

Approved 4-7-89  
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by SENATOR ROY M. EHRLICH at  
Chairperson

10:00 a.m./~~p.m.~~ on March 27, 1989 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Legislative Research  
Bill Wolff, Legislative Research  
Norman Furse, Revisors Office  
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Michael Lechner, Executive Director, Advisory Commttee on Employment of  
Handicapped, Department of Human Resources  
Mike Oxford, Legislative Liaison, Advisory Committee on Employment of the  
Handicapped, Department of Human Resources  
Carol Renzulli, Lawrence Coalition of Citizens with Disabilities  
Terri Roberts, Executive Director, Kansas State Nursing Association  
Pat Johnson for Dr. Lois Scibetta, Kansas State Board of Nursing  
Darlene Hall, Kansas Home Care Association  
Ray Petty, Topeka Independent Living Resource Center  
Barbara Bradford, 1521 Vermont, Lawrence, KS

Michael Lechner appeared in support of HB-2012 stating that the Kansas Department of Human Resources' Advisory Committee on Employment of the Handicapped strongly supports the bill. He further stated that this bill affirms the right to self-direction by those disabled individuals who are capable of and wish to manage their own care. (Attachment 1)

Mike Oxford appeared in support of HB-2012 stating that Kansas will be taking a leadership role in the nation with the passage of HB-2012 as other states are looking at this program as a model to improve their programs for in-home care. He further stated that HB-2012 is a low cost, effective solution toward solving one of the main issues surrounding the provision of in-home care services. (Attachment 2)

Carol Renzulli, Lawrence, appeared in support of HB-2012 as amended by the House Public Health and Welfare Committee. Ms. Renzulli expressed a hope that health care priorities would be placed before companion-type services, such as letter writing and reading mail. This would insure that daily activity needs would be met before other needs. (Attachment 9)

Terri Roberts, KSNA, appeared concerning HB-2012 stating that her organization supported a state model for the delivery of in-home care that provides for professional nurse supervision over services provided, including, but not limited to case management. (Attachment 3)

Pat Johnson appeared for Dr. Lois Scibetta, Kansas State Board of Nursing, in support of HB-2012 in its amended form which includes professional nursing over-sight. (Attachment 4)

Darlene Hall, KHCA, appeared in support of HB-2012 as amended which provides the structure necessary for the process of self-direction. (Attachment 5)

Ray Petty told the committee that this bill has been worked on for a number of years and a great deal of effort has been expended to bring HB-2012 to this point and encouraged passage of this bill. He stated that he was sure all would work to make this system viable for those who wished to live independently.

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 526-S, Statehouse, at 10:00 a.m./~~p.m.~~ on March 27, 1989

Barbara Bradford, Lawrence, appeared in support of HB-2012 stating the bill recognizes the civil rights of those Kansas residents who must depend on public money for attendant care services. (Attachment 6)

Chairman Ehrlich introduced his pages, Charity Muth and Lee Ann Achatz from Great Bend, Kansas.

Staff presented a Memorandum on HB-2108 and presented information concerning the two different definitions of "abuse" as they appear in HB-2206 and HB-2108. Janet Schlansky, Director of Community Services, SRS had suggested in her testimony that these two statutes be looked at and made more consistent. Following discussion among staff it was concluded that more consideration was needed before any consistency was attempted since the two issues do not necessarily fit together. Staff explained the 1988 Missouri statutes which had been requested by the committee. The Missouri law has no penalty for failure to report and no listing of specific persons who are mandated to report. (Attachment 7)

Written testimony was presented to the committee from Stephen Mashburn, Wichita, Kansas who related how the Home & Community Based Services he receives have deteriorated in the past few years with a tremendous increase in administration fees between 1986 and 1988 along with a decrease of funds for in-home care. (Attachment 8)

The committee adjourned at 10:45 a.m. and will convene at 10:00 a.m. Tuesday, March 28, 1989 in room 526-S

