainly not with persons who are deafblind. Membership throughout the Deafblind Taskforce has provided information to the effect that their deafblind family members or clients have received well meaning services under the DD Reform Act, but that there has not been sufficient emphasis on getting providers or providing accommodations which allow for successful communications.

The DD Reform Act goes out of its way to make the point that nothing there-within should be regarded as creating entitlement to services. At the same time the Act assures that it is the right of a developmentally disabled individual to be provided assistance to obtain food, housing, clothing and medical care; protection from abuse, neglect and exploitation; and a range of services and supports, which assist in the determination of individual needs. Senate Bill 284 simply acknowledges that the ability to communicate is one of the needs which belongs on this list.

The balloon language is proposed in consideration of requests made by some other advocacy groups within the developmental disabilities field. There is no question that 284 started out as strictly a deafblind bill. That is after all the population the Deafblind Taskforce exists to represent. Some of the other advocacy groups pointed out, however, that persons who can not speak because of cerebral palsy, persons who are developmentally disabled blind, or developmentally disabled deaf also have similar need for communications accommodations. It was also pointed out that defining deafblindness so specifically might unintentionally disenfranchise some of the other populations simply because they are not as specifically defined. The other groups in question agreed not to oppose this legislation if the extreme detail of the deafblind definition were removed and some other technical changes were to be made. In a spirit of cooperation, these requests are being honored.

I know that the DD Reform Act represents the negotiations and hard work of many advocacy groups. I understand why many who labored over it so long and hard are reluctant to see it opened up for amendment. Given these concerns, I would like to close by stating some of the things Senate Bill 284 would NOT do.

SENATE BILL 284 WOULD NOT CHANGE THE OVERALL SIZE OF THE DEVELOPMENTALLY DISABLED POPULATION OF KANSAS. The people being addressed via this proposed legislation have already been found eligible for services under the DD Reform Act. They meet the definition of developmental disabilities as it currently exists in the statutes. The issue is insuring that the services provided under the Act are offered in a way which will address the unique communications needs of the individuals.

SENATE BILL 284 IS NOT ADDING APPRECIABLE NEW SERVICES TO THOSE OFFERED THROUGH THE DD REFORM ACT. It is simply insuring that existing services are offered in a way which will be useful, which will allow the developmentally disabled person to benefit.

Thank you for your consideration of this legislation. Please listen to what some of the family members of deafblind have to say about this bill. They can explain the need much better than I can.

EXISTING STATUTES

CURRENT H.B. 284

BALLOON FOR H.B. 284

(All involved statutes are listed below. New language is underlined. Language to be struck is shown in ~~strikeout mode~~.)

(All involved statutes are listed below. Language from the original statutes to be struck is presented in ~~strikeout mode~~. New language to be added to the original statute is underlined. This balloon language is presented with reference to the original statute rather than referencing add ons and ~~strikeouts~~ relevant to the originally introduced 284.)

Statute # 39-1802
Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM Title Policy of state.

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Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM Title Policy of state.

It is the policy of this state to assist persons who have a developmental disability to have:

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(a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community;

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(b) access to a range of services and supports appropriate to such persons; and

(b) access to a range of services and supports appropriate to such persons; and

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(c) the same dignity and respect as all persons

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Statute # 39-1803
Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM Title Definitions.

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As used in the developmental disabilities reform act:

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(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.

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(b) "Affiliate" means an entity or person that meets standards set out in rules and regulations adopted by the secretary relating to the provision of services and that contracts with a community developmental disabilities organization.

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in the manner proven to provide the most effective form of communications for the developmentally disabled individual. Such accommodations may involve, but are not limited to, the use of specific types of sign language and sign language interpretation, interveners, operation of assistive technology devices, Braille, large print, and tape recordings of written materials

in the manner proven to provide the most effective form of communications for persons with developmental disabilities. Such accommodations may involve, but are not limited to, the use of specific types of sign language and sign language interpretation, other communications assistance, Braille, large print, and tape recordings of written materials.

(c) "Community services" means services provided to meet the needs of persons with developmental disabilities relating to work, living in the community, and individualized supports and services.

