

MINUTES OF THE HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES.

The meeting was called to order by Chairperson Jo Ann Pottorff at 3:30 p.m. on February 12, 1995 in Room 521-S of the Capitol.

All members were present except: Rep. JoAnn Flower
Rep. Susan Wagle

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: John House, SRS Attorney
Tom Laing, InterHab
Sherry Diel, Kansas Advocacy Council
Jane Rhys, Developmental Disabilities Council

Others attending: See attached list

Chairperson Pottorff opened the meeting for hearings on **HB-2957, an act concerning social and rehabilitation services institutions and community care; communication; amending K.S.A. 76-12b01 and 76-12b11 and repealing the existing sections.**

John House, Attorney for Social and Rehabilitation Services appeared in support of HB-2957. Mr. House directed members attention specifically to the "limited" purposes and confidentiality provisions of **HB-2957 (Attachment #1)**. The SRS position is that under current law patient information cannot be shared with Community Developmental Disability Organizations (CDDOs) without specific signed consent from the individual, parent or guardian.

Members were advised that in order for the Community Developmental Disability Organizations (CDDOs) to plan for the arrival of people from institutions they need to know who is in institutions and what their needs are if they were returned to their community. Questions were raised as to whether or not there is a real need for this bill. If there is a need, are these the proper statutes under which to address the issue? Are there not conflicts with K.S.A. 65-5061 thru 5605, specifically K.S.A. 65-5602 which appears to be directly opposite to the proposed amendment?

Tom Laing, Executive Director, InterHab explained some of the background leading to the perceived need for this bill. However, InterHab believes the matter can be handled administratively under existing law (**Attachment #2**). Staff is not certain this bill takes care of the interaction between the 65-5061 series and proposed revisions.

Sherry Diel, Kansas Advocacy & Protective Services, Inc., appeared in support of the limited disclosure of patient records as proposed in HB-2957 (**Attachment #3**). Discussed the philosophy of the guardians positions and the abrogation of patients rights. KAPS sees no conflict resulting from this bill.

Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities, stated this organization strongly supports the idea of informed choice, while at the same time they support confidentiality measures (**Attachment #4**).

Members discussion raised several questions in regard to the need for this bill. They would like to know approximately to how many persons this would apply, and is this the proper method to remedy the perceived problems. Members asked staff to take a look at statutes involved, check the interaction of the statutes and see if this duplicates present statutes, and explore whether or not there is already a means by which needed information can be shared. Staff Revisor, briefly explained some of the potential conflicts and statutes which need to be explored. The Chair appointed a sub-committee to work on resolving these questions.

The minutes of the February 5, 1996 meeting were approved.

The next committee meeting will be on call. The meeting adjourned at 4:45 p.m.

Kansas Department of Social and Rehabilitation Services
Rochelle Chronister, Secretary

House Select Committee on Developmental Disabilities

Testimony on H.B. No. 2957

February 12, 1996

Madam Chairman and Members of the Committee, on behalf of Secretary Chronister, thank you for this opportunity to speak in favor of HB 2957. My name is John House, Staff Attorney within the Department of Social and Rehabilitation Services. This Bill was introduced at the request of the department. We believe it is necessary to implement the provisions of the Disability Disabilities (DD) Reform Act passed last session. In the Reform Act, now found as KSA 39-1801 and following sections, Community Developmental Disability Organizations (DCCOs) were made the central point of application and referral for DD services. The CDDO is now the agency that determines who is and who is not eligible for community services and at what level of care they can best be served. The CDDO is responsible for being familiar with the types of services available in the community, and has the responsibility to inform persons seeking DD services about those community services and what might be available to assist them.

The Secretary's draft implementing regulations for the Reform Act further builds upon this concept of the CDDO being the central focus of obtaining services by giving the CDDO a "gatekeeper" role with regard to admissions into the state institutions. This is intended to complete the circle or mirror the central point role the CDDO has with regard to planning for community services whenever a person being served in a state institution is ready to or is thought possibly ready to exit an institution.

The intent behind the proposed amendment to KSA 76-12b11 which this Bill would make is to facilitate the CDDO's role. Normally, signed releases of information and consents will be utilized to allow the CDDO and the state institution to exchange records and information in order to allow the CDDO to make judgments as to whether particular individuals would be appropriate to be or are not yet ready to be served by community providers. However, that is sometimes a cumbersome process and is susceptible to abuse by persons intent on thwarting the Reform Act's intent. This amendment simply allows the direct exchange of this information for the limited purposes stated, those being to allow the CDDO to:

- 1) determine whether a proposed admission to a state institution could be avoided where community services would meet the needs of that person;
- 2) determine when an individual already institutionalized might be able to be served in the community; and
- 3) help to plan for continued services for someone about to leave a state institution.

