

Approved \_\_\_\_\_

Date 1-25-89

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Marvin L. Littlejohn at \_\_\_\_\_  
Chairperson

1:30 /a.m./p.m. on January 19, 1989 in room 313-S of the Capitol.

All members were present except:

Rep. Cribbs, Rep. Hochhauser, Rep. Foster, all excused

Committee staff present:

Bill Wolff, Research  
Norman Furse, Revisor  
Sue Hill, Committee Secretary

Conferees appearing before the committee:

Carol Renzulli, Lawrence Coalition of Citizens w/Disabilities  
Fred Markham, Paula Clevenger, Sherri Axline, Interested Citizens  
Sharon Joseph, Board Member, Nat'l Multiple Sclerosis Society  
Robert Mikesic, Independence, Inc., Lawrence, Kansas  
Kay Cook, R.N., Interested Citizen  
Marilyn Scarbrough, R.N., Interested Citizen  
Mike Donnelly, Executive Director, Three Rivers Independent Living  
Resource Center, Wamego, Kansas  
Lois Scibetta, R.N. Ph.D., Ks. Board of Nursing  
Kalen Lee Beaumont, V. President, Lawrence Coalition of Citizens w/  
Disabilities, (Printed testimony only)

Chairman called meeting to order with announcements. Hearings will continue on **HB 2012** on Monday, January 23rd, in room 423-S. He asked conferees to highlight remarks if possible so that we can recognize as many conferees as possible. He thanked all present for their cooperation.

Chair called on several persons who were not able to testify at meeting yesterday. Some were available this date, some unable to return.

**HEARINGS CONTINUED ON HB 2012:-**

Carol Renzulli, (Attachment No. 1) noted proponents of HB 2012 say there will be no changes in regulations of the bill passes, however she wonders. She noted concerns about those persons who cannot or do not choose to be self-directed. Agrees the Pennsylvania Model works well there, but is concerned if it will work that way in Kansas. Feels nurses have more important things to do other than empty bedpans and give out medications in the home setting, but does not wish to take away SRS's responsibility to call in a nurse if it becomes necessary.

At this time a letter from Frederick M. Markham, President of Lawrence Coalition for Citizens w/Disabilities was handed to Chair. (This indicated they wanted the letter made available only to committee members, and not to have it read before the body present at meeting). This letter is indicated as Attachment No. 2).

Paula Clevenger, Lawrence, Ks. gave testimony for herself, Mr. Markham, and Sherri Axline. (They were all three present at the podium as she spoke. (Attachment No. 3 gives details). She said since Interim, they realize members of that committee have gained good insight and understanding of the needs of those trying to live independently. Those with disabilities who have testified during Interim are pleased with HB 2012, feel it goes far beyond what they hoped. The bill will allow them to shop, manage own medications, manage own attendants. The action of the committee has renewed our faith in the democratic process. There are still concerns, i.e., this is an optional program available for those

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,  
room 313-S Statehouse, at 1:30 /a.m./p.m. on January 19, 1989.

HEARINGS CONTINUE ON HB 2012:--

Paula Clevenger continues:--

who believe they are capable of living a more self directed life, and we believe those persons have the right to choose. We realize there is confusion and resentment that some nurses think they are being left out, but we read lines 46-49 of the bill and see no reason why or have no objection to include nurses having a vital role in supervision of the medically maintained attendant care. With some clarification, and some revision, lines 46-49 can be allowed to play a major role in this program, but without changing the intent of the bill of the disabled living an independent and self directed life.

Sharon Joseph, Board Member, National Multiple Sclerosis Society spoke, and offered hand-out, (see Attachment No. 4. for details). She thanked committee for the many favorable features of this legislation, and hopes it will also incorporate the proposed amendments by the Kansas Department of Human Resources' Advisory Committee on Employment of the Handicapped for reasons given earlier by testimony by Michael Lechner. She answered questions.

