Approved 1-25-89
Date

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 23, 1989 in room 423-S of the Capitol.

All members were present except:

Rep. Ben Foster, excused

Committee staff present:

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

Conferees appearing before the committee:

Jack Beauchamp, Franklin County, Kansas
Janet Schlansky, Department of SRS
Ben Coates, Department of SRS
Dick Morrissey, Director Bureau of Adult & Child Care, Health/Environment
Ray Petty, Exec. Dir. Topeka Resources, Ks. Advisory Independent Living
Mike Oxford, Dept. Human Resources, Ks. Adv. Commisison on Employment of the Handicapped.

Chairman called meeting to order and invited Mr. Jack Beauchamp to present his request for legislation. He gave hand-out, (see Attachment No. 1), which is draft of a bill that will speak to giving medical care to school pupils who are currently not receiving care when needed. Many do not have a SRS card that would entitle them necessary care, so they are being overlooked. He answered questions, no, I would have no objections to this bill being joined into an at risk bill.

Rep. Weimer made a motion this bill be introduced and returned to this Committee, seconded by Rep. Amos, motion carried.

HEARINGS CONTINUED ON HB 2012:

Janet Schlansky, Department of SRS offered printed testimony, (see Attachment No. 2, along with A,B,C,) for details. She noted there are no easy answers to this issue brought forth in **HB 2012.** There are three major issues they hear as testimony is presented, i.e., client control, definition of what are medical and non-medical procedures, and the inadequate use of in-home care services. She outlined each of these issues, and gave background for the benefit of new committee members reviewed in-home services. New definitions provided in this bill are clear and consistent and can be incorporated into programs being managed by SRS. Challanges are, i.e., who has the responsibility for recruiting, hiring, training, scheduling, supervising, evaluating, firing, paying attendants. She spoke to the issue of Medical vs. non-medical procedure. Their Department ideally would like resources available to explore a variety of options to provide care. It is their goal to carry out programs as outlined by the legislature. Other concerns, i.e., who has the right to determine criteria for who will be eligible for these services. Without changes in the Nurse Practice Act, the consumer issues will not be addressed. A more clear interpretation needs to be made.

Ben Coates, Department of SRS gave hand-out, (Attachment No. 3). He noted the need for care in not taking away from one service to give to another. This is a complex problem.

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE,

room 423-S Statehouse, at 1:30 a.m./p.m. on January 23, 1989

HEARINGS CONTINUED ON HB 2012:--

Mr. Ben Coates, SRS continued:

Mr. Coates stated they service 22,000 people daily in long term care. He broke down the care services in categories. He noted problems, i.e., delays in payment of staff, recruiting of new attendants. He asked that Legislators keep in mind Department of SRS serves a much larger group of clients than was heard during Interim, therefore whatever is decided on this bill, this large group of consumers could be affected as well. New and or expanded services will require additional funding, or groups now being serviced will be cut back. He noted concerns about making large scale changes that would accommodate small sub-groups at the expense of other larger community based clients. He asked also this committee consider concerns of Department of SRS about increased liability. He answered numerous questions.

Dick Morrissey, Department of Health and Environment, (see Attachment No. 4), spoke to concerns in **HB 2012.** Definitions of "individual in need of in-home care", "attendant care services', and "health maintenance activities are broad and contrary to current home health agency licensure requirements. We are also concerned about training costs associated with home health aide certification. He summarized his remarks, then gave recommendations i.e., legislation enabling appropriate individuals to direct their own care is important, yet should not undermine existing statutes which have been designed to provide quality home care services to frail/elderly Kansans. As written, **HB 2012** is in conflict with current statutes. We recommend this Committee clarify the policy related to self-directed care, versus home health agency licensure requirements governing aide training and their supervision. He answered numerous questions.

Ray Petty, Executive Director, Topeka Independent Living Resource Center gave some background information for the benefit of new Committee Members of Independent Living situations. (See Attachment No. 5) for his printed text. He noted that clarification of **HB 2012** is needed. Suggested amendments, i.e., lines 84-87 be revised, and he detailed language. He spoke to other concerns, i.e., need to specifically refer to assessment of which persons are capable of self-directed care, and yes, children could be excluded from the bill, however, he would advocate soon-to-be adults should be included as potential consumers of these services being discussed. He spoke to the issue of those who are disabled, but not ill, and need assistance, not medical care. He answered questions.

Mike Oxford, Ks. Dept. Human Resources offered printed testimony, (see Attachment No. 6, also 6-A-B-C-D-E. He spoke to changes that have now made clear in second paragraph, health maintenance activities are included. He outlined health maintenance activites; Act 150 requires Attendant Care Service be provided statewide; the range of choices now is left up to the individual consumer; many services will be determined by available funds; spoke of the Pennsylvania law now being implemented; directed members to read the instructions for administering self-directed care, and the review of same. He gave a comprehensive testimony.

Chair had to ask Mr. Oxford to conclude his comments due to the time constraints.

Chair apologized for not having more time for conferees. There will be hearings continued again tomorrow on **HB 2012,** and Chair noted it is the hope of committee these hearings can be concluded so that discussion and action can begin on this bill.

Meeting adjourned 3:03 p.m.

GUEST REGISTER

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

Date *Jan 23, 1989*

Name	Organization	Address
George A. Dugger	Ks. Dept. on Aging	Rm. 122-S DSOB
Lee Graybeal	Topeka Indep. Living Resource Center	Topeka
Amelia Evans	"	"
Frances Kastner	Ks Physical Therapy Assn	Topeka
Catharina C. Paal	SRS Medical Programs	OSOB 628S
Erna Berkley	Board Member Topeka Indep. Living Resource Center	Topeka
[illegible]	[illegible]	Topeka
[illegible]	Alcohol Serv. [illegible]	Topeka
[illegible] Rockett	St. Francis - Wichita	Topeka
K B Ballard MD	Clinicare K C Kan	
Dorothy Ballard	Citizen	Shawnee Mission KS
George [illegible]	AARP Capital Area Task Force	Topeka, Ks
[illegible] Reser	KDHE	Topeka
Richard Morrissey	KDHE	TOPEKA
Bonnie [illegible]	KSBN	"
Belva Chang	KSBN	"
LEONORA S. MILLER	none	KCMO
Ray Petty	Topeka Ind. Liv. Resource Center	Topeka
Linda [illegible]	KS Home Care Assoc	Lawrence
M. [illegible]	[illegible]	Topeka
[illegible]	KSNA	Topeka
Don Powers	SRS	"
Carol Rengel	LCCD	Lawrence

GUEST REGISTER

HOUSE PUBLIC HEALTH AND WELFARE COMMITTEE

Date 1-23-89

Name	Organization	Address
Mike Oxford	KACEH	Topeka
Ron Seaton	"	"
Allen Spoonemore	SRS	Hoisington 606N
Bob Mikesic	Independence Inc	Lawrence
Fred Markham		Lawrence
Nelda Swaltney	SRS - Rehab SVS	Topeka
Paula Woodward	LCCD	Lawrence
Sherri Axline	LCCD	Lawrence

HOUSE BILL NO. _____

By

AN ACT concerning school districts; requiring boards of education thereof to adopt policies for the provision of health care services to pupils with health care needs.

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

Section 1. As used in this act:

(a) "Board" means the board of education of any school district.

(b) "School district" means any public school district organized and operating under the laws of this state.

(c) "Professional employee" means any person who is regularly employed by a board in a professional capacity and who is performing duties for which certification is required by the state board of education.

(d) "Pupil" means any person who is regularly enrolled in and attending any of the grades kindergarten through 12 maintained by a school district.

(e) "Pupil with health care needs" means any pupil less than 18 years of age whose health or physical, mental or emotional condition requires health care services.

(f) "Parent" means and includes natural parents, adoptive parents, stepparents, guardians and custodians.

(g) "Health care services" means hospital, medical, surgical or dental treatment or procedures.

(h) "Physical, mental or emotional abuse or neglect" has the meaning ascribed thereto in the Kansas code for care of children.

Sec. 2. (a) Whenever it appears to any professional employee of a school district that a pupil enrolled in the school district is a pupil with health care needs, the professional

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attm #1
1-23-9

employee shall report the matter to the superintendent of the school district. The superintendent shall notify the parents of the pupil of the report. Such notice shall describe the health care services which the pupil appears to be in need of, inform the parents of any free or low-cost health care services available in the area, and request the parents to respond to the notice. If the response of the parents to the notice indicates that the parents are financially unable to pay the costs of providing the pupil with the needed health care services and that the pupil is not eligible for medical assistance under K.S.A. 39-701, and amendments thereto, the school district, with the consent of the parents, may cause the pupil to be provided with the needed health care services and may pay the costs thereof from the general fund of the school district.