(d)(e) "Community services" means services provided to meet the needs of persons with developmental disabilities relating to work, living in the community, and individualized supports and services.

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(d) "Community developmental disability organization" means any community mental retardation facility that is organized pursuant to K.S.A. 19-4001 through 19-4015 and amendments thereto.

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(e) "Community service provider" means a community developmental disability organization or affiliate thereof.

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(new g) "deafblindness" means a condition which restricts central visual acuity to 20/200 or below in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions; accompanied by a condition resulting in a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition. The term "deafblindness" also refers to a person who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives. For purposes of this act, deafblindness as defined herein must be manifested before the individual has reached 22 years.

(f) "Developmental disability" means:

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(new 2) deafblindness; or

(2) a severe, chronic disability,

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which:

(A) Is attributable to a mental or physical impairment, a combination of mental and physical impairments or a condition which has received a dual diagnosis of mental retardation and mental illness;

(B) is manifest before 22 years of age;

(C) is likely to continue indefinitely;

(D) results, in the case of a person five years of age or older, in a substantial limitation in three or more of the following areas of major life functioning: Self-care, receptive and expressive language development and use, learning and adapting, mobility, self-direction, capacity for independent living and economic self-sufficiency;

(E) 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

(F) does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as a result of the infirmities of aging.

(g) "Institution" means state institution 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 nine beds or more as defined by subsection (a) (4) of K.S.A. 39-923 and amendments thereto.

(h) "Mental retardation" means substantial limitations in present functioning that is manifested during the period from birth to age 18 years and 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.

(i) "Secretary" means the secretary of social and rehabilitation services.
History

which:

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(E) reflects a need for a combination and sequence of special interdisciplinary or generic care, treatment, specialized communications techniques or other services which are lifelong, or extended in duration and are individually planned and coordinated; and

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History

History: L. 1995, ch. 234, S. 3; Jan. 1, 1996.

Statute # 39-1804

Chapter 39.--MENTALLY ILL,
INCAPACITATED AND DEPENDENT PERSONS;
SOCIAL WELFARE Article
18.--DEVELOPMENTAL DISABILITIES REFORM

Title Implementation of act; powers and duties of secretary of social and rehabilitation services; reports.

(a) Except as otherwise specifically provided in this act and subject to appropriations of federal and state funds, the secretary, after consultation with representatives of community developmental disability organizations, community service providers, families and consumer advocates, shall implement and administer the provisions of the developmental disabilities reform act in accordance with the following policies. Persons with developmental disabilities shall:

(1) Be provided assistance to obtain food, housing, clothing and medical care; protection from abuse, neglect and exploitation; and a range of services and supports which assist in the determination of individual needs; and

(2) 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; be assisted in finding transportation to support access to the community; and receive 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, subject to the provisions of appropriation acts, shall annually propose and implement a plan including, but not limited to, financing thereof which shall: (1) Provide for an organized network of community services for persons with developmental disabilities; (2) maximize the availability of federal resources to supplement state and local funding for such systems; and (3) 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

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(c) The secretary shall report to the legislature the number of persons with

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developmental disabilities 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 comprehensive community services system for persons 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 developmentally disabled are allocated between services delivered in institutions and community services.

(e) Subject to the provisions of this act and appropriation 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 result and outcomes of the implementation of this act to assure the attainment of maximum quality and efficient delivery of community services.

History

History: L. 1995, ch. 234, S. 4; Jan. 1, 1996.

Statute #39-1805

Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Powers and duties of community developmental disability organization.

In addition to any other power and duty prescribed by law, and subject to appropriations, a community developmental disability organization shall have the power and duty to:

(a) Directly or by subcontract, serve as a single point of application or referral for services, and assist all persons with a developmental disability to have access to and an opportunity to participate in community services, except in those circumstances in which the secretary determines, subject to an immediate hearing before the district court located in the county in which the person with a developmental disability resides, participation in community services is not the appropriate

developmental disabilities 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 comprehensive community services system for persons with developmental disabilities.

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Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Powers and duties of community developmental disability organization.