SENATE  
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE March 27, 1989

(PLEASE PRINT)  
NAME AND ADDRESS

ORGANIZATION

Richard Morrissey

KDHE

GREG RESEE

KDHE

My Nelson Holloway

KHCA

Mike Oxford Topeka

KACEH

Mike Lechner Topeka

LI

Barbara Brudford Lawrence

KU RIT Center

Pat Johnson

State Board of Nursing

Janette Pucci

Bd of Nursing

Mark Intermill Topeka

Kansas Coalition on Aging

Paul Renzulli

Lawrence CCD

Lox Graybeal

TILRS, Inc

Ray Petty

Topeka Independent Living  
Resource Center

Martha Gaberars

KACEH

Allyn D. Fokker Topeka

SRS

Janet Schalansky

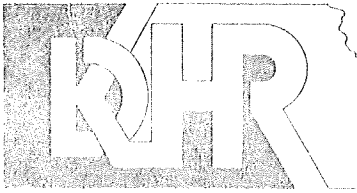
SRS - AS

Terri Roberts

Kansas State Nurses' Assoc.

Sian Colyer

KSNA

ADVISORY COMMITTEE ON EMPLOYMENT  
OF THE HANDICAPPED1430 S.W. Topeka Boulevard, Topeka, Kansas 66612-1877  
913-296-1722 (Voice) • 913-296-5044 (TDD) • 561-1722 (KANS-A-N)

Mike Hayden, Governor

Dennis R. Taylor, Secretary

TESTIMONY ON HB 2012: MARCH 27, 1989  
MICHAEL LECHNER, EXECUTIVE DIRECTOR

Members of the Senate Committee on Public Health & Welfare, thank you for the opportunity to testify on House Bill 2012. I commend those of you who sat on the Interim Study for producing a bill which will make significant and positive differences in the way self-directed Kansans with disabilities may live their lives. HB 2012 is the product of hard compromises among home health agencies, nurses, disability rights advocates and consumers.

HB 2012 is a strong piece of legislation which affirms the right to self-direction by those disabled individuals who are capable of and wish to manage their own care. This important right has been traditionally ignored or compromised under the guise of protecting the client from harm and protecting the bureaucracy from liability.

HB 2012 would allow unlicensed people to be paid for providing attendant care to individuals with disabilities. Currently, unlicensed people are permitted to provide attendant care services in the home as long as they do not receive payment for it. It is very difficult to hire anyone to perform these services; to acquire these services gratuitously is more than close enough to impossible.

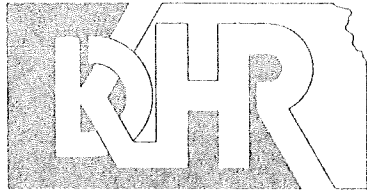
HB 2012 provides for the expansion of services available to clients of the SRS' Home & Community Based Services (HCBS). These services are not currently available because there is no state law which defines them as part of attendant care services.

HB 2012 mandates the inclusion of consumers in the planning, start-up, delivery and administration of attendant care programs. This mandate is crucial to the success of the HCBS program, for it allows input from those whom the program affects before policy decisions are made and it gives administrators feedback from various consumer perspectives.

The Kansas Department of Human Resources' Advisory Committee on Employment of the Handicapped strongly favors and supports HB 2012. We ask that you report this bill favorably.

Again, I thank you for your excellent work on this significant legislation. I will be pleased to entertain any questions.

SRT/KW  
3-27-89  
Attachment 1

ADVISORY COMMITTEE ON EMPLOYMENT  
OF THE HANDICAPPED1430 S.W. Topeka Boulevard, Topeka, Kansas 66612-1877  
913-296-1722 (Voice) • 913-296-5044 (TDD) • 561-1722 (KANS-A-N)

Mike Hayden, Governor

Dennis R. Taylor, Secretary

March 27, 1989

TESTIMONY IN SUPPORT OF HOUSE BILL 2012  
Presented by Mike Oxford, Legislative Liaison

Thank you for the opportunity to appear before the committee. My remarks will be brief as just about everything that could be said, has been said, during the course of the interim study and while the bill was being worked in the other chamber.

House Bill 2012 is a low cost, effective solution toward solving one of the main issues surrounding the provision of in-home care services. How can in-home care be provided which maximizes individual choice and independence while at the same time maximizing health and well being? House Bill 2012 goes a long way towards answering this basic question. It does this by allowing for increased flexibility and most importantly, consumer input throughout the whole process of assessment and service delivery.