(b) Failure or refusal of the parents of a pupil with health care needs to respond to a notice under subsection (a) or to provide the pupil with needed health care services or to consent to the provision thereof shall constitute physical, mental or emotional abuse or neglect and the same shall be reported as provided in K.S.A. 38-1522, and amendments thereto.

(c) No school district which in good faith causes a pupil with health care needs to be provided with health care services and no health care provider who in good faith provides health care services to a pupil with health care needs, after a consent has been obtained as provided in this section, shall be liable in any civil or criminal action for failure to obtain consent of a parent.

(d) When the costs of the provision of health care services to a pupil with health care needs has been paid by a school district and the parents of the pupil become possessed of financial resources in excess of the amount possessed at the time the school district paid such costs, it shall be the duty of the parents to reimburse the school district for the expense incurred by it. Moneys received by a school district under this subsection shall be deposited in the general fund of the school

PHRC
attm #1
pg 2
1-23-9

district, shall be considered reimbursements to the school district for the purpose of the school district equalization act, may be expended whether the same have been budgeted or not, and amounts so expended shall not be considered operating expenses.

(e) The board of every school district shall develop and adopt a policy for effectuation of the provisions of this act.

(f) Nothing in this act shall be construed to mean that any person shall be relieved of legal responsibility to provide care and support for a child.

Sec. 3. This act shall take effect and be in force from and after its publication in the statute book.

Attm #1
Pg 3
1-23-9

STATE DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES
Winston Barton, Secretary
January 23, 1989

Testimony concerning House Bill 2012

An act concerning individuals in need of in-home care; defining certain terms; directing the secretary of social and rehabilitation services to perform certain duties as part of the home and community based services program; providing an exemption from the Kansas nurse practice act.

There are no easy answers to the issues brought forth to this committee. SRS has for years truly struggled with the issues surrounding personal care and the provision of in-home care services. There is disagreement within our agency depending upon the professional's training and orientation and we range from staff supporting the Independent Living Model to the Medical Model.

As we have listened to the testimony, read the interim study committee's report, and from our personal observation, I believe that it is important to clarify the issues, because they are distinct and different. Also, because terms are used differently, it is important to understand what terms we use and how we apply them.

There are three major issues as we have heard the problem:

1. Client control, as an employer, over the individual who performs the attendant care tasks.

2. Definition of what are medical and non-medical procedures particularly as it relates to: medication, bowel routines, and catheter care.

3. Inadequate use of in-home care services (which are broader than attendant care) and the feelings that SRS has not been as creative in providing options and putting their resources into vigorously pursuing new delivery methods.

I would like to respond to each of those issues, but first for the benefit of some of the new members of the committee, I would like to take a few minutes to review briefly the in-home services currently provided by the Department of Social and Rehabilitation Services. I have attached a handout which describes the four major programs which provide Home Health, Homemaker, Medical Attendant and Non-Medical Attendant Services. These services are provided either by employees of the Department of Social and Rehabilitation Services or through community agencies who have provider agreements with the Kansas Medicaid Program.

The program, which this bill addresses specifically, is the Home and Community Based Services Program. There are currently thirteen services provided in Home and Community Based Services designed to allow recipients who have been screened and have been determined eligible and in need of nursing home

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attm. #2
1-23-9

service to choose Home and Community Based Services. In Home and Community Based Services, an individual plan of care is developed which allows the recipients to remain in their own home or other community setting in lieu of a nursing home.

We believe the new definitions provided in House Bill 2012 are clear and consistent and can be incorporated into the programs managed by the Department of Social and Rehabilitation Services, although not all within the guidelines of existing funding sources. Currently, approximately 1,600 persons receive services in the Home and Community Based Services Program: 65% elderly, 10% mentally retarded/developmentally disabled, and 25% physically disabled (non-elderly).

There is a wide range of medical and social needs of persons currently receiving services in the Home and Community Based Services Program. Although I recognize the danger in making generalizations, I believe the best way to illustrate the range of persons being served is to give examples of the types of recipients receiving the services.

a. The elderly, for the most part, are quite ill. They have conditions which can reasonably be expected to deteriorate, need constant monitoring, and require frequent changes in the plan of care.

b. The non-elderly, physically disabled, are characterized by two major groups:

1. Persons who have a disability which may be the result of an accident and are unable to perform the activities of daily living because of resultant limitations. These individuals have a strong desire to direct their own services and feel competent to train, direct and supervise the attendant care needed. They find "a take care of" attitude offensive. Changes in their care plans are infrequent.

2. The second category are persons who either have been injured to the point that they are not longer able to direct their own care (e.g., head injury), or have a condition which is not static and needs constant monitoring and frequent changes in the plan of care.

The challenges we have faced in administration of the Home and Community Based Services Program is to balance the level of supervision and direction which must be maintained by the state agency in managing the Medicaid Program to adhere to both state and federal guidelines, and on the other hand giving recipients the flexibility they desire in directing the provisions of and control of the attendant care services they receive. I would now like to go back and review the three major issues we see facing this committee.

atlm 2
pg 2
1-23-9

CLIENT AS THE EMPLOYER

The first issue has to do with who has the responsibility for recruiting, hiring, training (generic and specific), scheduling, supervising, evaluating, firing, and paying the attendant, as well as determining the tasks that the attendant can perform.

New Section 2 of the House Bill 2012 requires the Secretary of Social and Rehabilitation Services to establish a program which allows the recipient all these tasks as well as even greater flexibility in managing care and supervising procedures which by statute must now be provided or supervised by a registered professional nurse.

The Department has worked with consumer groups, Home Health Agencies, and other interested groups over the last 3-4 years attempting to adjust the program to better meet the needs of the clients while adhering to the state and federal guidelines. House Bill 2012 directs the Department to implement some of different models. Examples of three methods of providing personal care services are:

1. Individual providers.
   a) Client/family member as the employer
   b) Client/family member assumes role of employer: SRS assumes role of designated agent.
2. Contract agencies: SRS contracts with provider agency for service.
3. Government Workers: SRS assumes role of employer.

Individual Providers

The non-medical attendant service, under HCBS, was provided by individual providers until July 1987. The recipient had an active part in recruiting their attendant, if desired. They could recommend a change in attendant, but could not dismiss or directly pay their attendant. The recipients were essentially on their own. Recipients and attendants work out their own schedules and the case manager only becomes involved when there is some difficulty or some need for re-assessment of hours. Even under this system, with the exception of withholding taxes and generic training, the young, severely disabled consumer wanted more control than was offered at the time. They wanted to train, supervise, schedule, evaluate, terminate, and pay their attendants.

Assuming the role of "designated agent" was explored by SRS as an alternative to the current system. It was not recommended because of the additional cost involved, administrative processing, as well as difficulty in working with the IRS and the Social Security Administration in determining the mechanics. It is our understanding that some of the issues have been resolved as other states have used this method of service delivery.

The only options that the agency has not pursued is providing a monthly stipend to the recipient for attendant care services.

Attm #2
P9. 3
1-23-9

Contract Agencies

In Kansas, Home Health Agencies and Local Health Departments are providers of medical attendant care. Kansas currently does not contract for non-medical attendant services, although it is allowable under a recent policy change.

Under this method, the provider agency assumes full responsibility for recruitment, training, supervision, and evaluation of the attendants. The major advantage of contract agency providers is to SRS as it relieves the agency of the daily on-going problems related to providing direct care services, seven days a week, 16 and sometimes 24 hours a day. The cost of the service remains competitive, compared to government providers, as the salaries fluctuate with current economic conditions. Home Health Agencies pay very close to minimum wage and generally experience high turnover. Recipients have less flexibility in scheduling their attendant with this type of service delivery.

HCBS recently approved a policy which allows areas the option of contracting with Independent Living Centers, Area Agencies on Aging, Home Health Agencies, or Local Health Departments for non-medical attendant care. Thus far, we have no providers.

Government Workers

For homemaker and non-medical attendant services, Kansas uses this service delivery method exclusively.

Under this option, SRS or another governmental agency would assume full responsibility for recruitment, training, supervision, and evaluation and necessary withholdings. Currently, Kansas is operating under this option with SRS being the service provider. The main advantage is less turnover and tighter supervision over the provider's job performance and recipients hours. Under civil service classification, attendants, over time, earn a higher rate of pay and receive more benefits than the other methods. As workers obtain seniority, there is less turnover.

It is clear that to meet the requirements of House Bill 2012, major changes will need to be made in how Social and Rehabilitation Services manages the program and in recruiting providers who are both willing to provide the service while at the same time allow the recipients the control stipulated.