Robert Mikesic, Residential Services Specialist, gave hand-out, (see Attachment No. 5), for details. HB 2012 provides a significant, previously missing opportunity for self determination and consumer involvement for persons receiving attendant services from SRS. Many now will be allowed to direct their own personal attendants in daily living activities, and increase our ability to manage our own lives and become more a part of the community than would be possible if we were living in an institutional setting. He answered numerous questions, i.e., yes, really only health maintenance situations need be done by an R.N., yes, the consumer needs to be an active participant in developing the care plan, and everyone involved needs to work together as a team; yes professional monitoring is necessary for the health aspects of the care plan.

Kay Cook, RN, offered hand-out, (Attachment No. 6). She spoke of her concerns in HB 2012 and asked it be delayed until more clear definitions of terms in language of bill is completed. As a family member of a physically and mentally handicapped person, she has concerns about mental and or physical abuse. As written, the bill would allow non-skilled untrained, and unsupervised persons to provide care. She supports the concept of the bill, but asked it not be passed prematurely. Feels it needs a lot of clarification. She answered numerous questions, i.e., lines 46-50 is too broad; yes, I do feel a need for supervision in the technical aspects of care programs. She cited personal experiences in regard to a family member whose care givers proved unsatisfactory at best.

Marilyn Scarborough, RN, and interested Citizen spoke to concerns on HB 2012, agreeing the bill will fill a great need, and the concept is good, but feels terms and definitions on Page 2, (d) beginning on line 4b do not realistically establish who will be teaching in the home setting. She is concerned the care giver needs to be properly trained and supervised so the recipient of the care is not at risk for care, abuse or neglect. She has witnessed all this in the past in her professional career as a nurse. She answered numerous questions.

(Attachment No. 7.)

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,  
room 313-S Statehouse, at 1:30 a.m./p.m. on January 19, 1989

HEARINGS CONTINUED ON HB 2012:---

Mike Donnelly, Executive Director, Three Rivers Independent Living Resource Center gave hand-out, (Attachment No. 8). He gave some personal background about his first personal attendant who taught him to do many tasks for himself, and how with proper care, and caring, he learned to turn his life around, become a professional and productive citizen. He spoke about dignity, what means to different people. It is his hope that legislators can see the way to insure the dignity, opportunity, and keep care cost effective for all Kansans with impairments. He answered numerous questions.

Lois Scibetta, R.N. Ph.D., State Board of Nursing gave hand-out, (Attachment No. 9). She offered this written statement, but said after listening to testimony for two days, she had comments that were not on that statement, i.e. we do still oppose HB 2012 in its current form; perhaps we can look at this a little differently than we have by separating the well-disabled from the ill-disabled so their care can be addressed differently. After hearing the testimony, it sounds like this is what we might need to do in order to cover all bases. We wonder how care can be provided, yet not open the window of the Nurse Practice Act. Many consumers need supervision and guidance in the health aspects of their care, and many do not, I agree with that. She then answered questions.

Please note (Attachment No. 10). This was offered to committee from Mr. Kalen Lee Beaumont, Vice President of Lawrence Coalition of Citizens with Disabilities. Mr. Beaumont was unable to speak in person this date.

Chair asked if anyone else present wished to give testimony. None responded. However, Mr. Michael Lechner did offer to answer questions. He did so, i.e., yes, if a self directed consumer goes to the Doctor for direction, the Doctor tells the Nurse to direct the patient, then the patient goes home and directs the care giver. There are some cases where the Nurse does have a role, he agreed with that. PCA means Personal Care Attendant he noted.

Chair recognized a group of Senior Nurses Students from Washburn University in the room. He welcomed them and invited them back anytime.

Meeting adjourned 2:45 p.m.

