

Approved 4-30-88
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

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

9:15 a.m./~~p.m.~~ on April 29, 1988 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Legislative Services
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Bob Mikesic, Residential Services Specialist, Independence, Inc., Lawrence,
Kansas
Senator Wint Winter, Jr.
Dana Wray
Gary Mosley
Dr. Lois Scibetta, Executive Administrator, KS State Board of Nursing
Linda Lubensky, Kansas Association Home Health Agencies
Terri Roberts, Executive Director, KSNA
Written testimony, Fred Markham
Written testimony, Barbara Bradford
Written testimony, Dana Dower
Written testimony, Karen Lee Beaumont

Bob Mikesic appeared before the committee in support of SB-756 stating he was extensively involved with persons receiving personal care assistant services through the HCBS program and a number of these people have experienced what seem to be a long series of difficulties receiving the type of services needed to accomplish daily living activities to maintain a self directed independent life style. Attachment 1

Senator Wint Winter appeared before the committee stating the need for SB-756 was brought to his attention by SRS who provides, through federal funding, assistance to the disabled to live independently. Federal HCBS regulations state that services provided in the home must be provided under state law. SRS, under the present law, cannot provide care in the home when the cost is more than nursing home care. At present, care comes under the Nurse Practice Act and results in limitations. Senate Bill 756 would apply to funding and the nursing shortage since it deals with amending a law which prohibits ordinary citizens from engaging in nursing functions. Senator Winter stated SRS does believe that a change in the Nurse Practice Act would be beneficial, however, SRS did not appear.

Dana Wray told the committee of notification by SRS that due to the Nurse Practice Act she was no longer eligible for HCBS and that she must find a nursing home within 30 days, this coming after living independently for nearly 8 years with the help of non-medical help with no problems. Ms. Wray stated that she had been able to train people to do what she required.

Gary Mosley spoke in support of SB-756 stating that he had worked with Ms. Dana Wray for approximately 8 years and during the time she was in a nursing home, SRS provided help to get her up and get to bed. Recently SRS has decided to bring under stricter interpretation the Nurse Practice Act. Mr. Mosley stated the people who help care for Ms. Wray are not making medical judgments but performing those tasks someone without disabilities would do on a daily basis.

Dr. Lois Scibetta appeared in opposition to SB-756, stating that SRS had not contacted the State Board of Nursing concerning this issue. Dr. Scibetta stated that the involved organizations need to work together to

Unless specifically noted, the individual remarks recorded herein have not been transcribed verbatim. Individual remarks as reported herein have not been submitted to the individuals appearing before the committee for editing or corrections.

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

room 526-S Statehouse, at 9:15 a.m./~~p.m.~~ on April 29, 1988

resolve this issue. It was further stated that SB-756 was a very broad bill, not the narrow bill claimed. Concern was expressed that the bill would establish two levels of care.

Linda Lubensky spoke in opposition to SB-756 stating sympathy for those in situations which had been related, however concern was expressed that any legislation will affect many others using HCBS services, not just those appearing before the committee. It was further stated that this bill would open doors to place responsibility on patients while the financial and other liabilities would rest with the state. Attachment 2

Terri Roberts appeared stating an interium study proposal has been requested and would relate to the entire picture of home health care being provided.

Written testimony was presented to the committee by Fred Markham stating he had employed attendants during 20 years of independent living. Mr. Markham stated he had used HCBS for the past 8 years and found it brought pride to individuals who are disabled and can manage their own style of living. Attachment 3

Written testimony was presented by Barbara Bradford stating that in 23 years she has never used medically trained attendants but has trained attendants in her normal daily routine and also trained them to care for her following an injury or illness. Attachment 4

Written testimony was presented by Dana Dower stating that she has worked as a personal care attendant for approximately 5 years with no formal medical training. Ms. Dower stated her training had been accomplished by her employer. Ms. Dower further stated each individual has certain individual needs and it would be difficult to learn the way of handling each situation in a class room setting. Attachment 5

Written testimony was presented by Karen Lee Beaumont stating she used HCBS workers to get out of bed mornings and to go to bed at night. Ms. Beaumont stated SB-756 would permit HCBS workers to continue to do so legally. Attachment 6

The meeting adjourned at 8:55 a.m.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE April 29, 1988

(PLEASE PRINT)
NAME AND ADDRESS

ORGANIZATION

Terri Robert RN

Kansas State Nurses' Organization

Linda Lubensky

Ks Assn of Home Health Acs,

Dr Lois R. Scibetta

Ks St Bd of Nursing

Fred Markham

Lawrence Coalition of Citizens
with Disabilities

Barbara Bradford

Lawrence Coalition of Citizens
with Disabilities

Bob Mikecic

Independence Inc.

