

Approved: 2-1-94
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 January 27, 1994 in Room 526-S of the Capitol.

All members were present except:

Committee staff present:

William Wolff, Legislative Research Department
Emalene Correll, Legislative Research Department
Jo Ann Buntin, Committee Secretary

Conferees appearing before the committee:

Robert C. Harder, Secretary, Kansas Department Health and Environment
Paul Klotz, Community Mental Health Centers of Kansas
Jerry Slaughter, Executive Director, Kansas Medical Society
Josie Torrez, Families Together, Inc.

Others attending: See attached list

Approval of Minutes

The Chair asked for consideration of the minutes of January 11, 12, 13, 18, 19 and 20, 1994. Senator Salisbury made a motion the minutes be approved as written, seconded by Senator Langworthy. The motion carried.

Introduction of bills

The Chair requested introduction of a bill that would direct the Secretary of SRS to appoint a managed care task force to include representatives of local hospitals, physicians in private practice, the Wyandotte County Health Department, University of Kansas Medical Center and other interested community groups that would study the feasibility of implementing a pilot managed care program covering all Medicaid eligible residents in Wyandotte County. Senator Jones made a motion the Committee recommend introduction of the proposed legislation, seconded by Senator Ramirez. The motion carried.

Bill Briefing

Staff briefed the Committee on the following bills:

SB 518 - More information to be supplied to the health care database

SB 577 - Establishing the health care data base fee fund

SB 519 - Neonatal screening program for genetic diseases

Hearing on SB 518-More information to be supplied to the health care database

Robert C. Harder, Secretary, KDHE, appeared in support of **SB 518** with recommended changes that would retain the reference to K.S.A. 65-425 to include home health agencies as defined by subsection (b) of K.S.A. 65-5101, community mental health centers and community facilities for the mentally retarded. Dr. Harder noted that with these recommended changes, the bill would broaden the scope of health care data collection and provide a better view of the utilization patterns, costs, quality and quantity of health care services in the state. A balloon of the bill was provided showing these recommended changes. (Attachment 1)

In answer to a member's question regarding clarification of facility as defined in K.S.A. 65-425, Dr. Harder noted that would refer to hospital ambulatory care, and that there is some confusion as to whether or not KDHE had properly included them, and for that reason they are defined in this way. State hospitals are included by reference in the statutes. It was noted by staff that language pertaining to that section needed to be changed, and Dr. Harder commented he would work with the Revisor's office to make those changes.

Paul Klotz, representing the Community Mental Health Centers of Kansas as well as speaking for the Kansas Association of Rehabilitation Facilities, appeared before the Committee in support of **SB 518**, and in particular, language that addressed the inclusion of mental retardation facilities. Mr. Klotz noted that Dr. Harder had included his group to sit on the advisory committee.

Jerry Slaughter, KMS, addressed the Committee in support of the concept of a comprehensive database in **SB 518** but expressed concern as to what data would be required and how often, especially in rural areas where physicians' time would be better spent taking care of patients. Mr. Slaughter noted that KMS supports the expansion contained in the bill with the addition of proposed amendments adopted by the governing board as noted in a balloon of the bill. The amendments basically require that any information collected pursuant to the law be confidential and released only pursuant to rules and regulations, not unlike a similar requirement in the vital statistics act. (Attachment 2)

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE, Room 526-S
Statehouse, at 10:00 a.m. on January 27, 1994.

Written testimony was received from Harold Riehm, Executive Director, Kansas Association of Osteopathic Medicine, in support of **SB 518**, and suggested in his testimony that in soliciting the participation of physicians and all health care providers, only data essential and important be collected, and appropriate attention always be given to matters protecting confidentiality of information. (Attachment 3) Written testimony was also received from Terri Roberts, Executive Director, Kansas State Nurses Association, in support of the concept of **SB 518** and questioned if licensed home health agencies would be included in the bill. (Attachment 4) There were no opponents to **SB 518**.