GUEST REGISTER

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

Date Jan 19<sup>th</sup>, 1989

Name	Organization	Address
George Boehel	AARP Capital Area Task Force	Topeka
Jeff Rockett	St. Francis - Wichita	Topeka
KEITH R LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR KANSAS	"
Elizabeth C. Taylor	Fed. of Licensed Practical Nurses	Topeka
Jan Allen	SRS - Adult Services	Topeka
Martine Finney	MS - Adult Services	Topeka
Janet Schalansky	"	"
Dr Lois R. Scibetta	KSBN	Topeka
Rita Rinckenbaugh	KSBJ	Coffeyville
Bob Mikasic	Independence, Inc.	Lawrence
Juan Melon	Gen. Observer - RN.	Independence, KS
Brian Smith	Sen. Boggs	
PAUL JEFFEISEN	<del>Letter</del> LC CD	Lawrence
Sharon Joseph	Middle American Mfg Soc	Over Park
Mike O'Rand	KACET	Topeka
Mike Lechner	"	"
Liz Primer	Washburn University	Topeka
John Kelly	DD Council	Topeka
Rob Tabor		Topeka
Michael Donnell	3 Rivers Ind. Living Center	Warrego
Phyllis A Heaune	Washburn University	Topeka
Stephanie Harte	Washburn Univ. School of Nursing	Topeka
KAREN CAUENDER	Washburn Univ. School of NSG.	Topeka
ALaura Scheuerman	"	Topeka KS
Dorothy Woodin	KSVA	Topeka KS

GUEST REGISTER

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

Date Jan 19<sup>th</sup>, 1989

Name	Organization	Address
Kathryne Sumner	Washburn Univ. School of Nsg	St. Marys
Debra Anderson	Washburn Univ " " "	Topeka, KS
Katrina Neibarger	Washburn Univ. School of Nsg	Topeka, KS
Don POUND	SRS BUDGET OFFICE	TOPEKA
Cheryl Neuhaus	Washburn University <sup>school of</sup> Nursing	Topeka
Lora Heckman	W.U. School of Nursing	Topeka
Judy Lynch	Washburn Univ. School of Nsg	Topeka
Yong Cork	W.U. School of Nursing	Topeka
Ann Betty	W.U. Sch. of Nursing	Leumock, KS.
Barb Cain Feux	W.U. School of Nursing	Manhattan, KS
Neur Nasenbank	Washburn University	Osage City
Nneka Obisral	Wash. University Nursing Student	Topeka, KS.
Audrey Kennedy	Washburn Un. Sch. of Nursing <sup>Assistant</sup>	Topeka, KS.
Terri Roberts	<del>TOP</del> KSNA	Topeka
<i>LaDawn G. Jones</i>	KSNA	Topeka, KS
WILLIAM R. EYER	BCII	OSAGE CITY
Melba Gwaltney	SRS - Rehab. Svs	Topeka
Joni 1703 <sup>1703</sup>	ot & ed ser	Topeka
Karen Thornton	SRS - Topeka	Topeka
Highland Mairsey	KDHE	TOPEKA
Greg Rose	KDHE	TOPEKA
Ray Petty	Topeka Ind. Living Res. Center	Topeka
Sister Dominic Haug	Golden Bell Home Health Services KS Home Care Association	Great Bend
Linda Lubensky	KS Home Care Assoc.	Lawrence (COVER)

Allyn Johnson  
Karl D. Stockbayer  
Catherine Creighton Seal  
Bob Corkins

SRS  
SRS-Planning & Research  
SRS  
Kan. Hospital Assn

606W Stocking  
1152W Oakley SOB  
6285 DSOB  
Topeka

*Carol R.*

Thank you, Chairman Littlejohn, for the opportunity to speak here today. When I spoke to the Interim Committee on the issue of self-directed care, I spoke of choices--the need for options.

Sometimes I think I overestimate my communicative abilities for I have been thinking, indeed, living the problems of the disabled for so long, I am like the person who starts in the middle of a joke and leaves the listener bewildered about the subject matter.

Certainly, the handicapped community has their own "language" and buzz words that have evolved with our movement and we assume that everyone knows this language. You, ladies and gentlemen of the committee know there is a legislative language that is understood when you talk to each other, but is not necessarily understood by others.