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Nothing in this amendment allows the CDDO to unilaterally prohibit an admission to a state institution, or require a discharge, or force any person to receive any community service they do not want. The consent of the person, their parent if the person is a minor, or their guardian if one has been appointed, is still required to do any of those things -- which is consistent with current law. It is only intended by this amendment to give to the CDDO the information the CDDO needs to fulfill its role in assessing and matching persons to potential community services.

With regard to confidentiality, it is was our intent, and we believe it is implicit in the provisions of the Reform Act, that any information about persons seeking or receiving services received by a CDDO will be maintained confidentially by the CDDO. We note that the provision of KSA 65-5601 thru 5605 which required such confidentiality are applicable to CDDOs now and would still be if this amendment as it is currently written were adopted. However, we would now suggest that the following additional language could be added at the end of the proposed amendment on page 3, line 12 of the Bill to make explicit this confidentiality of any records or information which may be provided to any CDDO by provision of this new law:

“Any community developmental disability organization in receipt of such records or information shall be subject to the same provisions with regard to the confidentiality of such records or information as the state institution is subject to and further as provided for in KSA 65-5601 to 65-5605, inclusive, and amendments thereto.”

Thank you and I'd be happy to answer any questions the Committee might have.

John House
Staff Attorney
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February 12, 1996

TO: Rep. JoAnn Pottorff, Chair
House Select Committee on Developmental Disabilities

FROM: Tom Laing, Executive Director
InterHab: The Resource Network for Kansans with
Disabilities

RE: House Bill 2957 - regarding the confidentiality of
files of persons living in state MR institutions

Thank you Representative Pottorff for making this time available to receive comments on HB 2957.

HB 2957 would require that information on all persons living in institutions may be shared between the institutions and CDDO's, without consent of the resident or the resident's legal guardian. We believe the bill is proposed to force disclosure of resident information against the wishes of some parents and guardians.

We believe this bill is unneeded.

Existing law already provides that (1) a superintendent shall identify residents who may be served in less restrictive settings, and (2) a superintendent may disclose information about residents if needed to assure appropriate care and treatment.

One issue that confused the disclosure question and gave rise to this bill was the state's promise to parents and guardians of WSHTC residents that they could choose service at another state institutions. That promise has made some unwilling to explore community options.

Additionally, such a promise is inconsistent with the law, which offers institutional care **only** under the following conditions:

According to K.S.A. 76-12b03, for a person to be admitted to an institution, the Superintendent must find that the institutional setting is the least restrictive available setting,

"No person shall be admitted to an institution ... (unless) placement in the institution is the least restrictive alternative available."

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Further, current law requires that the "least restrictive" finding be reviewed periodically as part of the Superintendent's annual review of the status of the institutional population, per K.S.A. 76-12b05:

"The Superintendent shall periodically review a person's status to insure that the criteria set forth in K.S.A. 76-12b03 is still being met. A review shall be conducted at the end of 90 days, 180 days and one year from the date of admission and at least annually thereafter. A copy of the review report shall be furnished to the person, a natural guardian or a guardian and the court having jurisdiction of the guardianship."

Such periodic and annual reviews, if properly conducted, will determine which consumers should begin the process of moving to less restrictive community settings, and their information should be already in the hands of the CDDO's, which are required by K.S.A. 39-1805 to assist in the securing of community services.

For those consumers who are found by the state to be in need of institutional services, there is no need to share their confidential information with CDDO's.

In all other cases planning should be currently underway for those who could be served in the community, and all information necessary should be made immediately available to CDDO's, as provided for in the Superintendent's authority, as set forth in K.S.A. 76-12b11:

"(a) The records .. shall not be disclosed except .. (2) Upon the sole consent of the superintendent of the institution .. after a written statement by the superintendent that the disclosure is necessary for the care, training or treatment of the resident or former resident. .. "

The statute clearly directs the superintendent to disclose information to assure that care and treatment is provided. While CDDO's are not mentioned in the statute, last amended in 1986, they were clearly defined in K.S.A. 39-1803, enacted in 1995, as the single access point for non-institutional services.

" .. a community developmental disability organization shall have the power and duty to: .. (a) 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 .. "

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Therefore, to contribute to the assurance that a resident or former resident will receive appropriate and adequate care, it is self-evident that superintendents should share relevant information with CDDO's.

Conclusion:

Residents of an institution (or their families or guardians) should be fully informed of services available in the community. This can be best accomplished by the exchange of vital information between the state and those charged with arranging for the provision of services, namely CDDO's.

Changing the law is not needed to accomplish those tasks; administrative action is needed.

If the above steps -- initial findings, periodic review, and appropriate sharing of information -- are not consistently or adequately being taken, the Secretary should take all necessary actions to protect the consumers' statutory right to less restrictive service settings.