Hearing on SB 577-Establishing the health care database fee fund

Robert C. Harder, KDHE, expressed his support for **SB 577** which establishes a fee fund in the state treasury for the health care database. It provides an account into which fees, charges or grant monies can be deposited and then subsequently used by KDHE to supplement costs of maintenance, provision of technical assistance and dissemination of information from the database. (Attachment 5) There were no opponents to **SB 577**

Hearing on SB 519-Neonatal screening program for genetic diseases

Robert C. Harder, KDHE, expressed his support for **SB 519** and noted that the bill recommends amending some language in K.S.A. 65-180, 181, and 183 to be consistent with recommendations of the American Academy of Pediatrics and the Centers for Disease Control and Prevention. New sections are recommended in order to better define follow-up activities, establish an advisory committee and institute a dedicated cost recovery system. (Attachment 6)

In answer to a member's question regarding the \$22.00 program fee assessed to all birthing centers for each infant, Dr. Harder noted that fee would be passed on to the patient or covered by insurance and be part of the delivery cost. The new fee would make the program totally self-supporting, encompassing some of the things KDHE is already doing in addition to what is proposed.

In regard to other genetic diseases that are detected from the same specimen, Dr. Roger Carlson, KDHE, commented that language change was needed to accommodate those additional genetic diseases that are not specific from the same specimen and is the intent throughout the bill. In order to carry out this program in locating infants and monitoring them, Dr. Harder noted that the expectation would be to have parental involvement and hopefully with parental consent. That is one of the reasons KDHE is proposing an advisory committee, and through that advisory committee would obtain consultation. Additional protection beyond would be specified by rules and regulations. Dr. Harder commented that he had not heard of any suggestion that they would do this without parental consent. Dr. Carlson noted that once the specimen has been through the lab, the test results are sent to the physician and the household, however, there are some infants that are difficult to locate and some that have the attending physician listed that is not the actual physician. It was noted by staff that some testing was originally done in private labs, and it was the department that came to the legislature several years ago and asked that the testing all be done in state labs so that they would be more uniform. At that time there was no cost to the parents and whoever was involved, so this would be a change in policy.

Josie Torrez, Families Together, Inc., commented they are in favor of the concept of the bill, and recommended to the Committee that "morbidity" be changed to "chronic illness," and on page 1, line 39, "on-going education and support activities for individuals," be changed to "and their families". During Committee discussion it was pointed out that the term morbidity and mortality are used interchangeable, and KDHE would not have a problem to better phrase that term. The Chair noted this should be checked with the Revisor as not to change that common understanding. (Attachment 7)

There were no opponents to **SB 519**.

A fiscal note was requested by a member of the Committee in regard to the advisory committee as referenced in **SB 519**. Dr. Harder noted that \$5,698 has been allotted to cover travel and subsistence expenses of the advisory committee. During Committee discussion it was noted that the governing board in **SB 518** currently exists and has been functioning since last summer, and that an audit would be performed by the year 1997 in regard to the health care database - such audit to be performed by Legislative Post Audit. Dr. Harder noted that individuals at KDHE and KHA will be setting up whatever mechanism necessary in the interest of establishing the audit, and comments were also made regarding confidentiality in supplying information to the database.

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

The next meeting is scheduled for February 1, 1994.w

GUEST LIST

COMMITTEE: SENATE PUBLIC HEALTH & WELFARE

DATE: 1-27-94

NAME	ADDRESS	COMPANY/ORGANIZATION
WILLIE W. CRAFT	KDHE/KHEL	
Josie Torres	Topeka	Families Together
Kay Domingo	KANSAS / BEN	
SHELBY SMITH	Wichita	EPMA
GARY Robbings	Topeka	Ks Optometric Assn
Kobun Walker	Topeka	SRS
Peggy Jarman	Wichita	PCAL
Jennifer Brandenberg	R.C.	PCAL
KEITH R LANDIS	TOPEKA	CHRISTIAN SCIENCE GROUP ON PUBLICATION FOR KS
Michelle Peterson	Topeka	Ks Gov Consulting
Andy Deper	Lawrence	Sen. Burke
Jim Poth	Topeka	SRS
Linda Lubensky	LAWRENCE	KS Home Care Assoc
Carl Schmitthener	Topeka	Ks Dental Assoc
Chip Wheelen	Topeka	Ks Medical Soc.
Ric Vix	WICHITA	High School government group
Velda Rodriguez	Wichita	High School gov. class
Victoria Alton	Wichita	" "
Marie Delinger	Wichita	AP High school Gov.
Jamie Fisher	Wichita	" "
Ashley Simpson	Wichita	High School Govt Class
John R. Poth	TOPEKA	KDHE
Robert Hansen	LSOB	KDHE