When I came to the Interim Committee to talk of choices, I was perhaps unclear about what I meant. Looking back at that testimony I can see that it could be construed as talking about something as simple as wanting the choice of where and under what circumstances we would live. I want to take you a step back from the conclusions I came to in that prior testimony. I should have taken that opportunity to point out that there are many varying kinds of disability. There are those of us who are deemed to be medically stable, as in the case of spinal injury and often cerebral palsy and other kinds of birth defects. Another category of handicapped people (or to use my favorite euphemism "physically challenged") are those who are anything but medically stable. Their conditions are degenerative. This is also the case for the frail elderly.

*Attn #1.  
PAW  
1-19-9*

As with other populations who have similar problems, there is some disagreement in the handicapped community, about the best way to achieve "life, liberty, and the pursuit of happiness." Some people who are disabled are able to work, get involved with their communities' activities and feel, rightly so, that they can be self-directed. Most of the people in this room who are disabled are such folks. We like being independent. It's challenging for us. However, when we start pressing for legislation which would give us even more independence, we must remember that we are the lucky minority--that in fact 65% of the people who are HCBS clients are the "frail elderly," and there are a number of severely handicapped young people who, by virtue of the severity of their medical conditions never will be able to be totally self-directed. Within the disability movement there are dark suspicions that these people are probably slackers, chronic complainers or worse--that they are dependent. The plain fact is that they are.

My own disease process has defied the best doctors this country has to offer. I should be in a nursing home, and was for a short time, for I have a terminal illness and I've suffered a massive stroke. I am lucky to be alive much less be here with you today. This brief history of my condition is meant to show you that I have been in a position to be totally dependent, as well as being rather independent, as you see me today.

One thing I have observed over the years is that when one is making laws one must keep in mind the weakest people who would be affected--not the strongest. I have grave concerns that the regulations which are in place now to guide SRS in the handling of medical exigencies, will be superceded by this legislation.

*Attn #2  
Pg 2  
1-19-9*



I have been repeatedly told by the proponents of H.B. 2012 that there will be no changes in the regulations if this bill passes. I am told that there will be all kinds of options open to those who want to take advantage of them. I wonder.

Clearly, the people who are self-directed now, will continue in that mode, but I worry about those who cannot or do not choose to be self-directed. I have fought for the civil rights of the disabled for more than a quarter of a century, so the charge that I oppose this legislation because I've grown old and feeble-minded may apply, but I've never seen in those twenty-five years legislation which would affect so few.

I am further not comforted by the notion that the Pennsylvania Model works well there. Sometimes when states "borrow legislation" they buy a pig in a poke. One way or another the idea just doesn't translate. I certainly don't want nurses emptying bedpans or giving out medications in our homes --they have more important things to do--but I don't want to take away SRS' responsibility to call in a nurse if it becomes necessary.

Finally, there are other groups who are working on in-home care solutions which I could support wholeheartedly and I'm always a little anxious when people tell me this is the ONLY way out of a very knotty problem.

Respectfully Submitted,

  
Carol Renzulli

LCCD Lobbyist

533 Alabama

Lawrence, Ks 66044 Tel. (913)841-7719

*Attn. #1  
093  
1-19-9*

Frederick M. Markham  
2222 Yale Road, Apt. #7  
Lawrence, KS 66044

Rep. LittleJohn, Chairman  
Human Welfare Committee  
Topeka, Kansas

January 19, 1989

Dear Rep. LittleJohn,

As president of the Lawrence Coalition of Citizens with Disabilities, it is my duty to inform you that Carol Renzulli is no longer the group's lobbyist. This action was taken Friday, January 13th with a unanimous vote of the members present. This is because of Ms. Renzulli's position on the bill HB 2012. Her position on the bill HB 2012, is not representative of the majority of the Lawrence Coalition of Citizens with Disabilities. Therefore we decided to let each member speak for themselves.

Please regard any action on this bill by Ms. Renzulli as a representation of herself, and not the Lawrence Coalition for Citizens with Disabilities.

Please share this information with the other members of the committee.