KAPS KANSAS ADVOCACY & PROTECTIVE SERVICES, INC.

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MEMO TO: House Select Committee on Developmental Disabilities
FROM: Kansas Advocacy & Protective Services, Inc.
DATE: February 12, 1996
RE: Staff Report on HB 2957

INTRODUCTION

My name is Sherry Diel. I am an attorney with Kansas Advocacy & Protective Services, Inc. (KAPS) which is a federally funded non-profit corporation which advocates for the rights of Kansans with disabilities. We currently administer four (4) different federal programs: (1) Protection and Advocacy for Individuals with Developmental Disabilities (PADD); (2) Protection and Advocacy for Individuals with Mental Illness (PAIMI); (3) Protection and Advocacy for Individual Rights (PAIR); and (4) Protection and Advocacy for Assistive Technology (PAAT).

Pursuant to our federal mandates, it is the duty of KAPS staff to advocate for the expressed interests of persons with disabilities. As many of you know, the Kansas Guardianship Program was a part of KAPS until July 1995, when the guardianship program spun off as a quasi-public agency. As some of you may not know, KAPS separated from the guardianship program due to potential conflicts of interest which may arise between a KAPS client and the guardian which was recruited by the guardianship program. The issues raised by HB 2957 is a good example of such a such a potential conflict of interest because approximately 80 of the wards at WSH were determined by SRS to be in need of guardians and most of the volunteer guardians were recruited by the guardianship program at the time that the guardianship program was part of KAPS.

KAPS' GUIDING PRINCIPLES WITH RESPECT TO GUARDIANSHIPS AND HOSPITAL CLOSURE

With hospital closure on the horizon, KAPS staff believes:

- (1) SRS should explore the possibility of re-establishing family relationships between residents of Winfield State Hospital (WSH) and their family members. It is our understanding that only guardians have been contacted by SRS thus far. However, there have been instances where, due to distance or other reasons, family members were not appointed guardian of the

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person residing in WSH. With the availability of increased services in the community, those family members may now desire to become guardians.

(2) KAPS staff believes that persons with disabilities should reside in the least restrictive environment which meets their needs. We believe that the family member or guardian must be open to explore whether community services are available in the consumer's "home" county which meets the consumer's needs.

(3) KAPS staff has grave concerns about the appropriateness of a guardian who refuses to release information which would allow SRS to explore: a) whether family relationships can be re-established; and b) whether the consumer's needs can be served in a least restrictive environment.

(4) KAPS staff will endeavor to commit staff resources to ensure that both consumers and their family members and/or guardians have the information available to them to make informed decisions concerning the consumer's life. To the extent possible, both persons with disabilities and their families and guardians need to be open to receive information about options from a variety of viewpoints. We believe it is critical that education be provided to all persons with disabilities and their legal representatives.

(5) KAPS staff may represent a ward in a guardianship proceeding if the ward articulates a preference to live in a least restrictive environment when the guardian opposes the move and all reasonably available information suggests that the least restrictive environment is a feasible option. However, because of the conflict of interest issue previously addressed, KAPS staff may not be able to represent a ward who has a volunteer guardian recruited by the guardianship program prior to July 1, 1995.

(6) KAPS staff strongly believes that every person presently residing at WSH must have a community integration plan formulated, whether or not it is actually effectuated, for purposes of assisting the determination by the CDDOs, as the gatekeeper, whether the person's needs can be met in the community.

(7) KAPS staff believes that the Kansas Guardianship Program volunteer guardians will be open to explore successor guardianships in order to re-establish family relationships or to return the consumer to a least restrictive environment in the consumer's home county if the services are available to meet the consumer's needs. KAPS staff will be happy to assist this process in any way possible.

KAPS POSITION WITH RESPECT TO HB 2957

KAPS staff takes no position with respect to passage of the bill for the following reasons:

- (1) With the passage of the DD Reform Act and the promulgation of regulations thereunder, it is very clear that the CDDOs serve as the gatekeeper. No one enters an institution without passing through the CDDO. The CDDOs must annually review those persons who reside in the state institutions to determine if they can be served in a least restrictive environment. The CDDOs must have information about the residents of the state institutions in order to perform their gatekeeping function.
- (2) KAPS staff believes that the appropriateness of any guardian who refuses to sign a release to allow the CDDOs to perform their gatekeeping function must be questioned and we believe that SRS has a duty to refer these matters to the appropriate probate court for a determination as to whether the guardian is acting in the best interests of the ward.
- (3) KAPS staff believes that SRS already has policies in place in the form of the Community Integration Project which address these issues. Pursuant to page 15-16 of the Community Integration Project Handbook states in Section V.A.2 as follows:

Risk:

- a. The individual will not be allowed to choose an option which is likely to result in unacceptable risk to his/her safety and security.
- b. The individual will not be allowed to choose an option which is not supported by a legally appointed guardian.