Ray Petty

Topeka Res. Center for the Handicapped
CHRISTIAN SCIENCE COMMITTEE

KEITH R LANDIS

QW PUBLICATION FOR KANSAS

Kim Bahr

Topeka

Kaiser Permanente

Judy DUNN

Ks Occupational Therapy
ASSN.

Tom Bell

Ks. Hosp Assn.

Carolyn Mendenhall

KSNHA

Laura Green

KOITC

Statement of Robert Mikesic
Residential Services Specialist
Independence Inc. Lawrence Kansas

SENATE BILL 756

One of my primary job responsibilities at Independence Inc. is to maintain an emergency pool of personal care assistants (PCA's). This referral pool provides emergency back-up's when a person with a disability's regular PCA is unable to work due to illness, unexpectedly does not arrive, or is unable to come for whatever reason.

I have been extensively involved with persons who receive personal care assistant services through the Kansas Home and Community Based Services (HCBS) program. I am aware of six persons in Lawrence who utilize the HCBS program who could be described as severely disabled, non-elderly adults. I have been in regular contact with four of these consumers. These four participants in the HCBS program have experienced a long series of what seems to be a continuing pattern of difficulties receiving the types of services they need in order to accomplish their daily living activities and maintain a self directed, independent life style. I have been a sounding board for their frustrations and acted as an advocate with the local and state SRS offices, suggesting and encouraging solutions to the problems they were encountering.

These HCBS consumers have not been receiving PCA services through Independence Inc. as often as they have really needed a back-up PCA. This is due to:

1) We expect the the SRS/HCBS program to live up to its responsibility to provide PCA services. There is no reason why the entire range of services a person with a disability needs to live independently cannot be provided.

2) If consumers used the Emergency Pool of Independence Inc. they could not afford to pay for services needed beyond the first two hours which Independence Inc. pays for.

3) If consumers need a PCA to assist them with the tasks currently classified as medical and not provided by HCBS, again, they cannot afford to pay for the amount of time they need assistance in order to accomplish these activities of daily living.

It is not acceptable for consumers to have to depend on the goodwill of friends or family members in order to have all the tasks performed that assistance is needed with. This places the consumer in a dependent rather than an independent position. When friends or family are forced to provide PCA services, the resulting stress can lead to psychological abuse of the person who is disabled.

Persons with disabilities who are able to manage their own affairs have had sufficient experience with their own daily routines to be well qualified to train their own PCA's. They know from their own experience how certain tasks need to be performed. And they would be legally entitled to perform these activities were they functionally able.

Independence Inc. supports Senate Bill 756. The amendment would allow personal care assistants in the HCBS program to provide assistance with all the tasks of daily living that a person with a disability needs to accomplish in order to carry on with the rest of their lives in the style of self determination and independence that most American's are accustomed to, and all citizens of this country are entitled to.



KANSAS ASSOCIATION OF HOME HEALTH AGENCIES
4101 West Thirteenth
Lawrence, Kansas 66046

April 29, 1988

Dear Public Health & Welfare Committee member,

Please find attached a copy of the recently completed Nursing Task Force report as submitted to the Board of Directors for the Kansas Association of Home Health Agencies. The report is the result of a directive, by our Board, to explore the issues involved and to inform the Board of the advisability and ramifications of any changes to the regulations (Nurse Practice Act) that it might suggest. The directive was generated by questions concerning current restrictions on nurses disallowing the teaching of certain procedures to non-medical personnel, who would be reimbursed for their services.

It is our Board's wish to pursue the creation of a legislative interim study committee so that thorough consideration might be given to the various issues involved and to the resulting effects of any suggested changes to the Practice Act. The Board particularly wishes to emphasize the importance of looking at the "total picture", including the State's HCBS Homecare Worker program, the necessity of insuring statewide quality levels, and the need to address current care demands, safely as well as economically.

We feel that the subject is a very difficult and complicated one that should require careful deliberation before any legislative action is taken. Any changes will have a far-reaching impact on all Kansans who have, or will have, need of such services. We hope that Kansas will show the same commitment and responsibility to quality care for its citizens as it did in its passage of the licensure and certification requirements for home health.