Thank you for all your efforts on HB 2012.

Respectfully Submitted,

Fredrick M. Markham, President  
Lawrence Coalition for Citizens with Disabilities

P.S.

This letter is for committee information only and I ask that it not be read during the public hearings, Thank you.

*Attm. #2  
P.V.W.  
1-19-89*

Sherri L. Axline  
Paula R. Clevenger  
2222 Yale Rd. Apt. 5  
Lawrence, Kansas 66044  
Frederick M. Markham  
2222 Yale Rd. Apt. 7  
Lawrence, Kansas 66044

Testimony of September 1988

TESTIMONY FOR BILL HB 2012

We testified before the Intrim Committee concerning the many problems the disabled have in trying to live an independent life. At that time we must admit that we were skeptical how the members of the committee could gain an open insight and better understanding of our needs. However, reading the bill and the history written by this committee on the bill we realize that you have ~~to have~~ a complete understanding of some of the problems we are facing in trying to be as independent as possible.

We would like to take the opportunity to thank each member of this committee for working so diligently. To say this bill (HB2012) gets to the meat of the problem would be an understatement. It goes far beyond what we could ever hope it would and now allows attendents to act as an extension of ourselves. We can now do simple tasks such as: (1) shopping for ourselves, (2) managing our own medications, and (3) managing our own attendents.

With out a doubt , the action of the committee has renewed our faith in the democratic process. We can now walk out of this building with our heads high and say we are proud to be a Kansan and a United States Citizen.

Thank-you very much .

*D.H. W  
attm #3  
1-19-9*

We know there are people who have reservations on some aspects of the Bill HB 2012. We would like to address some of those reservations.

1) This is an optional program for those who believe they are capable of living a more self directed life.

Obviously, there are some people at this time who do not desire, or who cannot manage a self directed program to no fault of their own, but the creation of this new service does not in any way eliminate services currently provided under the current program, but rather, opens the door to more freedom of choice. We must realize that more freedom of choice leads to more responsibility. And with more responsibility there are more risks involved.

We believe people have the right to choose whether they want to take risks or not. Our experience tells us over and over again that one must be willing to take risks in order to grow. For us to take risks, we must be given the chance to take it. It would be ignorant to believe that everyone that takes risk at more independent lives will succeed, some will fail, and some will fail badly, but this is the cruel reality we all must face.

Nearly three years ago, seven people gave their lives for the progress of this country's space program.

From the moment they entered the program to the moment of the fatal tragedy, they realized there were risks involved. But deep inside they knew that progress would never be accomplished, goals would never be reached, or dreams would never be lived, if they allowed their fear to stand in the way. They knew that fear must be put aside to accomplish the job at hand. We, the disabled, are here to tell you that we are ready to put our fears aside and accomplish the job at hand. The job of being independent citizens. This bill HB2012 opens the door for this to happen.

2) We realize that there is confusion and resentment that the nurses think they are being left out but as we read lines forty-six (46), forty-nine (49), we see no reason why or have no objection to include nurses to have a vital role in the supervision or medically maintained attendant care.

We realize that if they desire such a role they must take on the responsibility of being there when needed. They also need to be sensitive to the fact that need only keep their duties to the medical aspect of training and medical supervision of our attendant care. Too many times, we have seen nurses come into our homes and tell us what to eat, drink or try to impose a treatment they feel is better, although, another treatment has been prescribed. They may work with us as a team, but they must not be allowed to play quarterback for that is our job and our job alone.

We are offended by the attitude that we are unable to make judgements about attendants who or who are not qualified for the job as an attendant. It is our experience that most attendants know their limitations. They know when and when not to seek professional medical advice for their clients. But there are no guarantees in life.

*Attn #3  
pg 2  
1-19-9*

Some attendants may make mistakes, poor judgements, and may not see every situation as critical as may be the case, but that can happen with even nurse supervision as it does in hospitals and nursing homes. This is a reality of life that we must face whether or not this bill passes or not.