In addition to any other power and duty prescribed by law, and subject to appropriations, a community developmental disability organization shall have the power and duty to:

(a) Directly or by subcontract, serve as a single point of application or referral for services, and assist all persons with a developmental disability to have access to, ~~and~~ an opportunity to, and communications accommodations required to, participate in community services, except in those circumstances in which the secretary determines, subject to an immediate hearing before the district court located in the county in which the person with a developmental disability resides, participation in

1-9

placement for such person because such person is presently likely to cause harm to self or others;

(b) provide either directly or by subcontract, services to persons with a developmental disability, including, but not limited to, eligibility determination; explanation of available services and service providers; case management services, if requested; assistance in establishing new providers, if requested; and advocacy for participation in community services;

(c) organize a council of community members, consumers or their family members or guardians, and community service providers, composed of a majority of consumers or their family members or guardians who shall meet not less than quarterly to address systems issues, including, but not limited to, planning and implementation of services; and develop and implement a method by which consumer complaints, interagency and other intrasystem disputes are resolved;

(d) provide, directly or by subcontract, information about affiliate and referral services to persons with a developmental disability whose particular needs can be met in the community or through government; and

(e) ensure that affiliates have the option to review referrals and waiting lists on a periodic basis to contact potential consumers with information concerning their services.

History

History: L. 1995, ch. 234, S. 5; Jan. 1, 1996.

Statute #39-1806

Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Establishment of system of funding, quality assurance and contracting.

To carry out the provisions of this act, the secretary shall establish after consultation with representatives of community developmental disability organizations and affiliates thereof, and families and consumer advocates:

(a) A system of adequate and reasonable funding or reimbursement for the delivery of community services that:

disability resides, participation in community services is not the appropriate placement for such person because such person is presently likely to cause harm to self or others;

(b) provide either directly or by subcontract, services to persons with a developmental disability, including, but not limited to, eligibility determination; explanation of available services and service providers; case management services, if requested; communications accommodations, if requested; assistance in establishing new providers, if requested; and advocacy for participation in community services;

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To carry out the provisions of this act, the secretary shall establish after consultation with representatives of community developmental disability organizations and affiliates thereof, and families and consumer advocates:

(a) A system of adequate and reasonable funding or reimbursement for the delivery of community services that:

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(1) For persons moving from institutions into the community, directs funding to follow in an amount not less than that which is required to reimburse community service providers for services as set forth in such person's plan for transfer from the institution to community services including expenses of relocation and initiation of services;

(2) consolidates federal and state funding sources;

(3) requires an independent, profession review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments. Such recommendation shall be adequate to support: (A) A system of employee compensation competitive with local conditions; (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) risk management and insurance costs; and (E) program management and coordination responsibilities;

(b) a system of quality assurance based on standards set out in rules and regulations adopted by the secretary which insures effective service delivery, fiscal accountability and networking cooperation and which allows community service providers to present evidence of attainment of national accreditation or compliance with state or federal laws or rules and regulations, or both, to indicate compliance with such standards; and

(c) a system of contracting that:

(1) Authorizes open and equitable negotiation between contracting parties or their designated agent or agents;

(2) authorizes mediation by an independent entity chosen by the parties to the contract in the event of contract disputes and if mediation is not completed prior to the end of any existing contract, authorizes an extension of time of such existing contract or entering into a temporary contract;

(3) requires achievement and maintenance of community services standards by community service providers;

(4) includes compensation for community services which meet the individualized needs of persons with developmental disabilities for community services; and

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(5) requires community developmental disability organizations to contract with those affiliates from whom a person with a developmental disability chooses services.

History

History: L. 1995, ch. 234, S. 6; Jan. 1, 1996.

Statute #39-1807

Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Failure of community service provider to comply with requirements, standards or laws; inspection and review of operations by secretary; mediation; written plan of correction; civil penalties; emergency orders.