GUEST LIST

COMMITTEE: SENATE PUBLIC HEALTH & WELFARE

DATE: 1-27-94

[illegible]

State of Kansas

Joan Finney, Governor



Department of Health and Environment

Robert C. Harder, Secretary

Testimony presented to

Senate Public Health and Welfare

by

The Kansas Department of Health and Environment

Senate Bill 518

The current statute K.S.A. 65-6805 requires health care data be submitted by medical care facilities and third party payors to the health care database as prescribed by the Health Care Data Governing Board. This statute is considered inadequate in providing the Governing Board authority to access information from all providers of health care in Kansas. Without data from physicians, other health care personnel, adult care homes, home health agencies, pharmacies, mental health, mental retardation facilities and laboratories, a complete view of the health care system activity would not be available to the database. Therefore, the information available for policy making would be seriously deficient.

However, it has come to our attention that some health care provider groups are not included in the bill as it is currently written. We propose changes be made to retain the reference to K.S.A. 65-425, to include home health agencies as defined by subsection (b) of K.S.A. 65-5101, community mental health centers and community facilities for the mentally retarded.

With these recommended changes, this bill broadens the scope of health care data collection and will provide a better view of the utilization patterns, costs, quality and quantity of health care services in the state. This bill will assist the Governing Board in developing a more comprehensive and informative health care database.

Testimony presented by: Robert C. Harder
Secretary
Kansas Department of Health and Environment
January 27, 1994

Senate PH&W
Attachment #1
1-27-94

SENATE BILL No. 518

By Committee on Public Health and Welfare

1-18

AN ACT relating to reporting of information to health care database; amending K.S.A. 1993 Supp. 65-6801 and 65-6805 and repealing the existing sections.

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

Section 1. K.S.A. 1993 Supp. 65-6801 is hereby amended to read as follows: 65-6801. (a) The legislature recognizes the urgent need to provide health care consumers, third-party payors, providers and health care planners with information regarding the trends in use and cost of health care services in this state for improved decision-making. This is to be accomplished by compiling a uniform set of data and establishing mechanisms through which the data will be disseminated.

(b) It is the intent of the legislature to require that the information necessary for a review and comparison of utilization patterns, cost, quality and quantity of health care services be supplied to the health care database by all medical care facilities as defined by subsection (h) of K.S.A. 65-425, and amendments thereto, and all other health care providers providers of health care services and third-party payors to the extent required by K.S.A. 1993 Supp. 65-6805 and amendments thereto and this section and amendments thereto.

(c) The information is to be compiled and made available in a form prescribed by the governing board to improve the decision-making processes regarding access, identified needs, patterns of medical care, price and use of health care services.

Sec. 2. K.S.A. 1993 Supp. 65-6805 is hereby amended to read as follows: 65-6805. Each medical care facility or representative of the facilities as defined by subsection (h) of K.S.A. 65-425, and amendments thereto, health care provider as defined in K.S.A. 40-3401 and amendments thereto; providers of health care as defined in subsection (f) of K.S.A. 65-5001 and amendments thereto; health care personnel as defined in subsection (e) of K.S.A. 65-5001 and amendments thereto; psychiatric hospital hospitals licensed under K.S.A. 75-3307b and amendments thereto; state institutions for the mentally retarded; adult care homes as defined by K.S.A. 39-923

facility as defined by subsection (h) of K.S.A. 65-425 and amendments thereto;

home health agencies as defined by subsection (b) of K.S.A. 65-5101;

community mental health centers and community facilities for the mentally retarded as defined by K.S.A. 19-4001 and amendments thereto;

1 *and amendments thereto; laboratories described in K.S.A. 65-1,107*
2 *and amendments thereto; pharmacies; and third-party payors, in-*
3 *cluding but not limited to, licensed insurers, medical and hospital*
4 *service corporations, health maintenance organizations, fiscal inter-*
5 *mediaries for government-funded programs and self-funded employee*
6 *health plans, shall file annually health care data with the secretary*
7 *of health and environment as prescribed by the board.*