It is the departments current feeling that to totally meet the requirement of the bill, a program must be developed which does not exclusively rely on Medicaid funds. For clients who choose to direct their care and who are in need of services which may not be considered medically necessary, a state only funded program needs to be developed. Some have suggested monthly stipends for attendant care for the consumer to use as they wish to meet their needs.

PH&W
Page 4
Attach #2
1-23-9

MEDICAL VS. NON-MEDICAL PROCEDURES

To fully understand what this means, it is important to understand that attendant care programs can be arranged on a continuum defined by the Medical Model on one end, and the Independent Living Model on the other. In the Medical Model, a physician's plan of treatment is required along with periodic nursing supervision and completion of certain functions by the licensed nurse. Attendants are recruited by the employing agency and accountable to the agency.

In the Independent Living Model the attendant is managed by the user. No medical supervision is required. Attendants are recruited by the user, paid by the user, and accountable to the user.

Kansas' orientation tends to favor the Medical Model. Kansas currently funds their non-medical and medical personal care programs almost exclusively with Medicaid funding. In order to be funded with Medicaid, the services must be medically necessary and in some instances prescribed by a physician and almost always either directly or indirectly be provided under the supervision of a registered nurse.

SRS has three types of attendant care services: homemaker, non-medical attendant, and medical attendant. All of these services are currently provided under the waiver. Homemaker and non-medical attendant are provided by SRS staff; medical attendant by Home Health Agencies or local health departments.

Currently the services provided by medical attendant or personal care services are the ones that recipients of the services feel strongly do not need to be under the supervision of a registered nurse and contracted through a Home Health Agency. It is their belief and the belief of proponents of the Independent Living Model that identifying these tasks as needing close medical supervision is costly and inadequate. As you have heard consumers testify, these tasks to them are routine and in order for them to live with some degree of freedom, need to be performed in a manner that is compatible with their life style, and for them, the rigidity of scheduling through a home health agency is unnecessary.

It is also important to note that it is the individual who assumes the responsibility for their own well-being and health, and determines the need to contact a medical professional. The big question is who has the right to determine an individual's level of competence to do this and should the criteria be any different for someone who is physically disabled versus someone who is not.

Section 3 of House Bill 2012 is a revision to the Kansas Nursing Practice Act. This amendment addresses the issues frequently raised by consumers as to their inability to have persons assist them with their activities of daily living. The issues of participant control extend beyond our agency's ability to provide the mechanism for the service to be delivered. Without changes in the Nurse Practice Act, the consumer issues will not be addressed. At a minimum, we asked the interim committee to assist by defining under what conditions the tasks that we have identified as most controversial can be performed.

Attm #2
HB 2012
1-23-89

INADEQUATE USE OF COMMUNITY-BASED SERVICES

We recognize the limitations of our existing service delivery system. We agree that the use and development of local resources have not been fully used and there exists a general lack of creativity in service delivery. It is not from lack of interest or desire, however, the role of the professional social worker has been severely minimized over the past five years in working with the elderly population due to the demands that Youth Services has placed on staff, particularly generic staff. We have approximately 39 FTE social workers who work with 8,000 in-home care cases; a ratio of 1:200. It is difficult to be creative when staff and resources are not available to provide minimal level of care and time to develop new resources. There are currently thirteen (13) services provided in Home and Community Based Services designed to allow recipients who have been determined eligible and in need of nursing home service to remain in the community. Many of these services have not been developed to their full potential for lack of professional staff.

The case managers currently used are part-time para-professionals who are required to work less than 20 hours per week. However to address the issues raised in the interim study committee, and to fully meet the intent of House Bill 2012, state resources are needed.

In summary we would ask that providing a participant-directed program not be solved in isolation of improving the overall community based long term care for elderly and disabled. We welcome the opportunity to pilot options that would support a single service delivery system which would provide a systematic process for assessing the recipient's needs, authorizing and coordinating a package of services, and monitoring the quality of care, regardless of the funding source.

We would like to have the resources available to explore a variety of options to assure the feasibility and in order that any report to the legislature by December 1989 has substance.

It is the department goal to carry out the program as outlined by the legislature and have appreciated the work of the committee over the interim to study this multifaceted program. We would be happy to provide any information or clarification you may desire.

Jan Allen
Commissioner of Adult Services
Social and Rehabilitation Services
913-232-7788

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296
attm #2
1-23-9

COMMUNITY-BASED LONG TERM CARE
ADULT SERVICES PROGRAM

	HOME CARE: SOCIAL SERVICE BLOCK GRANT (SSBG)	HOME AND COMMUNITY-BASED PROGRAMS (HCBS)
ELIGIBILITY	Income Eligible Personal non-medical need	Medicaid/Medikan Medical need Active treatment program for MR only
AGE	18 +	16 + 65 + (mentally ill only)
ALLOWABLE MAXIMUM	None	ICF-MR - $1,647 SNF - $ 970 ICF - $ 750
CLIENT OBLIGATION	No	Yes - Spenddown required to meet financial elig.
RECIPIENT	Elderly Physically Disabled Mentally Retarded/DD Mentally Ill	Elderly Physically Disabled Mentally Retarded/DD Mentally Ill (over 65 yrs.
SERVICES	1 Home Care -Homemaker -Household Maintenance -Non-medical attendant *Provided by either SRS Home Care staff	1 Adult Day Health 2 Residential Care 3 Residential Care/Training 4 Habilitation 5 Home Health Aide 6 Hospice Services * 7 Homemaker * 8 Non-medical attendant 9 Medical Attendant Care 10 Night Support 11 Respite Care 12 Wellness Monitoring 13 Medical Alert
CLIENTS SERVED (88)	6,453	1,621 clients 742 home care-mo. av.
EST. FY 89 BUDGET	$6,401,813	$ 631,695 (cs. mgrs.) $3,528,265 (service) $3,263,854 (home care)
FUNDING	73% Fed 27% State	54% Fed 46% SGF

Attm #2
1-23-9

LONG-TERM CARE
ALTERNATIVES TO ADULT CARE HOMES
MEDICAL SERVICES PROGRAMS

	HOME HEALTH AGENCY	PERSONAL CARE MEDICAID
ELIGIBILITY	Medicaid/MediKan Physician has certified the need for the service. Documented as medically necessary. Would require acute care hospitalization or an adult care home if the service were not provided.	Medicaid/MediKan Need long-term maintenance or supportive care. Without ACIL the recipient would be institutionalized. Other resources for care are not available. No possibility of rehabilitation. There is RN supervision.
AGE	All	All
ALLOWABLE MAX	None	None
CLIENT OBLIGATION	Spenddown Third party resources	Spenddown
RECIPIENT	All Medicaid/MediKan	All who meet medical criteria.
SERVICES	Skilled nursing Home Health Aide Physical Therapy Occupational Therapy Speech Therapy Respiratory Therapy Restorative Aide Medical Supplies and Durable Medical Equipment	Basic personal care and grooming. Assistance with feeding, diet and nutrition. Assistance with self-administered medications. Assistance with transferring or ambulatory needs. Assistance with bladder and bowel requirements.
CLIENTS SERVED- FY 87	8,103	27
EST. 1988 Budget	$1,696,249	$258,985
FUNDING (%state/federal)	45.07/54	45.07/54

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pg. 8
attm # 2
1-23-9

HOMEMAKER SERVICES

Eligibility Criteria:

1. Meet SSBG income eligibility guidelines or Title XIX guidelines.
2. Social worker or ACH screening team determines need for service and documents that the client:
   a. is living alone or with persons who are unable to provide the necessary assistance to maintain the home;
   b. is in danger of unnecessary, inappropriate institutionalization without homemaker services;
   c. is potentially at risk due to inadequate care which could result in abuse or neglect.

Services: General household activities which are provided in recipient's own home. No live in providers are allowed, nor can providers transport recipients.

Domestic Services- Routine cleaning limited to the following:
- Sweeping, vacuuming, washing and waxing of floor surfaces
- Washing kitchen counters and sinks
- Cleaning the bathroom
- Storing food and supplies
- Taking out garbage
- Dusting and picking up
- Cleaning oven and stove
- Cleaning and defrosting refrigerator
- Changing bed linen
- Miscellaneous domestic services, e.g. changing light bulbs

Heavy Cleaning: To be provided only when specifically authorized
-Thorough cleaning of the home to remove hazardous debris or dirt when:
Home care service initially granted
Resident's living conditions result in substantial threat to his/her health and safety.

Meal Preparation and Cleanup:
-Preparation of meals includes such tasks as planning, preparing foods, cooking, setting table, serving the meal, cutting food into bite-size pieces

-Meal cleanup includes washing and drying dishes, pots, utensils and culinary appliances and putting them away.