Whenever the secretary finds a community service provider has 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 service provider and identify deficiencies. The secretary and such community service provider shall choose an independent entity to mediate any dispute regarding the secretary's finding that such community service provider has failed to comply with such requirements, standards or rules and regulations and the secretary's identified deficiencies. If such mediation is not able to resolve any such dispute and the secretary finds that the community service provider has still failed to comply with such requirements, standards or rules and regulations, the secretary shall require a written plan of correction. If, after notice and an opportunity for hearing pursuant to the Kansas administrative procedure act, the secretary finds the community service provider has failed to carry out the plan of correction within 30 days of the submission of the plan of correction, the secretary may assess a civil penalty in an amount not to exceed \$125 per day for each day the provider has failed to carry out the plan of correction. The secretary may extend the time in which the provider has to comply with the plan of correction for good cause. The secretary may require the community service provider to maintain consumers in place until alternative community services can be secured with reasonable compensation for actual costs and to remove the designation as community service provider, except that in the event the secretary

related thereto; and

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History

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1-12

makes written findings of fact that there appears to be a situation involving imminent danger to the health, safety or welfare of the person with a developmental disability unless immediate action is taken, the secretary may issue an emergency order. Such emergency order shall be subject to the same procedures under K.S.A. 77-536 and amendments thereto. Upon entry of such an emergency order, the secretary shall promptly notify the community service provider subject to the order: (1) The content of the order; (2) the reasons therefor; and (3) that upon written request within 15 days after service of the order, the matter will be set for a hearing which shall be conducted in accordance with the provisions of the Kansas administrative procedure act. If no hearing is requested and none is ordered by the secretary, the order will remain in effect until it is modified or vacated by the secretary. If a hearing is requested or ordered, the secretary, after notice of and opportunity for hearing to the community service provider subject to the order, by written findings of fact and conclusions of law, shall vacate, modify or make permanent the order.

History

History: L. 1995, ch. 234, S. 7; Jan. 1, 1996.

Statute #39-1808

Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Act does not require community service provider to make certain expenditures.

Nothing in this act shall authorize the secretary to require a community service provider to make expenditures not in compliance with contracts or agreements entered into by the governing board of such provider.

History

History: L. 1995, ch. 234, S. 8; Jan. 1, 1996.

Statute #39-1809

Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE Article 18.--DEVELOPMENTAL DISABILITIES REFORM

Title Act does not create any entitlement to services.

Nothing in this act shall create any entitlement to services.

History

History: L. 1995, ch. 234, S. 9; Jan. 1,

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History

History: L. 1995, ch. 234, S. 9; Jan. 1,

1996.

Statute #39-1810

Chapter 39...MENTALLY ILL,
INCAPACITATED AND DEPENDENT PERSONS;
SOCIAL WELFARE Article
18.--DEVELOPMENTAL DISABILITIES REFORM
Title Rules and regulations.

The secretary may adopt rules and
regulations to carry out the provisions of this
act.

History

History: L. 1995, ch. 234, S.

10; Jan. 1,
1996

1996.

Statute #39-1810

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INCAPACITATED AND DEPENDENT PERSONS;
SOCIAL WELFARE Article
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10; Jan. 1,
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SOCIAL WELFARE Article
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History

History: L. 1995, ch. 234, S.

10; Jan. 1,
1996.

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February 10, 1998

My name is Vickie Vermillion. I am the parent of a deafblind young woman and am also a parent case manager for the HCBS Medicaid Waiver.

Thank you for allowing me to give testimony on the issue of House Bill 284 balloon amendment today.

This is a very important part of my life. I have a daughter who is deafblind and developmentally disabled. The past legislation defining deafblindness and the need for communication accommodations is a very good piece of legislation. However, it does not go far enough to implement the real pieces of work that ensure the bill is being carried out. For instance, with the current Medicaid Waivers, communication accommodations are not addressed. These waivers are wonderful and allow for the deafblind population to have supportive home care and respite care, but communication needs are not addressed. How are the deafblind supposed to communicate their wants and needs if the providers they currently use do not have the appropriate skills necessary to talk with them? Currently, service providers are difficult to find, train and keep because of the low hourly wage paid by the waivers. The new amendment presented by Michael Byington will allow for communication assistants in the waiver support system. By using communication assistants who are trained and certified in communicating with deafblind individuals (ie sign language) we are ensuring that the deafblind population is able to utilize the supports necessary for living in the community.