For those who are unable or unwilling to have very much input into their plan of care, House bill 2012 provides the protection and professional input that is needed in these cases. Supervision of the plan of care and service delivery will shift from social workers alone to include nurses and other health care professionals. Furthermore, training can be provided to consumers to enable them to become more independent and to take increasing control over their lives where this is desired and appropriate.

Kansas will be taking a leadership role in the nation with the passage of House Bill 2012. Other states are looking to this program as a model for them to use to rationalize and improve their programs for in-home care. Favorable support of this bill will affirm our state's leadership role.

Thank you very much. I would be happy to answer any questions.

ws:a:h2012z

SPH/W  
3-27-89  
Attachment 2



FOR MORE INFORMATION CONTACT  
Terri Roberts J.D., R.N.  
Executive Director  
Kansas State Nurses' Association  
(913) 233-8638  
March 27, 1989

## H.B. 2012 In-Home Care and Services for Handicapped and Functionally Disabled Persons

Chairman Ehrlick and Members of the Senate Public Health and Welfare Committee, my name is Terri Roberts R.N. and I am a registered nurse representing the Kansas State Nurses' Association. Thank you for the opportunity to speak on H.B. 2012.

As you may suspect, any proposed changes in the Kansas Nurse Practice Act K.S.A. 65-1113 are of great concern to Registered Nurses. Licensure laws of health care personnel were originally designed to protect the public through the limited use of titles. Today, Nurse Practice Acts continue to protect the public by limiting individuals performing nursing services, to those who are licensed to do so.

Currently the more than 20,000 R.N.'s in Kansas are responsible for supervising LPN's, LMHT's, Certified Medication Aides, Nursing Homes Aids, Home Health Aides and other unlicensed personnel employed by agencies providing health care in a variety of settings.

The Kansas State Nurses' Association supports a state model for the delivery of services in home care that provides for professional nurse supervision over services provided, including, but not limited to case management. We presented information about the Oklahoma Model during the interim study. It provides a statewide network of in-home services that is provided by unlicensed individuals called Non-Technical Medical Care providers. They receive 40 hours of training and they are supervised by Registered Nurses who make periodic visits to the clients they serve.

The Kansas State Nurses' Association strongly objected to the original definition of "health maintenance activities" due to the lack of parameters in the definition. The amended language on lines 51-57 is a compromise between representatives of nursing and the handicapped community. KSNA supports the new definition of health maintenance activities in this bill. We anticipate that rules and regulations to implement H.B. 2012 will address specific issues about training of those providing services that are paid for by SRS. It is critical that whomever is delivering the care is adequately prepared to do so. When licensed nurses deliver services to clients they are legally bound to act in a prudent and reasonable fashion, according to recognized standards of care in the delivery of services. Services that fall below the acceptable standard of care can be addressed by the client/consumer in two different arenas. The licensed nurse can be disciplined by the Board of Nursing, or the client/consumer can seek civil remedies for damages incurred as a result of the failure to act in a reasonably prudent fashion. Licensed nurses have tremendous motivation to appropriately serve the public. This client population is one that can be characterized as particularly vulnerable. The severely and multiply handicapped, and elderly individuals with chronic illnesses are at greatest risk for being exploited and/or abused by their caregivers.

H.B. 2012  
Kansas State Nurses' Association  
March 27, 1989  
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Philosophically speaking, Registered Nurses incorporate promoting self-care and health maintenance into their clinical practice. We recognize the need for individuals who are handicapped to maintain control over their lives. Some of the issues regarding flexibility in the HCBS program, control over attendant hours that were raised during the interim committee hearings are of concern. They must not however, be allowed to overshadow the need to protect the public.

The Interim Committee on Public Health and Welfare collected a tremendous amount of data. The report was very concisely written. It provides a very valuable explanation of the many variables that are impacting the home health setting and delivery of in-home services.

Thank you for the opportunity to speak.

# Kansas State Board of Nursing

Landon State Office Building  
900 S.W. Jackson, Rm. 551  
Topeka, Kansas 66612-1256  
913-296-4929



Lois Rich Scibetta, Ph.D., R.N.  
Executive Administrator

Bonnie Howard, R.N., M.A.  
Practice Specialist

Janette Pucci, R.N., M.S.N.  
Educational Specialist

TO: The Honorable Senator Roy Ehrlich,  
Chairman and Members of the Senate  
Public Health and Welfare Committee

FROM: Dr. Lois *Scibetta*, Executive Administrator

RE: HB 2012

DATE: March 24, 1989

Thank you Mr. Chairman for the opportunity to comment on HB 2012, as amended by the House Committee.