Routine Laundry
- Routine mending, laundry, ironing, folding and storing clothes on shelves or in drawers.

Shopping
-Reasonable food shopping and other shopping/errands limited to the nearest available stores or other facilities consistent with the client's economy and needs.

August 16, 1988

P&W
attm # 2-A
1-23-9

MEDICALLY-ORIENTED PERSONAL CARE

Eligibility Criteria:

1. Medicaid/MediKan recipient
2. Does not require continuous skilled nursing care, may need occasional episodic skilled nursing services.
3. Recipient is established in a supportive home setting.
4. There is a plan for coverage during the hours when the personal care attendant is not providing services.
5. The recipient is medically stable.
6. Care needs are identified in the treatment plan.

Services: Personal care services are medically oriented tasks which meet a recipient's physical requirements. Personal care services must be prescribed by the recipient's physician, and provided in accordance with a plan of treatment and supervised by a registered nurse. The physician must reauthorize the care every six months, and the supervising RN must review the care every three months. In addition to the services listed under non-medical, Medical Personal Care can include:

Basic personal hygiene and grooming to include bathing, care of the mouth, hair, nails, skin, and assistance with dressing.

Assistance with bladder and or bowel requirements, including helping the patient to and from the bathroom, or assisting with bedpan routines.

Positioning nonambulatory recipients in a bed or chair.

Assistance with simple maintenance physical activities.

The care of nonsterile dressings, the application of ace bandages and support hose.

Shopping for prescribed drugs and prescribed medical supplies.

Limitations:

1. Performed in individual's own home
2. Care is provided by a qualified individual who is not a member of the recipient's family
3. A maximum of 12 hours a day

August 16, 1988

Attach
2-B
1-23-9

NON-MEDICAL ATTENDANT CARE SERVICES

Eligibility Criteria:

1. Meet SSBG income eligibility guidelines or Title XIX guidelines.
2. Social worker or ACH screening team determines need for service and documents that the client:
   a. is living alone or with persons who are unable to provide the necessary assistance to maintain the home;
   b. is in danger of unnecessary, inappropriate institutionalization without homemaker services;
   c. is potentially at risk due to inadequate care which could result in abuse or neglect.

Services: Attendant care services which do not have to be delivered "under the direction of a licensed health care professional" and related housekeeping tasks. Tasks in addition to homemaker service are:

Consumption of food-feeding or related assistance to recipients who cannot feed themselves or who requires assistance with special devices in order to feed themselves. This includes the preparation of meals for the client.

Grooming-assistance with grooming, hair care, nail care (except for diabetic and peripheral vascular clients), clothing care, dressing, and assistance in and out of tub or shower, bathing activities that don't require medical supervision as determined by the screening team.

Transfers-assistance on an off seats and wheelchairs, or into and out of vehicles, and moving into and out of bed.

Prosthetic and Orthotic Devices-care of and assistance with putting on and removing prosthetic devices.

Routine menstrual care-apply external sanitary napkins and external cleaning.

Ambulation-consisting of assisting the recipient with walking or moving the recipient from place to place.

- Accompanying recipients to a medical clinic or physician's office.
- Medications-assisting with self-administered medications when ordered as prescribed by the patient's physician. This does not include prefilling of syringes for diabetics.

Limitations:

1. Performed in individuals own home.
2. No live-in providers.
3. No transporting of clients.

August 16, 1988

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1-23-9

Social and Rehabilitation Services
Testimony Presented to the House Public Health and Welfare Committee Concerning House Bill 2012

Thank you for the opportunity to address this committee and present some ideas and concerns surrounding HB 2012.

The interim committee study provided the Department a much needed opportunity to focus on its long-term care programs. These programs provide institutional and community based services for over 22,000 Kansans (13,000 adult care homes, 7,600 homemaker services, 1,600 HCBS). The major testimony presented involved the provision of in-home services, primarily for severely disabled clients requiring "medical services". This focus narrows the population down to approximately 15 percent of the average HCBS population, somewhere between 150-200 clients. This group is further narrowed to that group capable of self directing daily "medical" activities via an attendant, perhaps 75-100 current clients statewide (about one percent of the total community population).

Whatever the outcome of HB 2012, this committee should be cognizant that SRS is responsible for delivering services to a much larger group of clients than those heard during the interim committee and during these hearings.

The agency asks you to keep this in mind, because whatever decision you make here may impact the larger group as well. One major item of concern is that increased services to one sub-group do not take away services from another group. New services or expanded services will require additional funding. Current in-home programs are funded through the federal Social Services Block Grant Program (primarily homemakers about 7,000 clients) and a blend of Medicaid and State General Funds (HCBS, 1,600 clients) as indicated in earlier testimony, neither of the federal funding sources are good candidates for the type of expansions suggested; SSBG funds are projected to go down in FY 1990 and Medicaid funds may not pay for the type of services and/or delivery models requested.

The agency would endorse an experimental program that would provide clients with a monthly stipend that would provide funds to hire, train and direct their own attendants. Such a program would currently have to rely on state general funds, because many of the tasks would be non-medical in nature, and many of the "medical" tasks, according to current Medicaid regulations, can only be provided by or under the direction of a professional nurse. The HCBS waiver mandates that SRS provide adequate safeguards to ensure the health and safety of the client and since neither SRS staff nor professional medical personnel would be involved, the service may not meet this tests. The Agency would administer the funds for such a program, establish eligibility guidelines and monitor continued eligibility.

The agency would also welcome the opportunity to operate an experimental payment agent program. Such a program would allow the consumer more flexibility in the selection and scheduling of their attendants. Theoretically such a program could be funded using HCBS monies as long as all services performed are medically necessary, are performed by appropriately credentialed staff, and the

Attm. #3
PH&W
1-23-9

plan of care is monitored by SRS staff. This is essentially a return to the previous system before all attendants became state employees. Even though testimony indicates otherwise, let me assure you this was not an ideal state of affairs. Turnover was high, consumers had a hard time recruiting attendants, and much SRS staff time was involved resolving conflicts, finding new attendants, investigating complaints of wrongdoings, and resolving payment problems.

The agency would welcome consumer input into the development of new programs and the development of regulations for existing programs.

There are a couple of areas that require specific attention:

1) Under new section two, lines 74-78 the consumer takes over the control of their non-medical attendants. This is a major change and will require a total change of our current system. It will not allow SRS to remain as the employer of our current non-medical attendant work force. Since all current personnel transactions must be done within civil service guidelines and clearly cannot be exercised by non-agency personnel. The agency would suggest changing the wording in such a way to reflect that clients have a right to participate in these decisions.

2) Under new section one, lines 46-50 spell out health maintenance activities that can be performed by non-medical personnel after training. The agency would like to see language requiring a certification that the individual has received appropriate training and can now provide the services to a specific named individual. This certification should spell out circumstances and any provisions for changes in the plan of care.

The agency has concerns about potential liability for actions of employees or agents performing the "medical" tasks now allowed under this bill. The agency takes no specific position as the the desirability of the acts being performed by the general public. However, when these acts are performed under the auspices of an SRS program, we would like to be able to establish standards of practice and to enact our HCBS mandate of insuring the safety and well-being of our clients.

The agency would recommend that SRS employees be certified by the training physician/health professional, receive regular monitoring of delivery of services, and the client receive regular health assessments to monitor changing health conditions. Whether some of these new procedures will be allowable under Medicaid is an open question; however, current interpretations indicate they will not.

In summary, the agency views this bill as a positive step in enhancing services to a segment of our service population. We look forward to the development of new delivery mechanisms. We are concerned about making large scale changes that will accomodate a small sub-group at the expense of other community based clients (75-100 verses 9,000). These program expansions will require new monies and not merely a change in existing priorities. The

pg 2
#3

Secretary has instructed Adult Services to develop a responsive service delivery system to better serve all long-term care clients. This new system has been conceptualized and will be implemented in two SRS management areas this year. We are mindful of our obligations and ask your consideration of our concerns about increased liability and large scale changes in the current civil system.