The communication assistant piece needs to be implemented into all of the waivers available today with a mechanism for ensuring that these providers have the appropriate qualifications to perform the necessary tasks. It should also be noted that appropriate pay for the skill level required to do this work will ensure that the deafblind population is receiving the communication services necessary to be in the community.

For my daughter it means she will be able to access her community, have choice in her daily living, interact with whomever she chooses - just like all of us. This amendment will give Kim the opportunity to have a life!

I am speaking in favor of Senate Bill 284. My daughter, Sheila, is totally blind and is also deaf. She is 24 years old. As I look at what this intelligent, motivated, deafblind young woman needs in order to have any quality of life, it comes down to having communications accommodations available. The type of communications accommodation which works for Sheila is someone called an intervener.

I will explain why an intervener is important and the impact they have on a deafblind persons life. Information which normally is absorbed through the eyes and ears must be introduced through sign by the intervener. As you may probably know, these people don't come cheap.

Entertainment- Can you imagine leaving the house each day and have absolutely no idea where you are going, or even if you would like to be there or not? An intervener would explain what is about to happen so that Sheila may decide for herself whether or not she would like to participate in this activity.

Travel- Imagine if you will, driving through a dark tunnel with no light anywhere. This is what it feels like with no one to tell you if there are children playing, a police car or ambulance driving past. Yards with dogs and cats. Fields with horses and cows. The weather changes from rain to sleet then snow. Without an intervener, Sheilas' trip has been no different than traveling through this tunnel with no light.

Comfort- You're soon to be starting your monthly and really don't feel well. The last thing you want is to have a busy day, but nobody seems to understand why you're fussy. You may be constipated and don't know what to do about it and no one how to ask how you feel.

You're shopping for new shoes but the fit is slightly tight or to narrow, but not enough to be seen, and now you are expected to wear them. An intervener would communicate with Sheila to insure such occurrences don't go unnoticed.

Reasonable luxuries- Having someone Braille pictures so the images can be felt- experiencing happiness in remembrance of the past. Going shopping and being able to tell someone what type of bracelet or earrings you want.

Convenience- Either having a caretaker come over to cook, clean, and do laundry for \$6.50 an hour for the rest of her life. Or, someone to teach Sheila to maintain her own house and Braille her own shopping list, so she may be more self-sufficient. This is a goal for most people, and Sheila has already proven she is capable of reaching this goal with the help of an intervener.

ROXIE BREWER

Gytha Thon
Topeka KS
66611

Senators,

As a parent of a deaf-blind child I thank you for the opportunity to provide you with some of the insights and information you need in order to help families with deafblind sons and daughters.

A few years ago, I attended a very crowded stakeholders meeting - almost every professional in the state connected to deafblindness was there, as well as some parents and consumers. Communication- the ability to express and receive information- was the number one issue. The stakeholders recognized, as I hope you will, that the right to communicate is one of the most basic human rights.

Subsequent stakeholder and other meetings continue to focus on COMMUNICATION as the key to keeping these kids and young adults in their communities, with their families, and on their way to an independent, productive life. I think these are the goals we all should share for all children in Kansas. Deafblind children and adults deserve no less expectations, though the struggle to live a productive life may be harder won.

I'm here today as a parent and as an advocate for the families this legislation will help.

Last spring, as a paid parent consultant to the Kansas State Board of Education, I conducted a telephone survey of the needs and concerns of Kansas families who have a deafblind child. I am here today to tell you

I found their needs to be great and their concerns to be many. Communication was the number one priority identified. Without a communication system in place and used consistently, a child/person's mental and physical health, their behavior, their education, their relationship with family and community, their personal safety, and their human dignity can be adversely affected.

Behavior most often is affected by lack of communication, what may be construed as "bad" behavior is really a desperate attempt to communicate, perhaps something as simple as, "please give me a drink of water."