However with some clarification, and a little revision of lines 46-49 nurses can be allowed to play a major role in this program but without changing the intent of the bill of the disabled living an independent and self directed life.

One again we appreciate your work and support of bill HB 2012.

*Attn #3  
Pg. 3  
1-19-9*

TESTIMONY IN SUPPORT OF HB 2012  
BEFORE THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE  
JANUARY 19, 1989

Thank you for this opportunity to address you on this most important topic. There are many very favorable features of this legislation. The long hours of dedication by your committee are reflected in the quality of this bill.

HB 2012 is well thought out and covers the critical aspects of self-direction, self-determination and independent living. Thank you for recognizing that people with disabilities can direct their own care. Physical ability to do health maintenance activities is no different whether one performs the activities with or without assistance.

I appreciate this committee for working with the many parties concerned and involved with this topic. I hope you will incorporate the proposed amendments by the Kansas Department of Human Resources' Advisory Committee on Employment of the Handicapped for reasons previously stated by Michael Lechner.

If this bill becomes law, Kansans with disabilities will no longer have to "depend on the kindness of strangers" to live their lives as functional members of society.

Thank you again for your time and fruitful efforts over these long months.

Respectfully submitted:

Sharon R. Joseph  
Board Member  
National Multiple Sclerosis Society  
Mid-America Chapter  
6617 West 73rd  
Overland Park KS 66204-2026  
(913) 831-0638

ws\sj2012

*Attn #4  
PHW  
1-19-89*

THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE  
House Bill 2012

Robert Mikesic  
Independence Inc., January 19, 1989

Thank you for this opportunity to speak.

I am the Residential Services Specialist with Independence Inc., an Independent Living resource center for people with a physical or mental disability in Lawrence and the surrounding area. We spoke to the Special Committee during the interim study and really appreciate all the time and work that went into the making of House Bill 2012.

Independence Inc. strongly supports House Bill 2012. It follows the nationwide trend of supplying enabling legislation so that individuals with disabilities and senior citizens have more resources for living in the community rather than an institution.

The Special Committee's interim report and House Bill 2012 reflect a high level of understanding and a positive resolution of all the points made during the interim hearings. The bill provides a significant, previously missing opportunity for self determination and consumer involvement for persons receiving attendant services from the Kansas Department of Social and Rehabilitation Services (SRS). The many individuals who are capable and actively directing all other aspects of their lives, would now be allowed to direct their own personal attendants in daily living activities they would be legally entitled to perform were they functionally able to do so.

It is clear in the Special Committee's report (p.404) that one of the intentions of HB 2012 is to build flexibility into the SRS Program. In addition to self-direction there would also be an option for individuals not able or "who choose not to take responsibility for their own (attendant) care". Such individuals would have services provided by SRS or some other licensed professional or agency. Independent Living Centers will make every effort to enable consumers to succeed in a self directed plan; or assist them in securing attendant services from SRS or some other licensed professional or agency if that is their choice of what would really benefit them most.

Independence Inc. applauds that attendant care services as defined in this bill and through the amendment to the Nurse Practice Act, expands the range of services which attendants may perform for people with a disability. This will increase the consumer's ability to accomplish daily living activities in a cost effective manner. It will enable the individual to live with a genuine sense of dignity and freedom. This bill will greatly increase our ability to manage our own lives and live as part of the community rather than in a more institutional setting.

Independence Inc. wishes to thank The House Committee on Public Health & Welfare for this opportunity to voice our support for House Bill 2012.

attm # 5  
PHW  
1-19-89

01/19/89

HOUSE BILL #2012

Chairman, members of the special committee of Public Health & Welfare:  
I am here today as both a nurse and a family member. I am asking you to delay House Bill #2012 due to the need for more appropriate definition of terms.

As a family member of a physically and mentally handicapped person, I feel very strongly we need to protect them from adverse situations whenever possible. This bill would allow a non-skilled, untrained, and unsupervised person to provide care. This could easily become an extremely dangerous situation, allowing the handicapped to become a victim. Without proper education and ongoing supervision the potential for mental and/or physical abuse increases. I have had to deal with this type of situation both as a family member and a nurse and it is certainly tramatic from either level.