It is our hope that hasty action can be avoided so that these issues might be addressed comprehensively.

Respectfully,

Linda Lubensky
Executive Director



February 24, 1988

Final KAHHA Nursing Task Force Report

Since the appointment of the Nursing Task Force by the KAHHA Board, November 13, 1987, the group has met three times (January 12, 1988, February 9, 1988 and February 23, 1988).

The following people compose the Nursing Task Force:

Judy Bellome, Chairperson
Clinicare Family Health Services, Inc.
413 Division
Kansas City, KS 66103

Bernie Knipp
VNA of Greater Kansas City
527 W. 39
Kansas City, MO 64111

Pat Curtis
Harvey Co. Home Health, Inc.
P.O. Box 645
Newton, KS 67114

Marge Schlabach
Community Memorial Hospital
Home Health Agency
708 N. 18
Marysville, KS 66508

Terri Roberts, J.D., R.N., Executive Director of the Kansas State Nurses Association, and Bonnie Howard, R.N., M.A., Nursing Practice Specialist for the Kansas State Board of Nursing have continually met with the Task Force.

As stated in the December 15 letter from Linda Lubensky, the Task Force has been appointed "to study the current regulation by the Kansas State Board of Nursing that restricts nurses from teaching procedures to non-medical personnel, who will be reimbursed for their services." In addition, the Task Force,.. "is directed to explore the issues involved and to inform the Board of the advisability and ramifications of any changes to the regulations that it might suggest."

The nurse practice act does not prohibit a nurse from teaching basic Activities of Daily Living (ADL) procedures to non-medical personnel who are reimbursed for their services. ADL procedures do not fall under the definition of the practice of nursing, 65-1113(d), in the Kansas Nurse Practice Act.

Section 65-1124 does not prohibit gratuitous nursing by friends or members of the family, or the incidental care of the sick by domestic servants or persons primarily employed as housekeepers.

The nursing practice act does prohibit nurses from teaching certain procedures to non-medical personnel who are not under the supervision of a licensed professional nurse. Discretion of the law allows nurses to do select training.

At this time, the Task Force does not recommend any change or addition to the Nurse Practice Act. An "Interim Study" may recommend change or revision based on their finding.

Based on extensive study, the Task Force has identified these areas of concern with the following recommendations:

I. Home care training and care provided in the home by unlicensed personnel:

Issues and Problems Identified:

- A. There are inconsistencies in requirements between various Kansas state in-home care departments/programs in Kansas.
 1. Home Health licensure requires Kansas certified Home Health Aides to satisfactorily complete ~~14~~²⁰ hours of specified ⁹⁰ training to complete the Certified Nurse Aide Program, (KSA 39-932), with 20 additional hours to be certified as a Home Health Aide (KSA 65-5115).
 2. The Kansas Department of Social and Rehabilitative Services is exempt from the home health licensure requirements/regulations (KSA 65-5101).
- B. Current state regulations only recognize and certify one level of in-home, nonprofessional care provider. (The Certified HHA.)
- C. There is a lack of availability of training programs to meet the in-home service needs.
- D. There is a lack of funding for the training of HCBS Nonmedical Attendants.
- E. There is a lack of flexibility and coordination to provide opportunities for career development/growth for the nonprofessional in-home care provider.
- F. There is a lack of coordination and communication between state department programs related to training and regulation. (SRS, KS Department of Health and Environment and KS Dept. of Education).

II. Recommendations of Task Force

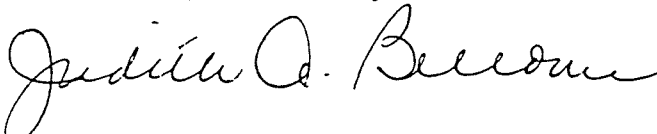
- A. Licensed Home Health Agencies would provide training to non-medical personnel not employed by such agency. Licensed professional nurses are not restricted from teaching ADL's to unlicensed individuals by the Kansas Nurse Practice Act (KSA 65-113 & 65-1124).

- B. KAHHA members would provide training to SRS workers. The training should be only those skills specifically identified in the 20 hour, Kansas Home Health Aide Training Manual. This service to the State would be reimbursed at a reasonable rate.
- C. Requests for training of unlicensed persons to perform skilled nursing services or services which require professional nurse judgement would not be provided by licensed Home Health Agencies. These services would be contracted through licensed home health agencies and supervised by licensed professional nurses (Registered Nurses).
- D. The Task Force proposes that KAHHA, as the professional state organization for home care, recommend that the state legislature appoint an "Interim Study" review of these identified issues and problems. Recommendation at this state level should influence any necessary legislative changes or budgetary revision.