January 23, 1989
Winston Barton
Secretary - SRS
296-3271

P93
Attn #3
Patrick
1-23-9

STATE OF KANSAS

DEPARTMENT OF HEALTH AND ENVIRONMENT
Forbes Field
Topeka, Kansas 66620-0001
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Mike Hayden, *Governor*

Stanley C. Grant, Ph.D., *Secretary*
Gary K. Hulett, Ph.D., *Under Secretary*

Morrissey

Testimony Presented
to the House Committee on Public Health and Welfare

by the

Kansas Department of Health and Environment

House Bill No. 2012

Background

The Kansas Department of Health and Environment provided testimony during the Special Committee on Public Health and Welfare's interim study on Proposals No. 37 and 40. Testimony provided background information pertaining to the development of the home health agency licensure statutes, differences between state licensure and medicare certification, home health aide training requirements, and problems and concerns related to regulation of in home care. It was recognized by the Department that certain populations (i.e. physically disabled with ability to supervise their own care) might be negatively impacted by the home health licensure statute under current third party reimbursement structures. During the interim study, the Committee learned that "home care" has many definitions, types of providers (over 200 licensed home health agencies), payers, and home health clients. The Committee's task was to enable disabled individuals to lead the most independent lives possible, including the hiring of personal care attendants, while satisfying liability concerns of human service agencies and third party payers. The Department understands and supports the concept of self-directed care requested by a number of conferees. However, there are several issues presented in H.B. No. 2012 which I would like to address.

Issues

H.B. 2012 addressed the problems faced by the physically disabled who desire to control their own personal care attendants in two substantial ways. First, the bill would enable the Department of Social and Rehabilitation Services' Home and Community-Based Services program to place more priority on providing that "individuals in need of in-home care who are recipients of attendant care services shall have the right to make decisions about, direct the provisions of and control their attendant care services, including, but not limited to, hiring, training, managing, paying and firing of an attendant." The modification of the program would seem to allow the independence sought by HCBS clients.

PHCW
attm. #4
1-23-9

The second major change created by the bill is broader in scope and impact. This includes the amendment of the Nurse Practice Act and the subsequent enabling of individuals "in need of in-home care" to control their in-home care with few statutory restrictions. While the Department supports the concept of H.B. 2012, there are concerns related to some of the bill's definitions.

During testimony before the Special Committee, KDHE related that the home health agency statute (K.S.A. 65-5112) exempts "individuals who personally provide one or more home health services if such persons are not under the direct control and doing work for and employed by a home health agency." Therefore, currently an "individual in need of in-home care" could have an individual attendant to provide home health services without being in violation of the licensure law. However, without the Nurse Practice Act amendment found in H.B. 2012, he/she may have been in violation of that statute.

The definitions of "individual in need of in-home care," "attendant care services" and "health maintenance activities" are broad and contrary to current home health agency licensure requirements. Although the interim study conferees requesting self-directed care were cognitive and able to make their own decisions, the definition of "individual in need of in-home care" is not limited to such individuals. Also, "attendant care services" includes some "health maintenance activities" which would be regulated by home health agency licensure requirements (i.e. catheter irrigation, wound care, administration of medications). These would, at a minimum, require provision by a home health aide.

A secondary issue addressed by the Special Committee during review of proposals 37 and 40 was the cost of providing home health aide training. The home health industry is particularly concerned about training costs associated with home health aide certification. Potential confusion may arise when home health agencies are hired to provide "attendant care services" to an "individual in need of in-home care" (i.e. large case load of functionally disabled, elderly clients) by providing "health maintenance activities" including but not limited to catheter irrigation and wound care, through non-certified individuals. The training could be provided by a "health care professional" (nurse) on staff of the agency. This scenario might lead to provision of home health services by non-certified personnel trained by home health agency staff. "Health care professional" is not defined.

It is likely that currently licensed home health agencies will be placed in a non-competitive position if large numbers of "individuals in need of in-home care" choose to self direct their care without benefit of home health agency intervention. Attorney General Opinion No. 86-135 found that physicians, when utilizing their own staff to provide home health services for a patient, need to be licensed as a home health agency. However, New Section 1(d) allows "health maintenance activities" to be undertaken "after training by and under supervision of the physician of the individual in need of in-home care or other health care professional."

Attm #4
pg 2
1-23-9

Recommendation

Legislation enabling appropriate individuals to direct their own care is important; yet it should not undermine existing statutes which are designed to provide quality home care services to frail and elderly Kansans.

H.B. No. 2012 is in conflict with existing home health agency licensing statutes. The Department recommends that Committee clarify the policy related to self-directed care versus home health agency licensure requirements governing aide training and supervison.

Presented by:

Richard J. Morrissey, Director
Bureau of Adult and Child Care
January 23, 1989

Attm #4
293
1-23-9

TOPEKA RESOURCE CENTER FOR THE HANDICAPPED

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Testimony to the House Public Health and Welfare Committee
House Bill No. 2012 - concerning individuals in need of
personal care assistance

Ray Petty, Executive Director
Topeka Independent Living Resource Center
January 23, 1989

Mr. Chairman and Members of the Committee:

First, I want to thank the Special Committee and its staff for doing a fine job drafting this much needed legislation. Their willingness to come to grips with the needs of persons with moderate to severe disabilities is evident in House Bill 2012. With a substantial part of the work accomplished, our efforts should now turn to clarifying the bill where that may be needed, to pass the legislation into law, and to then turn our attention to a successful implementation of the program. I am confident those tasks can and will be accomplished.

As many of you may already know, independent living centers such as the one I represent are private, not for profit corporations which are philosophically and statutorily committed to advocate for services which enable persons with disabilities to live as independent and "regular" a life as is possible. A fundamental tenet of our philosophy is that persons with disabilities and society at large are best served by empowering persons with disabilities to take control over their own lives and to pursue their personal goals. Being able to live in the community at large as opposed to institutions is central to that normalization process.

Personal care assistance, called "in-home care" in the bill, is obviously a key service needed by people with severe disabilities to maximize their independence. Whether a person is economically disadvantaged or competitively employed, activities of daily living (ADL) such as bathing, dressing, grooming, and other more personal activities involving natural bodily functions must be accomplished. The fact that these may be done in ways which differ from the majority of our populace does not detract from

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1-23-9

the fact that they are done, and that they will continue to be done. We are asking the state to recognize human resources readily at its disposal - namely, persons with disabilities who are capable of self-directed care.

One theme from last week's testimony calls for comment in this regard. While I do not question the motives of persons representing the nursing establishment, nor do I doubt for one second that registered nurses will play an important role on assessment, screening, and training teams, and on advisory bodies which seem to be implied in the bill, reference to the "most frail" or "most vulnerable" people in society does little to foster the independent living which most, if not all, of those advocates espoused in some form. Perhaps a distinction needs to be made between persons with long-lasting disabilities and persons who are acutely ill. Granted, it is consistent with independent living for persons in need of medical attention to be able to receive services at home when possible. But the people we are envisioning as the recipients of this self-directed personal care option are not confused or disoriented, nor do they have pressing medical problems which require high-tech nursing. When that kind of service is needed, even for people who otherwise direct their own care, I believe we understand that higher levels of supervision and training are called for. And we understand that some people may not choose self-direction and that others may not be capable - at least in the short term - of managing their own ADL. That does not appear to be a problem to SRS or to us, since agency-directed assistance will continue to be available as before.

It is important for persons with disabilities to be the primary overseers of their daily routines whenever and wherever possible. After all, the one person who will always be there when ADL routines are done is the consumer. Who better to know how these routines are done? Mention has been made of attendants being trained for a specific person's bowel care but that that attendant would not be capable of assisting another person with a particular bowel anomaly due to lack of training. Agreed. That's the reason you don't depend upon personal care assistants to know everything needed about a person's ADL and is precisely why consumers need to be responsible for managing their own care. That way, lower-cost providers can be utilized and more of the daily routines which pose barriers to full participation in society can be accomplished. The less a hassle ADL can become, the more effort people can spend on being successful in other areas of life - which all people treasure - such as work, family, recreation, and the like.

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My board of directors, like that of other centers, has a majority of members who themselves have disabilities. In regular meeting this past Tuesday, the Board of the Topeka Independent Living Resource Center, Inc. voted to support House Bill 2012 with two amendments. First, we would ask that lines 84-87 be revised to read: "(4) individuals in need of in-home care shall be included in the planning, start-up, delivery, and administration of attendant care services and the training of personal care attendants, including the promulgation of rules and regulations to implement this act." Second, we would ask that "in the residence of" be dropped from line 151. Earlier in the bill, reference to services such as transportation, escort, and shopping, which would necessarily be conducted outside the home, make this language inappropriate. [Adding "for" before "individual" in line 152 and making "individual" plural should clean up the language here].

Two additional areas of concern came to my attention last week as I discussed the bill with lobbyists for nursing organizations. While we certainly expect an assessment of which individuals are capable of self-directed care, it may be desirable to specifically refer to such a process in the bill, leaving details to rules and regulations. Also, concern was expressed that the bill in its current form could include minors among self-directed consumers. While I would agree that children are not among the expected population to be served by this bill, and I see no problem excluding them from the bill, I would advocate for 16 year-olds to be among the potential consumers of these services. Some sort of "transitional period" should be allowed so these soon-to-be-adults can prepare themselves for independent living away from their family home - in college, for instance.