8 Sec. 3. K.S.A. 1993 Supp. 65-6801 and 65-6805 are hereby re-
9 pealed.

10 Sec. 4. This act shall take effect and be in force from and after
11 its publication in the statute book.

6-1

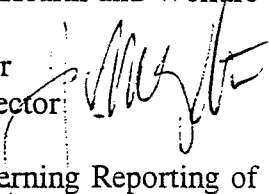


KANSAS MEDICAL SOCIETY

623 SW 10th Ave. • Topeka, Kansas 66612 • (913) 235-2383
WATS 800-332-0156 FAX 913-235-5114

January 27, 1994

TO: Senate Public Health and Welfare Committee

FROM: Jerry Slaughter
Executive Director 

SUBJECT: SB 518; Concerning Reporting of Information to the Health Care Database

The Kansas Medical Society appreciates the opportunity to appear today on SB 518. This bill would expand the list of health care providers who must report cost and other information to the health care database. Current law for the most part requires institutional providers of care, plus insurance companies, to file information with the Secretary of Health and Environment, as directed by the governing board of the health care database.

The expansion contemplated in SB 518 is significant, since it for the first time will require individual providers of health care to file information with the Secretary. While we do not oppose the reasonable gathering of information necessary to complete the full picture of data needs in our state, I must admit that we are going along reluctantly. Our reluctance stems from the fact that, especially in our rural areas, any unreasonable requests of individual physicians which are either costly or time-consuming will not only detract from patient care, but could impose a burden on smaller practices. The law is silent on the manner and extent to which data is to be gathered, which creates concern and uncertainty about the impact of this expansion on physicians across the state.

However, in the spirit of attempting to work cooperatively towards assembling a comprehensive database to aid the Legislature in better understanding and planning for health care reform in the coming years, we have agreed to support the expansion contained in SB 518, with the addition of the amendments adopted by the governing board which were mentioned by Dr. Harder in his bill request. We have attached a copy of those amendments for your information. The amendments basically require that any information collected pursuant to the law be confidential and released only pursuant to rules and regulations, not unlike a similar requirement in the vital statistics act.

We appreciate the opportunity to appear today, and would be happy to respond to any questions you might have.

JS/cb

Attachment

Senate PH&W
attachment #2
1-27-94

SENATE BILL No. 518

By Committee on Public Health and Welfare

1-18

8 AN ACT relating to reporting of information to health care database;
9 amending K.S.A. 1993 Supp. 65-6801 and 65-6805 and repealing
10 the existing sections.

11
12 *Be it enacted by the Legislature of the State of Kansas:*

13 Section 1. K.S.A. 1993 Supp. 65-6801 is hereby amended to read
14 as follows: 65-6801. (a) The legislature recognizes the urgent need
15 to provide health care consumers, third-party payors, providers and
16 health care planners with information regarding the trends in use
17 and cost of health care services in this state for improved decision-
18 making. This is to be accomplished by compiling a uniform set of
19 data and establishing mechanisms through which the data will be
20 disseminated.

21 (b) It is the intent of the legislature to require that the infor-
22 mation necessary for a review and comparison of utilization patterns,
23 cost, quality and quantity of health care services be supplied to the
24 health care database by all medical care facilities as defined by
25 subsection (h) of K.S.A. 65-425, and amendments thereto, and
26 all other health care providers providers of health care services
27 and third-party payors to the extent required by K.S.A. 1993 Supp.
28 65-6805 and amendments thereto and this section and amendments
29 thereto.

30 (c) The information is to be compiled and made available in a
31 form prescribed by the governing board to improve the decision-
32 making processes regarding access, identified needs, patterns of med-
33 ical care, price and use of health care services.

34 Sec. 2. K.S.A. 1993 Supp. 65-6805 is hereby amended to read
35 as follows: 65-6805. Each medical care facility or representative
36 of the facilities as defined by subsection (h) of K.S.A. 65-425,
37 and amendments thereto, health care provider as defined in K.S.A.
38 40-3401 and amendments thereto; providers of health care as defined
39 in subsection (f) of K.S.A. 65-5001 and amendments thereto; health
40 care personnel as defined in subsection (e) of K.S.A. 65-5001 and
41 amendments thereto; psychiatric hospital hospitals licensed under
42 S.A. 75-3307b and amendments thereto; state institutions for the
43 mentally retarded; adult care homes as defined by K.S.A. 39-923

28

1 and amendments thereto; laboratories described in K.S.A. 65-1,107
2 and amendments thereto; pharmacies; and third-party payors, in-
3 cluding but not limited to, licensed insurers, medical and hospital
4 service corporations, health maintenance organizations, fiscal inter-
5 mediaries for government-funded programs and self-funded employee
6 health plans, shall file ~~annually~~ health care data with the secretary
7 of health and environment as prescribed by the board.