Note: Terri Roberts, J.D., R.N., and Bonnie Howard, R.N., M.A., may be contacted to advise the KAHHA Board of the process to convene this "Interim Study". (Kansas Senator Erlich, Chairperson of the Health and Welfare Committee, and Marvin Littlejohn, Assistant Chairperson, are suggested information resource contacts. Jo Ann Peavler, L.P.N. of the Kansas State Board of Nursing is also a contact source to the legislative process.)

Thank you for the opportunity to chair this Task Force. I appreciate the hard work and input of all participants.

Respectrully submitted,



Judith A. Bellome, R.N.

Frederick M. Markham
2222 Yale Rd., Apt. 7A
Lawrence, Kansas 66046
(913) 841-6608

STATEMENT ON THE NURSES PRACTICE ACT:

My name is Frederick M. Markham and live in Lawrence, Kansas. I have lived independently on my own for over 20 years. My education level is several hours beyond a Master's Degree in Journalism.

I have employed attendants throughout the 20 years and more of my independence. I am proud of the fact that I have managed my attendant care program with intellectual and common sense skills.

Being as severely disabled as most would label me, I am happy to say that I am still alive and well today. I have been on the Home Community Based Program for eight (8) years now, and find that it's a program that has brought and can still continue to bring pride to individuals who are disabled and can manage their own style of living.

But, this type of independence can only exist if some vital changes are made in the Nurses Practice Act. Changes that will give the disabled citizens the right to direct their lives in which way they choose. While some decisions made by individuals, concerning their own life style may seem different from others to what some of us would consider to be "in the normal frame of society," is no reason to keep them from obtaining that style and quality of life. We are all individuals, equal in the eyes of GOD. Now, it's time for all of us to be equal in the eyes of each other. To be otherwise, would be an act of abomination in the eyes of GOD. I ask you to amend the Nurses Practice Act so that we all can have the right to the pursuit to dignity, happiness, and equality.

TESTIMONY RE PROPOSED CHANGES TO THE NURSE PRACTICE ACT, SB 756

I was spinal cord injured at T-10 (paraplegic) 23 years ago, and for the past 15 years have had limited hand use due to MS. As well as personal experience with disability and attendant care, I have, in addition to other jobs, been executive director and service coordinator at independent living centers in rural Missouri and Oklahoma. I was involved in committees implementing statewide attendant care programs in both states. In my present job as trainer for the Research and Training Center on Independent Living at KU, I travel extensively to other states to conduct workshops and training related to disability issues, some of which relate to attendant care. I am familiar with attendant care legislation in other states and with the reports on attendant care issues from the World Institute on Disability. I feel I can speak on the issue of attendant care with both professional authority and personal experience.

I have never used medically trained attendants. I train attendants myself to handle not only my normal daily routine, but my care following illness or injury. Attendants have done many things for me, both on a daily basis and following illness or injury, that are classified as "medical" procedures and prohibited to non-medically trained workers under the nurse practice act as it now reads. These things include bowel and bladder care, assistance with medication and wound dressings and range of motion. Attendants have never had any difficulty learning or doing the tasks I need done, and in addition to assisting me, have often assisted other consumers, with whose care they are not familiar, when there has been a need for that assistance at conferences and workshops involving large numbers of people with disabilities. I have never, using attendants I train myself, had any problem with getting reliable or quality care. The only times I have had difficulty being kept clean, getting proper exercise, getting fed right, or getting skin care adequate to prevent pressure sores is when I have been in the hospital surrounded by medical professionals, but without my own attendants.

If I need home health care such as supervision of IV antibiotics or pressure sore treatment, I get the help I need from the visiting nurses. Attendants do those things for me which, because of my physical limitations, I cannot, but otherwise would, do for myself. The ability of non-disabled people with no formal medical training to take pills, give themselves injections, change bandages, treat themselves with non-prescription medication, or treat minor injuries is rarely questioned. The only difference in a person with a disability is that he or she must direct another person to do these same things. Why should the same thing be taken for granted as part of daily living if you do it yourself, and suddenly become a "medical procedure" when you must direct another person in doing it for you?