I want to support the concept of the Bill, but do not want it passed prematurely. Please clarify and resolve the terms and definitions first.

Thank you,

Kay Cook, RN

PH & W  
Attn # 6  
1-19-9



01/19/89

HOUSE BILL #2012

Chairman, members of the special committee of Public Health & Welfare:  
Thank you for this opportunity to speak on House Bill #2012, which I  
agree with in concept.

As a registered nurse, I would like to express my concerns regarding  
Bill #2012. As an experienced nurse, I am very aware of the great  
need for attendant care services and of the difficulties individuals  
have in finding these services, especially the handicapped and home-  
bound. I do support the general concept of the bill, however, I want  
to express my anxiety regarding specific terms and definitions.

On page 2, item (d), beginning on line 4b, I do not believe  
realistically establishes who will be doing the teaching in the home  
setting. I believe teaching and supervision should be assigned to a  
qualified Registered nurse. I want to be assured the care giver is  
properly trained and supervised so the recipient of the care is not  
at risk for the improper care, abuse or neglect that I have witnessed  
in my past experiences.

Once again, I support the concept of House Bill #2012, but requesting  
that definition of terms be realistically examined and defined.

Thank you for your time.

Marilyn J. Scarbrough, RN

*PKW*  
*Attn. # 7*  
*1-19-89*



# Three Rivers Independent Living Resource Center

**Making Our Community  
More Accessible**

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Date: January 19, 1989

To: House Committee on Public Health and Welfare

From: Michael Donnelly, Executive Director, Three Rivers Independent Living Resource Center

Purpose: Testimony House Bill 2012

Dear Chairman Littlejohn and Members of the Committee,

I am here to offer my support for HB 2012. As a provider of Independent Living Services to people with severe disabilities, as well as a past recipient of attendant care services, I see nothing so important as providing the means by which an individual can remain in his/her own home. This piece of legislation would be another step toward insuring that capability.

Of course, the most important factor that should be considered when contemplating this legislation is that of human dignity, not money (money can not buy dignity, self respect or happiness). To institutionalize people because "the program" doesn't allow a specific task to be performed on their behalf, strips that individual of all their dignity, self esteem, etc. This is a loss that cannot be counted in dollars, it is worth all cost to preserve. When this becomes the case then it is time to change the program.

As a quadriplegic myself I know the realities of these issues personally. Becoming a quadriplegic in 1977 I, like many others, was faced with the issue of meeting my personal care needs. My options in north-west Kansas were not overwhelming to say the least. My own experience was one which I believe has the potential to be that of more and more Kansans with disabilities. I began receiving "non-medical" attendant care in January, 1978. The care I received then was considered "total care" as I was not capable at the time to fulfill my own personal care needs.

*attm # 8  
PA 460  
1-19-89*

My first attendant I hired was a fellow by the name of Jamie Calcara, alias "Hamburger Jake". Jake was a hard man in that when he knew I could perform a task he made me do it myself. I learned more from him than any therapist, doctor or nurse could ever have taught me. He taught me not to give up on life and that I was not just a person imprisoned by a paralyzed body. My experience is not unique.

However by August, 1979 I needed assistance with house keeping only, and by the following Spring no assistance at all. Without the necessary attendant care in the beginning, some of which would not be allowed under the current regulations, I would not have had the opportunity to learn self care and thus not be the participating, productive, employed citizen that I am. I am indebted to that "helping system" that no longer exists.

I hope that you as legislators can see the way to insure the dignity, to insure opportunity, and finally to insure cost effectiveness for all Kansans with impairments.

Attn # 8  
029 2  
1-19-9

# 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 Representative Marvin Littlejohn,  
Chairman and Members of the House Public Health  
and Welfare Committee

FROM: Dr. Lois Rich Scibetta, Ph.D., R.N.