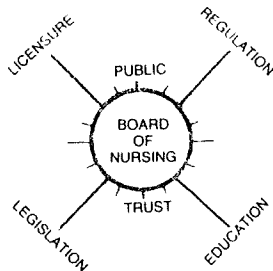
Originally, the Board of Nursing objected to this Bill because the professional nurse was omitted in A.(d)., regarding the supervision of health care maintenance activities. The section was amended to include professional nursing oversight, which is more acceptable to the Board.

Further, the Amendments to Section 3, (m), and Section 4, (b) is much more acceptable.

The Board support HB 2012 in its current amended form. Most of the concerns of the Board of Nursing have been addressed in these Amendments. The Board recommends favorable passage of HB 2012.

Thank you for the opportunity to state the Board's position. We will be happy to respond to questions.

LRS:bph



*SPH/ce*  
*3-27-89*  
*Attachment 4*





Kansas Home Care Association · 4101 West 13th Street · Lawrence, Kansas 66046 · (913) 841-2833

To: Senate Public Health and Welfare Committee  
From: Darlene Hall, KHCA Legislative Chair  
Date: March 27, 1989  
Subject: H.B. 2012

On behalf of the Kansas Home Care Association, I would like to express my appreciation for the opportunity to testify today in regards to H.B. 2012.

KHCA has followed H.B. 2012 closely since its inception during the Interim Study on in-home care services. Although supportive of the desire of the well-disabled for the option of self-direction, we strongly opposed the bill in its original form. It simply did not include the parameters that we felt necessary to prevent abusive and harmful situations for the public. Moreover, it did not designate an appropriate role for the registered professional nurse within the process.

In conjunction with KSNA, SRS, KDH&E, and representatives of the advocacy groups for the well-disabled, KHCA worked with the House Public Health and Welfare sub-committee on H.B. 2012 to address the concerns raised by the various interest groups. The resulting amendments, as accepted by the House Committee and the House Committee of the Whole, do succeed in providing the structure that we felt necessary for the process of self-direction. "Health Maintenance Activities" are limited to those activities that, in the opinion of the attending physician or licensed professional nurse, may be performed by the individual if he were physically capable. In addition, the procedure must be one which may safely be performed in the home. The amendments further limit the "individual in need of in-home care" to functionally disabled adults, but does not restrict the attendant services to just being provided in the individual's residence.

Section 4 (b) was included at the request of KDH&E in order to prevent the undermining of the home health licensure rules and regulations. The Kansas Home Care Association concurs with its intent, as we have no wish to see the quality of our industry compromised through the utilization of untrained staff. However, in order that home health agency staff may be considered as one of the options by individuals desiring self-direction, a regulation change will be necessary to allow our home health aides to perform "health maintenance activities" as defined in the bill. We have been in contact with KDH&E and have been assured that the regulation change should present no problems, following the passage of H.B. 2012.

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Attachment 5

We do however have one remaining concern. Some parts of the process concerning health maintenance activities are inferred rather than included in the language of the bill: the doctor or nurse would 1) decide whether the individual was mentally capable of self-direction, 2) decide what type of appropriate training was necessary for performing a health maintenance activity safely in the home, and 3) would then provide that training. The Kansas Home Care Association would hope that your committee would decide to have those details specifically addressed in the language.

H.B. 2012 is indeed "enabling" legislation. Its flexibility, however, is carefully limited to those well-disabled who are capable and desire the independence of self-direction. It does not "mandate" but allows for choices in appropriate circumstances...choices for the well-disabled to self-direct their care or not, choices to select their own level of caregiver, whether an untrained individual or a certified home health aide.

We do not anticipate that the provisions in H.B. 2012 will be widely used by the public. But, for some, the independence and autonomy that it could provide in their lives is of immeasurable importance. Consequently, we support the concept of H.B. 2012 and the amendments made in the House, while encouraging you to further delineate the specifics of the role of the doctor and nurse in regards to health maintenance activities.