- (1) Family guardians who unreasonably obstruct the quality of life for an individual ward must be referred to the court for reevaluation.
- (2) KAPS [now Kansas Guardianship Program] guardians who unreasonably obstruct the quality of life for an individual ward must be discussed with KAPS [now KGP] staff prior to requesting a court review.

KAPS staff believes that SRS already has policies in place to handle the situation where a guardian fails to sign a release of information to enable the CDDOs to perform their duties and that guardians who refuse to sign releases for this purpose must be reevaluated as not acting in the best interest of the ward. Because policies are already in place, we are not sure that a change in the confidentiality laws is required.

Thank you for the opportunity to address your Committee. If you have any questions, I will be happy to address them.

COMMUNITY INFORMATION SHEET

NAME	DOB	DDP INFO
COUNTY OF ORIGIN	SS#	Adapt. _____ Maladapt. _____ Health _____ Tier _____ DATE COMPLETED _____
STATE HOSPITAL	MALE FEMALE	
GUARDIANSHIP STATUS	FULL LIMITED NONE OTHER	
KAPS GUARDIANSHIP	YES NO	SRS CUSTODY YES NO

GUARDIAN NAME	RELATIONSHIP
GUARDIAN ADDRESS	GUARDIAN PHONE #
HAS RELEASE OF INFORMATION FORM BEEN SIGNED?	YES NO
DATE SIGNED	_____ - _____ - _____

FAMILY MEMBERS

NAME	ADDRESS	RELATIONSHIP	INVOLVEMENT

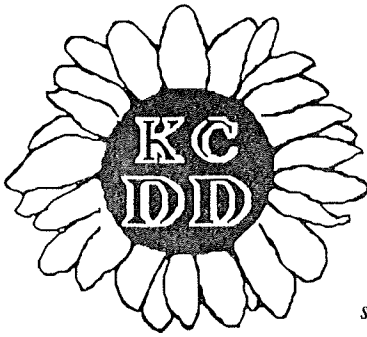
- HAS GUARDIAN OR FAMILY BEEN CONTACTED SPECIFICALLY TO DISCUSS COMMUNITY PLACEMENT? YES NO
DATE CONTACTED _____ - _____ - _____
- IS CLIENT OR GUARDIAN CONSIDERING COMMUNITY PLACEMENT? YES NO
CITY OR AREA PREFERENCE? _____
SERVICE PROVIDER PREFERENCE? _____
DESIRED TIME FRAME FOR MOVING? _____
- IS CLIENT OR GUARDIAN OPPOSED TO COMMUNITY PLACEMENT? YES NO
REASON FOR OPPOSITION? _____

- HOSPITAL STAFF COMMENTS _____

- HAVE PARENTS, GUARDIAN, OR FAMILY INDICATED THEY DO NOT WANT TO BE CONTACTED BY THE COMMUNITY SERVICE PROVIDER? YES NO
- HOSPITAL STAFF CONTACT PERSON _____ PHONE _____
DATE FORM WAS COMPLETED _____ - _____ - _____
- FORM SENT TO STATE OFFICE _____ - _____ - _____

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INSTRUCTIONS AND ADDITIONAL COMMENT SPACE ON BACK



Kansas Council on Developmental Disabilities

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

SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES

FEBRUARY 12, 1996

Testimony in Regard to H.B. 2957

AN ACT CONCERNING SOCIAL AND REHABILITATION SERVICES INSTITUTIONS AND COMMUNITY CARE; COMMUNICATION.

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

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities in support of H.B. 2957, amending the Developmental Disabilities Reform Act to permit state institutions to exchange information with Community Developmental Disability Organizations (CDDOs).

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 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 regarding their participation in society, just as you and I have choices.

I have mixed feelings about this proposed amendment. On the one hand I strongly believe in *informed* choice and I do not see how one can make an informed decision unless one knows all the options. Therefore I support the institutions providing information to the CDDOs regarding persons who are moving from the institution to the community.

On the other hand, I also support confidentiality and wonder if we are curing the wrong illness. If the problem with information exchange is the parent/guardian, shouldn't we be looking at whether this person truly has the consumer's best interests at heart?

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Unfortunately, I recognize that this involves legal action which takes time and costs money and which may not always be the most efficient/effective method to use in resolving this problem. The main concern here must and is the consumer. For that reason, and after much discussion with parents and consumers, we will support this amendment. I appreciate your time and the opportunity of providing testimony and I would be happy to answer any questions you may have.

Jane Rhys, Executive Director
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