What we need to carry on tasks of daily living and to work or attend school is physical assistance which we are mentally competent to direct. We are physically limited, not sick, and the assistance we need should not be defined as medical treatment and confined to health care professionals.

Neither do our physical disabilities limit our mental ability to control our own lives or our right and responsibility to manage our daily lives by our own decisions and with people of our own choice.

The attendant care I have had in the fifteen years I have needed it has been effective enough that during that entire time, I have worked full time, lived in my own home, traveled a lot, and been very active both nationally and in my own community. Since I work and pay my own attendants, my attendant care is totally under my own control.

Because no outside agency pays for or monitors my attendant care, I can get away with ignoring the law, as no state or private agency administering attendant services can. If I managed my attendant care within state law, I, like present HCBS consumers, could not get the degree and quality of care I need to survive, let alone work or travel. The limits of the law as it now reads limit the lives of Kansans with severe disabilities. Please support this proposed change to give us all the chance to live productive and satisfying lives.

Barbara Bradford
1521 Vermont
Lawrence, KS 66044

-work: 864-4095
home: 842-2910

TESTIMONY: SB 756

Dana Dower
1521 Vermont
Lawrence, KS 66044

I have worked as a personal care attendant for almost 5 years now. I am 22 and have no formal medical training.

I have worked mainly for one person for the past five years, but during that time I have worked on a regular basis for several other people, and have done attendant care for other disabled people at conferences and workshops my employer attends.

As an attendant, in addition to a lot of other things I do, I have done things that only nurses do most of the time, like change bandages, take care of injuries, take care of my employer after she has had surgery, give injections, do range of motion exercises, help somebody who is having trouble breathing, change an indwelling catheter, and check skin for pressure sores. The disabled person I take care of taught me how to do the things she needed me to do for her, and when I take care of somebody else, they show me how to do the things they need done. Almost everybody does things differently and seems to need different things, even when they have the same disability. After working at this for five years and taking care of a lot of different people with disabilities, I don't think you could go to school and learn a certain way to do it. The best way to learn is to have each different person teach you.

All you really need to do attendant work is common sense, caring about people, and being willing to do what you have to do. The things you need to do aren't that hard to learn, but it takes a lot of practice and experience to do some of it right. The practice and experience you need isn't what you get in school, it's what you learn doing it every day. In fact, sometimes what they teach in school isn't even right for the person you're taking care of. I have seen doctors and nurses who aren't used to disabled people get upset over things they shouldn't that are normal for the person, and then not get upset over something they should, like a pressure sore starting. The attendant who has been taught by the disabled person and is with them every day often knows more about what they need and how to do it than someone who has finished nursing school but hasn't been around disabled people.

As I said before, I didn't go to school for medical training, and I don't think I needed to or that anyone working as an attendant needs to. I have taken really good care of my employer going on five years and have done a good job working for other people too. I have always been able to learn what I needed to and do it right. It isn't right that there should be a law stopping attendants that work for the state from doing what they need to do for the disabled people they take care of, when they are able to do it, and a lot of the time do it better than nurses who don't know the person. People living on SSI can't afford to pay extra attendants just because the law won't let their own state-paid attendants do what they need. It makes sense to change that law.

STATEMENT ON AMMENDMENT TO
THE NURSE PRACTICE ACT
By Kalen Lee Beaumont
April 28, 1988

.....

I use SRS HCBS Homecare Workers to get out of bed in the mornings and to go to bed at night. It is important that these Homecare Workers can continue to perform the functions that they currently perform; such as administering medication and assisting me in the use of my nasal mask ventilator that has been specifically designed for use in the home.

This ammendment would assure that Homecare Workers who assist me with these activities can legally do so. It is also important that they can legally assist me with medications and my ventilator at my direction as these are functions I would perform for myself if I were physically capable of doing so.

Assisting those of us with physical disabilities in the performance of such functions as adminstering medications, assisting us with bowel routines, bladder routines, range of motion exercises, etc. is vital to us continuing our independent lifestyles. These functions are currently interpreted as "Medical"; however, these are functions that have been performed by our family members or Homecare Workers for years.

These reasons are why I personally feel this bill to ammend the Nurse Practice Act should be seriously considered and recognized as important to persons with physical disabilities living independent lives. This means we should have the control of directing our own assistance needs such taking medications, using equipment like the ventilator I use, etc.

Thank You for your time,

Kalen Lee Beaumont