(delete)

8 Sec. ~~84~~ K.S.A. 1993 Supp. 65-6801 and 65-6805 are hereby re-
9 pealed.

10 Sec. ~~45~~ This act shall take effect and be in force from and after
11 its publication in the statute book.

K.S.A. 1993 Supp. 65-6806 is hereby amended to read as follows: The secretary of health and environment shall make the data available to interested parties on the basis prescribed by the board and as directed by rules and regulations. It shall be unlawful for any officer, agent or employee of the state who possesses, stores or in any way handles any records, information or data collected pursuant to this act to disclose or disseminate any data or information contained in such records, except as specifically authorized by rules and regulations approved by the board.


Kansas Association of Osteopathic Medicine

Harold E. Riehm, Executive Director

1260 S.W. Topeka Blvd.
Topeka, Kansas 66612
(913) 234-5563
(913) 234-5564 Fax

January 27, 1994

To: Chairperson Praeger and Members, Senate Public Health Committee

From:  Harold Riehm, Executive Director, Kansas Association of Osteopathic Medicine

WRITTEN TESTIMONY ON S.B. 518 - PRESENTED ON THURSDAY, JANUARY 27, 1994

Thank you for the opportunity to offer the support of KAOM for S.B. 518. I am out of the State the day of the hearing so I am presenting KAOM's testimony in writing.

We have been a consistent supporter of efforts to improve the collection, analysis and dissemination of health care data in Kansas, including the recently formed institutionalized effort within Health and Environment.

In line with that we also support the specified provisions of S.B. 518 and pledge the cooperation of osteopathic physicians to assist in the collection of provider related health care data.

The only caveat we would suggest is that in soliciting the participation of physicians and no doubt, all health care providers, that only data essential and important be collected, and that appropriate attention always be given to matters protecting confidentiality of information.

Physicians are already inundated with forms and paperwork. What is added should have a valid and constructive purpose.

Recent communication from Dr. Harder suggests that efforts are being made to incorporate the views of providers not represented on the Board, through special invitations to meetings of the Technical Committee, etc. We are encouraged by these developments. Certainly, we would anticipate having some input into a system that will require participation of the physicians we represent.

With these understanding, we support passage of S.B. 518.

Senate PH&W
Attachment #3
1-27-94

For More Information Contact:

Terri Roberts J.D., R.N.
Executive Director
Kansas State Nurses Association
(913) 233-8638

January 26, 1994

Written Testimony Provided to Committee ONLY

S.B. 518 Amending Health Care Database Information Reporting Statute

Members of the Senate Public Health and Welfare Committee, KSNA is pleased to support the proposed changes to the statute that will permit the governing board to request, review and compare health care data from a broader range of healthcare entities. Health care data of this nature is not well coordinated and not available for policy makers to use in making decisions.

After our review of the proposed changes, (all the definitions added by K.S.A. 40-3401 and K.S.A. 65-5001 (f) and (e)), we are still **uncertain** if **LICENSED HOME HEALTH AGENCIES** will be included. The definition in part (f) of K.S.A. 65-5001 does not make specific reference to Home Health Agencies. We have spoken with staff at KDHE about this, and it is their intent that they be included. We hope that this will be clarified prior to passage by committee.

Thank you.

sb518

Kansas State Nurses Association Constituent of The American Nurses Association

700 SW Jackson, Suite 601 * Topeka, Kansas 66603-3731 * (913) 233-8638 * Fax (913) 233-5222
Carolyn Middendorf, M.N., R.N. -- President * Terri Roberts, J.D., R.N. -- Executive Director

Senate PH&W
attachment # 4
1-27-94

State of Kansas

Joan Finney, Governor



Department of Health and Environment

Robert C. Harder, Secretary

Testimony presented to

Senate Public Health and Welfare

by

The Kansas Department of Health and Environment

Senate Bill 577

The Health Care Data Governing Board is responsible for developing the policies and procedures for the health care database. Included in these policies and procedures will be those related to charges for providing data and information from the database to interested parties such as consultants, marketing agencies, researchers and others. Grant funds or donations may also be available from various agencies for entities such as the Governing Board to assist in database development.