I would be happy to answer any questions or provide any information that you might find helpful.

Sincerely,

A handwritten signature in cursive script that reads "Darlene Hall, RN". The signature is written in dark ink and is positioned above the typed name and title.

Darlene Hall  
KHCA Legislative Chair

Barbara Bradford  
1521 Vermont  
Lawrence KS 66044

Dear Sen. Ehrlich and Committee Members:

I am a Lawrence resident using private pay attendant care. I work full time at KU at a job involving irregular hours and extensive travel - which I could not do unless I controlled my own attendant care and had my attendants perform several services which are now classified as "medical procedures." These are not sophisticated procedures such as IV cancer therapy - rather, they deal with basic necessities such as irrigating a catheter, assisting with the bowel program, and skin and wound care. If my attendants could not assist me with these functions I could not last even one day without the situation becoming life-threatening. It is essential to the majority of severely disabled consumers that the proposed change to the nurse practice act outlined in HB2012 be passed to allow attendants to assist in these basic needs in order for these consumers to even live outside a nursing home, let alone lead independent and productive lives. Right now my own attendants and I violate existing Kansas law by doing what I need done every day. This does not bother my conscience. Twenty five years ago, as a civil rights worker, I violated laws segregating blacks from the rest of our society. I find a law which would unjustly imprison me in a nursing home by prohibiting the care I need in a manner I can control and afford to be just as objectionable, and no more defensible, than the Jim Crow laws which perpetuated segregation. I might add also that if I had to pay some home health care agency twelve bucks an hour (minimum wage to the attendant and the rest for their alleged "administrative overhead") I would have to go without the attendant care I need. It is financially difficult for me as it is to pay \$4.50 an hour (plus benefits, Social Security, and workmen's comp) to get the minimum level of assistance I need, treat my attendants fairly, and still meet other financial obligations.

A representative of The Clinicare Home Health Agency is displaying, in her testimony, a picture of a bedsore and testifying that it was the result of improper care by a private-pay attendant. I do not doubt that testimony, nor is the photo an exaggeration - pressure sores are dangerous and ugly open wounds, they can go down to the bone and can require surgery and months of hospitalization to heal. The point I would like to stress is that the great majority of pressure sores originate in hospitals and nursing homes, not as a result of poor care at home, especially not in cases of self-directed, consumer controlled attendant care. This is not only my own personal experience and that of most disabled people I know, but is also supported by data in a research project conducted by Glen White who is on the staff of the Research and Training Center on Independent Living here at KU. Any stories you are handed concerning neglect, physical and sexual abuse, and rip-off by attendants can be easily topped by a much greater incidence of these abuses in nursing homes.

S P/A/W  
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Attachment 6

HB2012 is an effective response to the needs and concerns of disabled Kansans relying on attendant care services to lead full and productive lives. It credits these disabled Kansas residents with the intelligence and capability to direct this needed attendant care, and removes from the medical arena that physical assistance needed to carry out normal bodily functions and assist in the self-treatment of minor illnesses and injuries. It recognizes that remaining within the confines of one's home does not constitute living in the community, and allows for attendant care while doing errands, attending community events, shopping, eating out, and traveling.

But most importantly it recognizes the civil rights of those Kansas residents who must depend on public money for attendant care services. Those who are able to pay for their own attendant care have been able to hire, train, schedule, and manage their own attendants, to get attendant care when and where they need it, and direct their care so it is done the way they want it. They have been able to attend school and work because they may have the needed degree of flexibility in their attendant care that provides the needed degree of flexibility in their lives. These basic rights have been denied to those who have had to rely on HCBS, which, as the interim study committee stated so very well, is "so over-regulated and restrictive as to make normal life impossible." Social workers make medical decisions, and assume the consumer's prerogative of choosing, scheduling, and training attendants. The present program fosters a situation where those who have money have the right to control a very important and deeply personal aspect of their own lives, and those who are poor do not have these rights, being denied them by present Kansas law and an appalling lack of respect for their human rights on the part of the agency allegedly serving them by administering the HCBS program. This bill recognizes the basic rights of our citizens who rely on HCBS for attendant care by returning these rights to them by changing the law and involving them in the regulations and administration of their own program. HB2012 enables them to control their own lives and ends this intolerable discrimination based on money alone.