I felt privileged to have spoken with so many families, and I was impressed by their love of their children and their commitment to helping their children live a productive life in their communities. This is why I advocate for them today and ask you to support this most needed piece of legislation.

Thank you.

A handwritten signature in cursive script, appearing to read "Cynthia Thomas".

Steve and Jacque Clifton
321 Driftwood Court
Rose Hill, Kansas 67133
(316) 776-9662

February 6, 1998

Senator Sandy Praeger, Chair
Senate Public Health and Welfare Committee
State Capitol
Room 128
Topeka, Kansas 66612

RE: Senate Bill 284

Dear Senator Praeger and Committee Members:

My husband and I are writing to let you know of our support for Senate Bill 284 with the balloon proposed by Michael Byington. As parents of a deafblind three-year-old son, this matter is very important to us.

When our family first learned that our son was born with a syndrome that, in addition to several serious medical problems, is highly associated with deafblindness, we were devastated. We thought that the outlook for his future was grim. Thankfully, our child, like so many other children with special needs, is very resilient. He fought through some very hard times and came through with a wonderful disposition and zest for life that amazes everyone. He is truly a joy and a very special young man.

We are fortunate to have a wonderful support system and we have met some truly wonderful people who taught us that deafblindness does not have to mean total isolation with little hope for a fulfilling future. They educated us and helped us see how vitally important it is that a deafblind person have communication -- not only to be able to interact with others but to release a deafblind person from the isolation that can come with this often misunderstood disability.

I hope that you and your committee understand and agree that all people should have the right to the type of communication that best suits their needs. My son is not yet eligible for the MR/DD waiver, which the communication proposal is for, but he may very well someday need the support this waived program provides. Please help us assure that our son will be able to attend school and communicate with his peers and teachers, learn to use the English language to read Braille and have a whole world of information and imagination open up to him through interacting with his environment.

Senate Public Health & Welfare
Date: 2-10-98
Attachment No. 5

Page 2
Letter to Senator Praeger

We sincerely hope that this addition to the MR/DD waiver program gets the serious attention that it deserves. For too long, Kansas children with deafblindness have been sorely misunderstood and neglected by people who are supposed to be in a position to help. Through education the needs of deafblind individuals will be better understood and the future generation of deafblind children and adults will have a more productive and fulfilling place in society.

Thank you for your time and consideration in regards to this important issue. Please help all people with specialized communication needs and support Senate Bill 284.

Sincerely,

A handwritten signature in cursive script that reads "Steve + Jacquie Clifton". The signature is written in dark ink and is positioned above the typed name and address.

Steve and Jacquie Clifton
321 Driftwood Court
Rose Hill, Kansas 67133
(316) 776-9662



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Scott Letts, Deputy Director

Doug Phelps, Attorney

Kari Ramos, Advocate

Michelle Rola', CFO

Ron Pavelka, Attorney

Memo To: Senate Public, Health and Welfare Committee

From: Sherry C. Diel, Deputy Director

RE: SB--284 Proposed Amendments to the Developmental Disabilities Reform Act

Date: February 10, 1998

KAPS Information

Kansas Advocacy & Protective Services, Inc. ("KAPS") is a federally funded non-profit corporation which advocates for the rights of individuals with disabilities. Our Agency also has federal authority to serve as an independent agency to investigate claims of abuse or neglect involving persons with disabilities. Our Agency is authorized to advocate for the rights of Kansans with disabilities using legal, administrative and other appropriate remedies. Similar organizations exist in each state and territory of the United States.

KAPS currently administers four (4) federal programs: 1) Protection & Advocacy For Persons With Developmental Disabilities ("PADD"); 2) Protection & Advocacy For Individuals With Mental Illness ("PAIMI"); Protection & Advocacy For Individual Rights ("PAIR"); and Protection & Advocacy for Assistive Technology ("PAAT"). Combined, these four programs authorize KAPS to serve any Kansan with a life-long disability. Unfortunately, our funding is not as broad as our authority. Therefore, KAPS sets annual priorities, taking into account input from the public, in order to target our efforts where we can assist the most individuals with disabilities. For those individuals with disabilities who we are unable to serve, KAPS maintains a centralized information and referral system to provide limited advice to the caller and referrals to other agencies who may be able to assist the person.