Two members of my organization, Lee Graybeal, our independent living specialist, and Amelia Evans, a board member and past president, are here to present their views, both as advocates and as experienced self-directed personal care assistance managers.

Thank you.

Attm #5
893
1-23-9

Mike Oxford

KANSAS DEPARTMENT OF HUMAN RESOURCES

ADVISORY COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED
1430 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

January 19, 1989

To: Members and staff of the House Committee on Public Health and Welfare

From: Mike Oxford, Legislative Liaison

Subject: HB 2012 (Personal Assistance)

I spoke with Anne Zenzinger on Tuesday. She is the Program Manager of the Pennsylvania Attendant Care Program. She was enthusiastic about this bill and wished good fortune for its passage.

There are several issues still on the table. Based on testimony from conferees thus far, I would like to offer the following information which will address some of these remaining areas of concern.

Health maintenance activities seem to be of over-riding concern. Testimony has been heard about such activities being in a range from the routine to the extremely complicated. The Kansas State Nurses' Association presented testimony indicating that, in Pennsylvania, there are restrictions on the delivery, type and scope of health maintenance activities. This is not the case.

Please refer to attachment" A". These two pages are from the 1988 and 1989 program requirements. The Kansas State Nurses Association referred to the 1986-87 requirements. The reason for the change has to do with context and legislative intent. The intent of Act 150 which allowed for this program was to insure that individuals with disabilities would have the legal right to control their own lives, completely. The language in the old program requirements was not sufficiently clear in this respect. People in Pennsylvania and in Kansas are capable of controlling all of their personal assistance.

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1-23-9

I would like to reiterate that what is being sought by consumers is not a whole new program for self-directed people only, but additional options within the existing infrastructure which would allow for self-direction where it was desired and appropriate. Obviously, not everyone is capable of complete self direction, nor is everyone desirous of being completely self-directed. These people also need in-home care, but feel more comfortable with a traditional service delivery system. Others simply need to have their interests and well being supervised and attended to by third parties.

People who are not self-directed should be able to have their guardians, conservators, spouses, family members or other appropriate representatives be present at and involved with the assessment and the establishment of the plan of care. These representatives should, where it is possible and agreeable, be able to direct the care of the individual needing in-home care services.

Some people will want to direct some services, but not others. For example, some people will feel comfortable directing chore services and home-maker services, but will not want to direct health maintenance activities. The essence of this idea came up in discussion by members of the Public Health and Welfare Committee of the Silver Haired Legislature. This example, again, indicates that a range of options is what is needed and wanted. It is <u>choice</u> which is paramount here. Many people will undoubtedly <u>choose</u> to have all or part of their care directed by third parties, but they have been involved in the decision making process. They have had a choice in the matter. Most people are rational decision makers and will not choose a course which will be injurious given input into and information about the assessment and plan of care. The emotional well being which derives from being able to make choices about one's own life in one's own home in any and all matters should be heeded.

Please refer to the pages labeled "B". This emphasis on consumer control and range of options is purposeful. It makes it abundantly clear that truly individualized plans will be used, not generic "grocery lists" where you are given a list set in stone as to type, amount, delivery schedule and so on.

Attm #6
P 9 2
1-23-9

Another related issue has to do with supervision and monitoring. See attachment "C". From the xeroxed copies, it is clear that this also varies on an individual basis. All consumers in Pennsylvania must be evaluated at least once a year and usually by a nurse. This allows for monitoring to be done in the least intrusive manner, usually at the convenience of the consumer.

It is clear that the Pennsylvania Model is intended to serve everyone on an individualized basis, emphasizing independence and consumer choice. It is not just for self-directed people. Who is capable of what amounts of self direction? Here is an interesting method for determining self direction in New Jersey. It involves, mainly, common sense. See Attachment "D".

These issues are addressed in HB 2012. The bill is a good one. The interim report is complete, concise and well put. Adding the option of consumer control to the Kansas personal assistance programs is an idea whose time has come. It will work if you let it.

Thank you for your time. I would be glad to answer any questions or provide copies of any part or all of the Pennsylvania program requirements and guidelines. I have included a copy of the table of contents for this purpose.

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Attm. #4
893
1-23-9

A

F. Consumer Hospitalization

Consumers of Attendant Care Service who are temporarily hospitalized may continue to receive Service as long as they meet eligibility requirements and the services provided by the attendant do not duplicate or replace those services available through other third party payers. Providers shall conduct an assessment of need and adjust the service plan accordingly. Such plans shall be reviewed by the provider at least every two weeks; continued payment for services beyond 30 days shall be subject to approval by the Department.

G. Health Maintenance Activities

Act 150 recognizes the obligation of the Department and providers to strive to ensure the basic right of consumers to live in the community and to participate to the fullest extent possible in activities of normal daily living. Providers are required by Act 150 to provide Health Maintenance Activities at the consumer's request.

1. Health Maintenance Activities are those routine activities of daily living which are necessary for health and normal bodily functions. These Activities would be carried out by the consumer if they were physically able or by family members or friends if they were available. These activities include but are not limited to:

   a. Catheter irrigations
   b. Administration of medication, enemas, and suppositories
   c. Wound care

2. Unless determined otherwise by the assessment and agreed to in the service plan, the consumer will direct and supervise the attendant in the specified Health Maintenance Activities. Attendants may perform Health Maintenance Activities under the following conditions:

   a. The consumer has indicated that he/she has been adequately instructed by the appropriate health professionals and is thereby qualified and able to instruct and supervise his/her attendant in Health Maintenance Activities. A statement to this effect is included in the service plan.

   b. At the consumer's request, the attendant will be instructed in Health Maintenance Activities by health professionals as arranged by the provider.

   c. The attendant is instructed and monitored in Health Maintenance Activities by the consumer, the consumer's physician, and/or a health professional as appropriate.

Attm. #6-A
PA&W
1-23-9

d. The provider will monitor the attendant's performance of Health Maintenance Activities during the routine monitoring visits and through consultation and input from the consumer regarding his/her satisfaction with the service.

e. Disposable items or devices are used in caring for the consumer whenever they are obtainable.

f. The attendant's prior experience and work history do not indicate unsafe performance of such activities.

g. The consumer has appropriate arrangements in place to respond to health emergencies; a statement to this effect is included in the service plan. Information on the arrangements for health emergencies is also made available to the attendant(s) either by the provider or by the consumer.

h. The provider, the consumer, the attendant(s), and others who have committed to provide Health Maintenance Activities must sign the service plan. Copies of the service plan should be given to all persons providing Health Maintenance Activities.

i. If at any time there is an indication that the Health Maintenance Activities are not being carried out adequately by the attendant or not being adequately supervised by the consumer, the provider has the right and responsibility to intervene and provide appropriate corrective measures.

H. Program Monitoring and Quality Assurance

Providers shall have an established quality assurance program which periodically monitors and evaluates the quality of services provided to consumers. Providers are responsible for monitoring their Attendant Care Program and subproviders. Monitoring is to be accomplished using the Attendant Care Program Monitoring Instrument, to be developed by the Department. Attendant Care Program providers are also subject to monitoring and evaluation by Departmental staff.

I. Provider's Personnel

The provider is responsible for maintaining adequate and competent personnel to ensure that the agreed level of service delivery is available. Providers are encouraged to employ mentally alert adults with physical disabilities in the program.

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B

ATTENDANT CARE PROGRAM REQUIREMENTS

I. INTRODUCTION

A. History of the Attendant Care Program

The Department of Public Welfare initiated a three-year Attendant Care Demonstration Program in October 1984. Deinstitutionalization and preventing institutionalization are major goals of the Attendant Care Program. The Program was developed to help mentally alert, physically disabled persons who cannot perform daily living tasks by themselves, to remain independent in their own homes or in other community living arrangements through the use of Attendant Care Service. A major innovation of the Program is that consumers have the right to direct their own service; i.e., screening, interviewing, hiring, training, managing, paying, and firing attendants.

The three-year demonstration program enabled the Department to define the Pennsylvania Model of Attendant Care Service based on policies that provide for a continuum of care. This service delivery model has received national recognition. These policies support the concept that, to the maximum extent possible, the assistance provided be directed by the person receiving the service and that the service be provided in a manner consistent with the consumer's capacity to manage it.

Act 150, signed into law on December 10, 1986, requires that Attendant Care Service be provided statewide. The Act took effect on July 1, 1987. By December 1987, Attendant Care Service was available in all 67 counties.