RE: House Bill 2012

DATE: January 18, 1989

Thank you Mr. Chairman for the opportunity to comment on HB 2012. The Board have asked me to express their serious concerns and opposition to HB 2012.

The concern and opposition are a result of the basic services to be provided under "Attendant Care Services," (Line 24), most particularly the definition of "Health Maintenance Activities", include, but are not limited to, catheter irrigation; administration of medication, etc." (Lines 46-50, p.2)

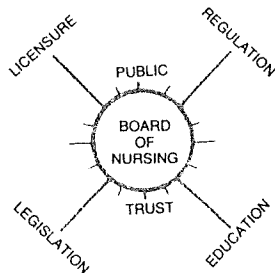
We believe that if these services are provided by untrained and unsupervised individuals, it will put the public at risk.

The bill has been described as a "window" which will assist the handicapped to train, hire and fire their own caretakers. We believe that if the State is involved in the reimbursement aspect, and these funds are expended by a State department (SRS) that the State should have some regulatory oversight.

The term physician supervision probably will not work very well. Traditionally physicians do not supervise patient care. With the liability issues involved, it is doubtful that this will change (supervision) in the near future.

Many of the persons who would be effected by this bill live alone, and family members would not be able to oversee or supervise the individual's care, particularly if the individuals involved become acutely ill.

We believe that this bill would be dangerous and potentially harmful to the public at large. Would it be possible to accomplish what we want to accomplish, that is, self-determined care without any regulatory changes?



*PHW.*  
*1-19-89*  
*Attn # 9*

The Honorable Representative Marvin Littlejohn  
Chairman, and Members of the House Public Health  
& Welfare Committee  
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Thank you for this opportunity to comment Mr. Chairman. I would be happy to  
respond to questions.

LRS:bph

Attn #9  
Pg 2.  
1-18-9

Beaumont

Thank you for the opportunity to have my statement presented today. H.B. 2012 is a dangerous bill. It would legislate for the few and endanger the lives of many. Let me clarify my reasons for feeling anxious about this legislation. Self-directed care is a good philosophy for those who have the energy and physical strength to direct their own care, but other philosophies must be respected as well. Persons with stable disabilities must learn to understand those with degenerative and progressive disabilities. I will now explain my situation.

I have muscular dystrophy, a degenerative neuromuscular disease. I am severely physically disabled and I accept it. I rely on the services of 9 (nine) or more personal attendants each week. This makes complete self-direction unfeasible based on the amount of stamina it would require to take applications, screen, interview and maintain the work positions and schedules of 9 (nine) or more people. It would be unrealistic to expect me to put my health on the line so as to pretend I have no dependency as a result of my disability.

H.B. 2012 is so ambiguous without major revisions, it would give SRS the power to no longer accept responsibility for my care and the care of all other severely disabled persons who use HCBS services throughout Kansas. It is up to you here today to determine your own positions. If you support this legislation and you are wrong, will it effect your life? I know it will jeopardize mine.

Can you, here today, accept the potential consequences of this bill? It could mean we would no longer have any recourse other than the federal court system to make SRS responsible for our medical safety in the community. SRS would have no control

P.H. (all)  
Attn. #10  
1-19-9

of our care if this bill becomes law; most severely disabled people would not have sufficient income for legal fees resulting from a court challenge.

If it is your decision to support H.B. 2012, as a few disabled citizens in Kansas do, this is obviously your right; it is also my right to oppose it and I do based upon my own conclusions about its content. Let me make it perfectly clear, I oppose this legislation based upon my own views. My decision is not influenced by anyone else. I came to this decision by means of my own reasoning abilities.

Remember if this bill becomes law, I will live with the consequences and most of you will not. Also remember, if any disabled persons health or independence was lost as a result of such a law, the precedent for it has been set into motion by you who support it.

Respectfully Submitted January 18, 1989,

*Kalen Lee Beaumont*

Kalen Lee Beaumont

Vice President, LCCD

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*Attn #10  
Pg 2  
1-19-9*