Comments Regarding SB-284

KAPS was one of several agencies who participated in the development of the Developmental Disabilities Reform Act ("DD Reform") during the 1995 Legislative Session. The Act took effect on January 1, 1996. KAPS was also one of several agencies that worked on the regulations to implement DD Reform in 1996, and KAPS served as the consumer representative during mediation of the regulations. SRS recently invited a group of stakeholders back to the table to review and make recommendations to the regulations. That process is completed and the draft amendments are currently moving through the approval process.

The definition of developmental disability in DD Reform was carefully crafted to mirror the federal definition of "developmental disability" contained in the Developmental Disabilities Assistance Act, 42 U.S.C. § 6000 et seq. This sets up a functional definition which c:

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consider each person's unique abilities. Basically, the person must suffer a physical or emotional impairment of a long-standing nature before the age of 22 and the impairment must affect 3 out of 7 of the person's life activities including:

- ◆ self-care;
- ◆ receptive and expressive language;
- ◆ learning;
- ◆ mobility;
- ◆ self-direction;
- ◆ capacity for independent living; and
- ◆ economic self-sufficiency.

The only material differences between the state and federal definitions are that if a person meets the state definition of "mental retardation" they are automatically considered a "person with a developmental disability" under state law and a person who has a sole diagnosis of mental illness is not considered developmentally disabled under state law.

We believe the functional definition of determining whether a person meets the criteria for services under DD Reform is appropriate. It is virtually impossible to list every category of disability which should be automatically classified under the umbrella of "developmental disability". Rather, each individual with a disability is unique. The stakeholders recognized the difficulty of listing specific types of disabilities for automatic coverage when DD Reform was originally passed.

We also believe that the regulations appropriately address the communication needs of persons with disabilities. Specifically, 30-63-21 (Person-Centered Support Planning) requires the service provider to list the "necessary activities, training, *materials, equipment, assistive technology*, and services which are needed to assist the person to achieve the person's preferred lifestyle". (Emphasis added). Furthermore, proposed amendments to 30-63-21 requires the provider(s) who develop the plan must describe how opportunities of choice will be provided, including specifying means for permitting the person to indicate their preferences "by whatever communication methods that person may possess, *including a description of effective communication methods utilized by the person*". Notwithstanding, the provider(s) must comply with the federal Americans With Disabilities Act.

Finally, we believe that the system has adequate protections built in to address disputes concerning eligibility or failure to provide appropriate services, including appropriate communication appropriations. Each Community Developmental Disability Organization ("CDDO") must have an internal grievance procedure in place. Formal due process procedures are also available. KAPS has successfully appealed eligibility determinations and currently has several appeals pending.

In the event that the Committee adds a new category to the definition of "developmental disability", we ask that the impact on appropriations for DD Reform be considered. Thank you for the opportunity to address your Committee. Should you have any questions, I will be happy to address them.



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

PUBLIC HEALTH AND WELFARE

February 11, 1998

Testimony in Regard to SB 284 CONCERNING THE DEVELOPMENTAL DISABILITIES REFORM ACT.

Madame Chairwoman, Members of the Committee, I appear today on behalf of the Kansas Council on Developmental Disabilities in opposition to SB 284 Concerning The Developmental Disabilities Reform Act.

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.

As an individual who participated in the creation of the 1995 Developmental Disabilities Reform Act, the development of its 1996 accompanying regulations, and the 1998 revision of the regulations, I believe that it is important that I tell you of the philosophy of the Act as well as my concerns with the proposed revisions. On page 1, line 24 (c) I have no problems with the addition of a definition of "communications accommodations." I do wish to point out that current regulations (Attachment A) show that a person is to be communicated with by using whatever communication methods he or she possess and we are proposing to expand that to include a description of effective communication methods utilized by the person (in bold on the handout). I do have concerns with line 39 (g) which adds the term "deaf-blindness" to the definition

When we created the law the House Select Committee on Developmental Disabilities spent many hours with consumers, service providers and advocates writing each line in the bill. Our philosophy was that we

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did not want to include a laundry list of disabilities and conditions and their definitions. We wanted this Act to serve those who have the most severe disabilities and we wanted to reduce the waiting lists for individuals to receive services. Therefore, we wrote the eligibility requirements to reflect a “functional” definition. Attachment B shows both the federal definition and the Kansas definition.