The report of the interim study committee is the best document I have ever seen a legislative entity produce on attendant care, and in my past experience and present job I have seen many similar documents. It reflects an excellent understanding of the background of independent living and consumer control, the issues involved, the problems with the present program, and proposed solutions. I strongly recommend that all committee members give this document a thorough reading and re-reading. The interim study committee is to be commended on a job well done.

In the causes of basic human rights and quality of life for Kansans with disabilities, I urge you to pass HB2012 favorably, and in a timely manner, out of committee.

Thank you,

# MEMORANDUM

March 24, 1989

TO: Senate Committee on Public Health and Welfare

FROM: Kansas Legislative Research Department

RE: Definitions of Adult Abuse

At the time of the Committee hearings on H.B. 2108, the Committee requested definitions of adult abuse as they appear in the Kansas act that concerns the reporting and investigation of abuse and neglect of residents of adult care homes, federal and state hospitals, and adult family homes (K.S.A. 39-1401 et seq.) and as set out in the applicable Missouri law.

Under K.S.A. 39-4101, abuse is defined as "neglect, willful infliction of physical or mental injury or willful deprivation by a caretaker of services which are necessary to maintain physical and mental health." The statute further defines the term, neglect, to mean "the failure of a caretaker to maintain reasonable care and treatment to such an extent that the resident's health or emotional well-being is injured." There is no definition of exploitation, nor is fiduciary abuse included in the definitions found at K.S.A. 39-4101.

The Missouri statutes that concern the offering of services to the "eligible adults" are found at V.A.M.S. 660.255 through 660.295. An "eligible adult" under the Missouri law is "a person sixty years of age or older or a handicapped person between the ages of eighteen and fifty-nine who is unable to protect his own interests or adequately perform or obtain services which are necessary to meet his essential human needs." V.A.M.S. 660.250.

The Missouri statute does not define abuse, rather it refers to likelihood of serious physical harm. The latter is defined as one or more of the following:

"(a) A substantial risk that physical harm to an eligible adult will occur because of his failure or inability to provide for his essential human needs as evidenced by acts or behavior which has caused such harm or which gives another person probable cause to fear that the eligible adult will sustain such harm;

"(b) A substantial risk that physical harm will be inflicted by an eligible adult upon himself, as evidenced by recent credible threats, acts, or behavior which has caused such harm or which places another person in reasonable fear that the eligible adult will sustain such harm;

"(c) A substantial risk that physical harm will be inflicted by another upon an eligible adult as evidenced by recent acts or behavior which has caused such harm or which gives another person probable cause to believe the eligible adult will sustain such harm;

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"(d) A substantial risk that further physical harm will occur to an eligible adult who has suffered physical injury, neglect, sexual or emotional abuse, or other maltreatment or wasting of his financial resources by another person;"

Although the Missouri law states that any person having reasonable cause to suspect that an eligible adult presents a likelihood of suffering serious physical harm and is in need of protective services shall report such information to the Department of Social Services, it apparently does not mandate that any specific individuals report suspected abuse. There is no penalty for failure to report and no listing of specific persons who are mandated to report. Copies of the Missouri laws are available should the Committee wish to review them.

Stephen Mashburn  
1200 W. 34th St. So  
Wichita, KS 67217  
Phone (316)-529-3075

FOR YOUR INFORMATION  
SENT BY  
ROY M. EHRLICH  
STATE SENATE  
March 18, 1989

To: Senator Roy Ehrlich  
Chairman Public Health & Welfare Comm.  
re: HB 2012 In-Home Care

Dear Roy,

I have desired to speak out on the subject of In-Home Care so many times over the last 16 years I could cry. You see, the people needing help the most, like myself, are dependent on other people for transportation to/from public hearings, writing and mailing letters, and are often severely restricted financially from long distance phone calls to legislators like yourself. You would not believe the red tape via telephone I went through to find out about the progress of this particular legislation. If I didn't have a few friends at SRS, I still would be in the dark. I have been a quadriplegic since August of 69 and have lived most of the last 19 years in Kansas except for 1973 in Denver Colorado and 1975/76 in Berkely California. I have firsthand experience with In-Home care programs in three states, and close contact with people and independent living centers all across the nation, and I feel I am highly qualified to address this subject.