B. Program Goals

Attendant Care Service is targeted to help eligible adults under the age of 60 who are mentally alert and physically disabled to achieve one or more of the following goals to improve their quality of life:

1. To live in the least restrictive environment as independently as possible;
2. To remain in their homes and to prevent their inappropriate institutionalization; and,
3. To seek and/or maintain employment.

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III. PROGRAM REQUIREMENTS

A. Pennsylvania Attendant Care Model

Based on the analysis and experience of the demonstration program, the Pennsylvania Attendant Care Model of service delivery has been developed. All providers, statewide, must implement the Pennsylvania Model. Under the Pennsylvania Model as required by Act 150, consumers have the right to make decisions about, direct the provision of, and control their Attendant Care Service. Consumers shall, to the highest degree possible, self direct the recruiting, hiring, training, supervision, management, payment, and firing, if necessary, of an attendant.

Each Attendant Care Program provider shall provide a continuum of care that enables the consumer to choose the mode of care ranging from agency management to complete consumer control of service. A continuum of care enables mentally alert adults with physical disabilities to enter the Program and progressively attain higher levels of control over the service they receive. The full range of Attendant Care Service, as outlined in the Pennsylvania Model and required by Act 150 shall be available to all consumers.

The provider shall design and provide a program which meets the following requirements:

1. Consumers have the right to make decisions about, direct the provision of, and control their Attendant Care Services. This includes hiring, training, managing, paying, and firing an attendant.

2. A provider shall have an array of support activities available to assist and support a consumer. Such assistance shall be provided at the request of the consumer.

3. To the maximum extent feasible the range of personal care services needed should be provided by a single attendant or the same attendants, rather than several attendants.

4. Attendant Care Service must be available any day of the week or any hour of the day or night, depending upon the personal care needs of the consumer. It must be available at such places where the Service may be required (e.g., home, work, school, recreation, travel), to afford consumers maximum independence in their daily lives.

5. A continuum for managing service delivery, ranging from consumer management to the maximum extent feasible to agency management must be available from all Attendant Care Program providers. This will provide a choice of services and assist consumers to function at their maximum level of independence.

pg 2- Attm B-6 1-23-9

B. Program Planning

Providers must include mentally alert adults with physical disabilities in the planning, start-up, delivery, and on-going monitoring of the Attendant Care Program. Consumer involvement in these activities is required at the local level.

C. Attendant Care Advisory Committee

1. Each provider shall establish an Attendant Care Advisory Committee that meets regularly. Consumers and attendants shall be represented on the committee. Representation from consumers and consumer organizations must constitute at least 51 percent of the membership.

2. The committee shall advise the provider on matter of policy, program operations and community relations.

D. Eligibility Requirements

1. Providers shall ensure that Attendant Care Service is provided according to the requirements established in Sections VIII and IX of this document. A copy of the eligibility requirements must be furnished to each Attendant Care Program subprovider.

2. Under the Attendant Care Program, consumer eligibility may be determined by the contracted provider or by a subprovider. Records must be maintained to document consumer eligibility and include actual eligibility determination/redetermination forms and related documents (Appendix A) for every consumer receiving Attendant Care Service.

E. Nondiscrimination

Applicants or consumers may not be discriminated against on the basis of race, color, religious creed, handicap, disability, ancestry, national origin, age or sex, except as required by the eligibility requirements of the Attendant Care Program.

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Attm. 1-23-9

VII. ATTENDANT CARE PROGRAM WAIVERS

Under certain conditions, the Department in its discretion may grant waivers to particular requirements of the Attendant Care Program. The provider may request a waiver if the waiver will assist the provider in meeting the overall Attendant Care Program objectives, and the waiver requested is not in conflict with: Act 150; the federal Social Service Block Grant prohibitions; and, the Pennsylvania Attendant Care Model and amendments thereto.

To request a waiver from an Attendant Care Program requirement, the provider must make that waiver request in writing, providing justification for the waiver, a citation of the provision for which the waiver is requested, and any alternative requirements that the provider proposes to substitute in place of the waived requirements.

Letters requesting waivers to Attendant Care Program Requirements should be submitted to:

George B. Taylor, Deputy Secretary
Office of Social Programs
Room 529, Health and Welfare Building
P.O. Box 2675
Harrisburg, Pennsylvania 17120

VIII. ELIGIBILITY FOR ATTENDANT CARE SERVICE FUNDED THROUGH THE ATTENDANT CARE PROGRAM

The following eligibility requirements must be used for the provision of Attendant Care Service funded through the Attendant Care Program. This section applies to persons applying for or receiving Attendant Care Service and governs providers receiving Attendant Care Program monies to provide Attendant Care Service.

A. General Eligibility Criteria

Applicants must have an in-person, consumer assessment and formal eligibility determination completed prior to being accepted into the Program.

To receive Attendant Care Service, a person must comply with all of the following:

1. Be an adult.

2. Be a mentally alert individual with a physical disability or handicap, who meets all of the following requirements:

   a. Experiences any medically determinable physical impairment which can be expected to last for a continuous period of not less than twelve months;

Eff 4 B-6 1-23-9

F. Intake/Application for Service

Requests for Attendant Care Service must be screened through an initial interview. A record of those individuals determined ineligible for Attendant Care Service shall be entered into an inquiry log maintained by each provider. At a minimum, each inquiry log entry must include:

1. An identifying number;
2. The name of the person;
3. The address of the person;
4. The telephone number of the person;
5. The name of the caller and referring entity or individual, if any;
6. The nature of the inquiry;
7. The disposition of the inquiry;
8. The date of the inquiry; and,
9. The name of the intake worker.

G. Consumer Assessment and Service Plan

1. The provider shall conduct a multi-disciplinary in-person assessment to establish the consumer's needs. The assessment shall evaluate the consumer's capacity and willingness to select and direct the attendant; establish the consumer's functional capacity; determine the absence or presence of any physical illness as distinguished from functional disability; and evaluate the nature of the home environment and the availability of family or friends willing to assist in providing care for the consumer.

2. Providers are encouraged to use the Department's Attendant Care Program Assessment Summary Form. If the Department's Assessment Summary Form does not meet the provider's needs, the provider may use another assessment form if:

   a. The format, at a minimum, contains all the information on the Department's Assessment Summary Form; and,

   b. The provider's assessment form is approved in writing by the Department before it is used.

3. The provider and the consumer shall negotiate and sign a service plan based on the assessment of consumer needs.

attm. #6-C PHW 1-23-9

4. The service plan shall describe the goals for service as established with the consumer, how services will be provided, the service delivery option selected, the time and number of service hours to be provided, documentation on health maintenance activities, a description of the emergency and back-up systems in place for Attendant Care Service, any unique circumstances established by the assessment, and training documentation, if applicable. The service plan must clearly state and in detail, the providers, attendants, consumers, family members, friends and other service agencies' responsibilities in the delivery of services.

5. The provider shall review the service plan with consumers and the provision of Attendant Care Service to consumers on a regular basis. Monitoring visits shall take place in the consumer's home at least once during each year of Service to the consumer. Monitoring shall be done more frequently if necessary as determined by the provider or the consumer. Circumstances which warrant frequent monitoring include, but are not limited to: a progressive disability, terminal illness, complaints on the quality of service provided, or in cases of suspected non-compliance with the program requirements. Whenever possible, monitoring visits shall be conducted at the consumer's convenience. Providers should supplement the in-home monitoring visit(s) by contacting consumers over the phone.

6. If some of the items described under the service plan are contained in other documents, such documents should be located in the consumer's file along with the service plan for reference.

H. Attendant and Consumer Training

Consumer and attendant training programs shall be carried out in accordance with the Attendant Care Program Training Guidelines established by the Department. **Providers are ultimately responsible for the contents of their training programs and for ensuring that attendants and consumers are trained.**

I. Service Coordination

1. Providers shall coordinate with the Office of Vocational Rehabilitation, county governments, and other sources of support services including family and friends who are available to provide back-up services according to the service plan, to avoid duplication and to integrate service.

2. Providers shall coordinate with the Area Agency on Aging (AAA) to facilitate the transfer of consumers age 60 and over to the Department of Aging's Attendant Care Program. Coordination activities with the AAA must include, but not be limited to, the following activities:

0992 6-C 1-23-9

a. AAAs and the Department's providers shall meet to develop a process for the transfer of consumers between the two programs; and,

b. The process shall include a system for the Department's provider to give advance notice to the AAA of consumers' impending sixtieth birthdays. A minimum of 90 days advance is suggested, and ideally, AAAs should be notified a year or more prior to a consumer's sixtieth birthday.

c. The AAA shall assume responsibility for an individual on the person's sixtieth birthday, and the service plan developed by the AAA shall take effect (as set forth in the Aging Program Directive No. 86-20-1 in Appendix D).