On page two, line (2) developmental disability is expanded to include deafblindness.

My concern is that adding different populations to this definition, could result in an expansion of the number of people served and thus a return to the waiting lists of the past. If the legislature wishes to add to the definition of developmental disabilities, then we would hope that there would be a corresponding increase in funding for the new populations being served.

Many individuals with deafblindness do qualify under the DD Reform Act and are being served. These are individuals whose disabilities occur before 22 years of age; are likely to continue indefinitely; result in a substantial limitation in three or more of the following areas of major life functioning: Self-care, receptive and expressive language development and use, learning and adapting, mobility, self-direction, capacity for independent living and economic self-sufficiency; and reflect 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.

There are many people with developmental disabilities being served under the DD Reform Act. The types of disabilities are numerous and diverse. I do not believe that it is possible to list the many types of disabilities which could qualify one under the DD Reform Act nor do I believe that there should be an attempt to do so. Rather, if someone is denied service under this Act and believes that they should qualify, they should make an appeal through SRS. Several such appeals have been made and individuals have been found to be eligible. Please do not change a conscientiously studied, carefully crafted law if other means of addressing individual issues are at hand.

I appreciate the opportunity of presenting testimony and would be happy to answer any questions you might have.

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are needed to assist the person to achieve the person's preferred lifestyle;

(4) describe how opportunities of choice will be provided, including specifying means for:

(A) permitting the person to indicate the person's preferences among options presented to the person, by whatever communication methods that person may possess, including a description of effective communication methods utilized by the person;

(B) providing the necessary support and training to allow the person to be able to indicate the person's preferences, including a description of any training and support needed to fully participate in the planning process and other choice making; and

(C) assisting the person or the person's guardian to understand the negative consequences of choices the provider knows the person might make and which may involve risk to that person.

(5) describe when it is necessary necessary to do so, to the person and their support network, how the preferred lifestyle

Definitions of Developmental Disabilities

I. What are Developmental Disabilities as defined by federal law?

Public Law 104-180, as amended, the Developmental Disabilities Assistance and Bill of Rights Act of 1996 defines a developmental disability as:

A severe, chronic disability of a person five years of age or older which -

- is attributable to a mental or physical impairment or combination of mental and physical impairments, and,
- is manifested before the person attains age twenty-two, and
- is likely to continue indefinitely; and
- results in substantial functional limitation in three or more of the following areas of major life activity:
 - Self-care
 - Receptive and expressive language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living; and
 - Economic self-sufficiency, and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

II. What are Developmental Disabilities as defined by Kansas law?

The Department of Social and Rehabilitation Services (SRS) is the primary state agency which provides services and other assistance to individuals with developmental disabilities. The Commission on Mental Health and Developmental Disabilities Services serves those with developmental disabilities.

The Developmental Disabilities Reform Act, passed by the 1995 Kansas Legislature, created a Developmental Disabilities system of services in Kansas. The definition of developmental disabilities, stated in the Act, is as follows:

(f) "Developmental Disabilities" means:

- (1) Mental retardation; or
- (2) a severe, chronic disability, which:
 - (A) Is attributable to a mental or physical impairment, a combination of mental and physical impairments or a condition which has received a dual diagnosis of mental retardation and mental illness;
 - (B) is manifest before 22 years of age;
 - (C) is likely to continue indefinitely;
 - (D) results, in the case of a person five years of age or older, in a substantial limitation in three or more of the following areas of major life functioning: Self-care, receptive and expressive language development and use, learning and adapting, mobility, self-direction, capacity for independent living and economic self-sufficiency;
 - (E) 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
 - (F) does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as a result of the infirmities of aging.

K.S.A. 39-1801 *et seq*