I have been a client with HCBS (Home & Community Based Services) since the programs' inception in 1982. I have watched HCBS go from "better than nothing in the past" to a good program with potential of becoming a great one. Unfortunately, the last two years I have watched HCBS turn into an administrative nightmare. ie. Two years ago, my HCBS case gross budget was only \$554.00/mo. My "non-medical attendants" could work up to 104 hours/month at \$4.67 per hour which totals \$485.68 a month leaving a balance of \$68.32 for administrative costs (case management). Now, my gross HCBS budget is up to \$776.00/Mo. My attendant may work a maximum of only 80 hours a month at the reduced rate of \$4.18 per hour which totals \$334.40 a Mo. leaving a balance of \$441.60 a month for administrative costs. These figures come from Topeka SRS and supervisory staff in Sedgwick county who have always informed me of changes because a close working relationship and if they didn't, I would have demanded to know the 'why' behind the changes whether they are financial, types of care, who decides what care I need & when, or who trains workers.

Lets look at the monthly figures on my case.

1986 = \$ 68.32 to administrate \$485.68 worth of In-Home Care  
1988 = \$441.60 to administrate \$334.40 worth of In-Home Care

The State has gone from spending \$68 to pay for \$485, to spending \$441 to pay for \$334 of non medical care in only two years! What infuriates me is there are fewer Case Workers now, and the workers who did not lose their job at HCBS have had their hours reduced with more paperwork. Even they would like to know where the money goes! While HCBS workers have been unable, I have the right to demand to know! I, along with hundreds of other clients have been ripped off by an inconsiderate, high powered, money-only

Stephen Mashburr  
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Wichita, KS 67217  
Phone (316)-529-3075

motivated professional nursing lobby group that is working hand in hand with a 'high level' SRS administrative lobbying force. Not only are they denying needed services to persons like myself, they are robbing the taxpayers of Kansas and they KNOW IT!

Oh, they claim to have the "client's" best interests in trying to force disabled citizens to rely only on certified medical workers for all their attendant care needs. When I go in the hospital, I have to direct Registered Nurses in my care. *SRS is going to know more about my care needs than me?* Give me a break! I do not mind directing my own care and am quite capable of managing my own care plan. *I have been taught by professional physicians, physical therapists, and nurses (as a condition of my release) in some of the finest rehabilitation centers in the country, to not only manage my care plan, but to train attendants myself.* I am not alone, as hospitals provide this training to every mentally capable paraplegic, quadriplegic, and others before their release.

When I lived in California(1976), I received a \$450 check each month and access to a list of non-medical attendants, medical attendants, and emergency workers. It was my responsibility (and privilege) to hire/fire, set hours and pay-scale; direct my own care, provided I give my SRS case worker the names and Social Security # of my attendants for IRS purposes, and approximate daily and weekly schedule; ie. ( John Doe- 2 hrs am M-F; Bill Doe- 2 hrs pm M-F; \$3.50/hr; Mary Doe- live-in weekends; \$25 & meals )

SRS/HCBS has never in 7 years been able to find attendants for me to even interview except once, and he didn't want to work for me after he found out I did not do drugs. I have found, hired, trained,(and even fired 3), all my attendants and dozens of volunteers to make up for HCBS deficiencies (many more recently).

I cannot urge you strongly enough to carry out a program using California as an example of a cost-effective, easily administrated, and keeping personal dignity & self worth for competent persons, also allowing family members (who many times must quit work to help) payment for providing the same services attendants do. *It is time to act and quit saying all you crippled gimps go back to California if you want decent public assistance.* We don't say that about other minorities! *Believe me, that is exactly what Kansas has been doing except for a brief breath of fresh air a couple of years back.* What we have now is fast becoming a stench of government waste and red tape. We have earned the dubious honor of being known as the worst in all fifty states, when it comes to SRS Aid, by the finest rehabilitation center in the world - Craig Rehabilitation Hospital in Denver Colorado. Just talk to the Executive Board, Doctors, or their National SRS Coordinator. OR we can take action by asking "why is California considered the best, and why can't Kansas seem to learn from them?"