This bill establishes a fee fund in the state treasury for the health care database. It provides an account into which fees, charges or grants monies can be deposited and then subsequently used by KDHE to supplement costs of maintenance, provision of technical assistance and dissemination of information from the database. The legislation is necessary because current administrative procedures do not allow agencies to access user fees necessitating the establishment of a specific fee fund.

Testimony presented by:

Dr. Robert C. Harder
Secretary
January 27, 1994

Senate PH&W
Attachment #5
1-27-94

State of Kansas

Joan Finney, Governor



Department of Health and Environment

Robert C. Harder, Secretary

Testimony presented to

Senate Public Health and Welfare Committee

by

The Kansas Department of Health and Environment

Senate Bill 519

The Kansas Department of Health and Environment holds statutory responsibility to screen all Kansas newborn infants for several genetic deficiency diseases. KDHE is also responsible for educational programs which provide information about the diseases, for the establishment of medical consultation for high-risk infants, and for the provision of treatment products. Rapid detection of these medical conditions during the first thirty days of life along with appropriate supportive therapy has effectively prevented mental retardation and other adverse health effects in our children. The successful operation of this program, which has screened nearly one million Kansas infants since 1965, is an important public health priority.

Senate Bill 519 recommends amending some language in K.S.A. 65-180, 181, and 183 to be consistent with recommendations of the American Academy of Pediatrics and the Centers for Disease Control and Prevention. In addition, new sections are recommended in order to better define follow-up activities, establish an advisory committee, and institute a dedicated cost recovery system.

Particular emphasis on improving follow-up of high-risk infants is necessary to assure that no infants are lost in our present highly mobile society which now often begins with hospital discharge only twelve hours after birth. An advisory committee will establish an essential communication link between medical professionals, hospitals, new parents, and the neonatal screening program. The cost recovery system will provide the necessary funds to support laboratory screening tests, tracking and follow-up of high-risk infants, medical consultation, and treatment products for infants in need of supportive therapy.

There are currently 37,000 to 38,000 live births in Kansas each year. We would propose to begin cost recovery on July 1, 1994, by establishing a \$22.00 program fee assessed to all birthing centers for each infant evaluated. In turn, birthing centers can recover this cost through a

*Senate PH&W
Attachment #6
1-27-94*

specimen collection fee recovered from third party insurers. Within one year, the entire newborn screening program would be supported by user fees to result in a saving of \$600,000 of state general revenue each year. This cost recovery proposal is similar to the program fee structures which are now present in thirty-two states.

In summary, the newborn screening program has served to protect the health of Kansas infants for nearly three decades. It is important that we continue to strengthen the effectiveness of this program through revisions recommended in this legislation.

Testimony presented by: Dr. Robert C. Harder
Secretary
January 27, 1994

TESTIMONY ON SENATE BILL 519

January 27, 1994

Thank you for allowing me to testify on SB 519. My name is Josie Torrez and I work for Families Together, Inc. in Topeka.

We are a proponent of this bill as a neonatal screening program is a wonderful concept as the medical profession could then get the ball rolling to provide a follow up program which will locate infants with abnormal newborn screening test results, monitoring these babies to assure appropriate testing and monitoring therapy and treatment for the babies with confirmed diagnosis of genetic diseases that may cause mental retardation or other chronic illnesses. This bill would also provide on-going education and support activities for individuals with confirmed diagnosis and it would provide the necessary treatment for diagnosed cases for as long as medically indicated. We also favor the concept of every physician having knowledge of a case shall report the case to the Secretary of Health and Environment for them to maintain a registry.

We would like your committee to consider word changes in this bill. On page 1, line 23 and page 2, line 1, the word "morbidity" could be seen as offensive to some. We would like this change of wording to read "chronic illness". We feel it would have the same meaning. Also, on page 1, line 39, "on-going education and support activities for individuals", could read "and their families".

We are pleased to see an advisory committee that would be created to advise the Secretary of Health and Environment include five individuals or parents of a child with a diagnosis of one of the diseases for which screening is done under this act. Who else, but the parents would know what worked and what did not work for their child and how to make this program better?

We see this bill as a way for parents of babies with genetic diseases or chronic illnesses to get the early intervention services they desperately need for their children. The earlier intervention is provided, the less the severity of the disability.

We thank you for considering our word changes.

Senate PHCA
Attachment # 7
1-27-94