I would be happy to come to Topeka and make myself available for input and to answer questions. The only hitch is; I would have to



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to find volunteer help because HCBS does not pay for the same care outside of the home as I need if I go to the doctor or visit friends or relatives or participate in any other out-of home activities like "normal" 1st class citizens. You would not believe how many people are held hostage in their home through their financial dependence on Kansas public assistance.

It is time to quit spending more money to administrate less and less care. \$441.60 to administrate \$334.40 worth of In-Home Care is not only asinine but wholly preposterous! Especially when contrasted with two years ago when it only cost \$68.32 to administrate \$485.68 worth of my attendant care.

Think about it; an INCREASE in Administrative SPENDING of 648% coupled with a DECREASE OF 145% on care with a monthly budget increase of 148%. How is this BENEFITING the very people the HCBS program exists for?


My attendant gets .49 cents an hour less, his hours reduced by 24 hours a month; I cannot get anyone to answer a job add that says " Max 20 hrs/week, \$4.18/hr, 7 Days/week, work 2 months then get paid for 1st month (Would you?)"; my Total monthly budget has increased by \$222/mo or 148%; and now nursing groups still want to oppose HB 2012.

*I'm sorry, but all I see here is losers. Because if Kansas does not reverse directions, HCBS is on the verge of being "administrated" right out of existence, thus forcing hundreds into nursing homes, which will cost the State much more than is wasted now.*

I'm 35 years old and I've been in MEDICAID nursing homes before and I would rather die than go back. Meanwhile, somebody is getting rich at the expense of the handicapped, the elderly, HCBS caseworkers, and the tax-payers of this State. Speaking for many SRS workers, all the recipients of HCBS services & those who could be, all the nonmedical attendants, & those who've quit, and me, where is the money going? I come up with the sum difference of \$524.56 in the ratio of Care vs Administration monies between fiscal 86 and now. Where is the \$524.56? PLEASE answer me.

I thank you for taking time to read the details of this rather lengthy letter. I hope this reaches you before it's too late, and that you would notify me of your opinions, answers, and progress. I am a member of the 4th District Republican Committee but I am a person first and I see way beyond my case to others worse off than myself. Talk is cheap but love is precious and true compassion moves one to action. Please feel free to call me anytime between 12:00 noon and 2:00 AM 7 days a week. I would be happy to answer any questions you might have.

Sincerely yours,



Stephen Mashburn

Testimony before Senate Public Health and Welfare H.B. 2012

Chairman Ehrlich, members of the committee, thank you for the opportunity to speak with you today. I am very pleased with the excellent revisions which were made in Subcommittee, ably chaired by Representative Amos. The eight amendments which were developed in the House Committee allow me to urge you to support the amended version of the bill which is before you. I would like to congratulate all who participated in this form of Proposal 40. I would point out that the R.N. and the L.P.N. Associations have worked with some of us who had real concerns about having the opportunity to have a licensed nurse called in, if there were to be a medical need. SRS is to be congratulated for their sincere desire to make this bill meet ALL their clients needs--not just a privileged few.

I have a little concern that perhaps some of the provisions of the bill will be hard for SRS to deliver. I refer in particular to New Section 1, lines 48-49. Very simply, it is my understanding that we have precious few attendants as it is, and we have greater need for some of the outlined tasks, than those of companion-type services, transportation, letter writing, reading mail, and escort. I am aware of one young man who suffers from Duchenne Muscular Dystrophy, which has rendered him a quadriplegic, who has for a number of months tried to live on two meals a day. He calls me almost daily to tell me how hungry he is. Unfortunately, he is unable to feed himself. SRS has told him that they cannot find anyone who can come in to help him around noontime. His doctor is concerned about his state of malnourishment. He feels very good about living alone, about having his own apartment, about living as independently as

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Attachment 9

possible. The only point I'm making is that maybe this committee might think about health care priorities; thus the effect would be to insure that Activities of Daily Living needs would be met first so that minimally, all SRS clients will be able to eat three meals a day, if they so choose. I urge the members of this committee to support this version of H.B. 2012.

Respectfully submitted,

A handwritten signature in cursive script that reads "Carol Renzulli". The signature is written in black ink and is positioned below the typed name.

Carol Renzulli

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Lawrence, Ks 66044

Lobbyist, Lawrence Coalition for Citizens  
with Disabilities