IV. SERVICE REQUIREMENTS

A. Attendants

1. **The provider is ultimately responsible for recruiting, managing, training, hiring, contracting with, and paying attendants.** Consumers have the right to choose and perform these tasks to the extent possible. The provider must offer consumers the option of performing all of these tasks, some of these tasks, or none of these tasks.

2. The provider or the consumer must have a written agreement with each attendant which is signed by both parties. The written agreement, at a minimum shall include:

   a. The date the consumer has been determined eligible for Attendant Care Service.

   b. The number of service hours authorized per day or week.

   c. A description of the provider and/or consumer's employer responsibilities including, but not limited to, the employment status of the attendant, payment of taxes, and, if applicable, benefits and insurances provided.

3. The attendant may be asked to consent to a criminal record check, if requested by the provider, subprovider or a consumer.

4. Attendant Care Program funds shall not be used to pay attendants who are relatives of the consumer.

Page 3
attm 6-C
1-23-9

5. To the maximum extent feasible, the range of personal care services needed must be provided by a single attendant or the same attendants rather than several attendants and agencies. Attendant Care Service is predicated upon the assumption of a high level of bonding between the consumer and the attendant.

6. Providers are encouraged to hire public assistance clients as employees in the Attendant Care Program.

B. Support Activities

1. If requested by consumers, providers shall provide either directly or under purchase arrangements, an array of support activities. Support activities assist consumers in managing their Attendant Care Service and in other aspects of independent living. They include but are not limited to:

   a. Recruitment of attendants
   b. Screening and training for consumers and attendants
   c. Supervision
   d. Payroll services related to Attendant Care Service, management and assistance in linking consumers to services such as transportation, income maintenance, housing, medical and related services
   e. General assistance with the direct provision of Attendant Care Service

2. Support activities shall be provided at the specific request of the consumer. Support activities must be mutually agreed upon by the consumer and provider.

3. If a provider documents a consumer's frequent inability to satisfactorily perform one or more of the following activities, a provider may make the use of specified support activities a condition for continuing to receive Attendant Care Service:

   - Directing the attendant's performance of Attendant Care Service (including the provision of basic and ancillary service);

Pg. 4
Attm. #6-C
1-23-9

- Fulfilling employer related responsibilities where applicable;

- Meeting other program requirements which result in the provision of quality service (including but not limited to, recruiting, screening, and training attendants);

After documenting the consumer's unsatisfactory performance, the provider may then provide the needed support activities until the consumer is able to achieve the desired level of independence.

C. Service Hours

Each Attendant Care Program provider's average hours of Service to all consumers per seven-day week shall not exceed 40 hours per week.

D. Emergency and Back Up Services

1. The consumer shall take primary responsibility for arranging back-up services, especially for emergencies. The provider shall make provisions for back-up attendants in the event that the consumer's own system breaks down. The use of family, friends, and neighbors shall be encouraged since these sources are dependable and usually available on short notice.

2. Providers must have the capability, directly or through subproviders, to respond to emergencies related to the provision of Attendant Care Service 24 hours per day, seven days per week.

E. Out-Of-State Travel

Attendants may accompany consumers on business trips, vacations, or other temporary stays away from home. However, the following conditions shall apply:

1. The roles and responsibilities of the consumer and attendant for Attendant Care Service shall be the same as when at home;

2. The provider shall not be responsible for any of the costs associated with the travel for the consumer or attendant;

3. Requests to change the number of service hours shall be subject to an assessment of need by the provider;

4. Consumers shall be subject to all Program requirements including monitoring; and,

5. Payment for Attendant Care Service to consumers who are out-of-state for more than 30 days shall be subject to prior written approval by the Department.

D

PERSONAL ATTENDANT DEMONSTRATION PROGRAM

INSTRUCTIONS FOR ADMINISTERING THE SELF-DIRECTION QUESTIONNAIRE

The Self-Direction Questionnaire is administered to each applicant as part of the assessment process. All questions should be independently answered by the applicant in his/her own words. No coaching or assistance should be provided by the evaluator or anyone else. The questionnaire may be administered in its written form, or orally. If the applicant has a communication impairment or a physical limitation, the answers may be recorded (but not edited or altered in any way) by the evaluator or by a proxy designated by the applicant. Taped or brailled responses are acceptable.

The applicant should be advised that this questionnaire will not be graded or scored but the responses will be used by the evaluator and the PADP staff in determining the applicants suitability for participation in the demonstration program.

Any protest or complaint about a specific question should be indicated by the applicant on the questionnaire (or recorded by the evaluator).

The Self-Direction Questionnaire should not be left with the applicant for completion. It is to be administered during the assessment visit and attached to the PADP Assessment Form.

REVIEW OF THE SELF-DIRECTION QUESTIONNAIRE

The evaluator should review the Self-Direction Questionnaire as a way of gaining further insight into the capacity of the applicant to manage and direct attendant services. The responses should show an ability, on the part of the applicant, to analyze a situation, plan action, give directions, explain a need or procedure and deal with problem situations. There are no "correct" answers, but the responses should reflect some ability on the part of the applicant to take responsibility for themselves.

For some applicants this questionnaire may seem insulting, however it is necessary for us to make crucial decisions as to who will be selected for participation in the demonstration, and in some instances the applicant's responses to these questions will reveal that they are not yet ready for services which require that they assume a good deal of responsibility.

PHRCW
6-D
1-23-9

PERSONAL ATTENDANT DEMONSTRATION PROGRAM

SELF-DIRECTION QUESTIONNAIRE

APPLICANT NAME: _____
DATE: _____

Instructions: Following are a set of questions related to managing attendant care and situations common to independent living. Please give your own answers to these questions. There are no "right" or "wrong" answers. You are being asked to analyze situations, and plan a course of action. Be as specific as possible in giving your answers. Please accept my apology if these questions seem too elementary. This questionnaire will be used by the program staff to evaluate your ability to direct and manage an attendant.

William A. B. Ditto, MSW
State Program Director

1. If you were going to advertise for an attendant in a newspaper, what would your ad say? Be sure to describe briefly what you want the individual to do.

Pg. 2
6-D
1-23-9

2. You have attendant service scheduled at 8:00 AM and you have to be at work at 9:00 AM. It is now 8:30 AM and the attendant has not arrived. What steps would you take in dealing with this situation - list them.

3. Please give the following information about two (2) prescription medicines you currently take or have taken in the past. If you have never taken any prescription medicine, skip this question.

- name of the drug
- your dosage (times, amounts, etc.)
- the reason for taking this medicine
- possible side effects you know of
- any special precautions, or other information

Pg. 3
6-D
1-23-9

4. Your attendant has been 15 minutes late in arriving six out of the last seven days. How would you handle this situation? Be specific.

5. You have a newly assigned attendant and you must explain the assistance you need in carrying out your morning routine. List your activities, in order, and explain what the attendant will need to do for you.

Pg 4
6-D
1-23-9

6. The attendant program coordinator informs you that no attendant is availalbe to you for the upcoming weekend. You are living alone. What are your options in dealing with this situation. Please list all the options you can think of.

7. Your attendant appears to be drunk when showing up for work one evening. How would you deal with this situation? Detail your plan(s)

Pg. 5
6-D.
1-23-9

8. Your attendant asks you about your disablility. Briefly describe the nature of your disability, and how it limits your physical functioning, so that the attendant can understand.

9. You notice that your attendant is careless in cleaning the bathroom and it is dirty. Describe two ways in which you could deal with this situation.

Pg 6.
6-D.
1-23-9

10. Please list the qualities you would be looking for in hiring/selecting an attendant. List four or more.

11. Your attendant does not know how to (a) transfer you out of bed or (b) prepare a hot meal. Select either (a) or (b) and explain what you could do about this.

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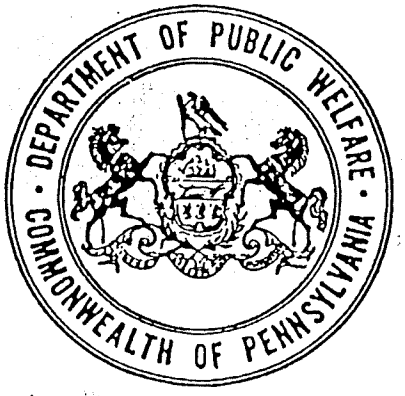
6-D
1-23-9

COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF PUBLIC WELFARE
OFFICE OF POLICY, PLANNING AND EVALUATION

1988-1989
ATTENDANT CARE PROGRAM REQUIREMENTS



ROBERT P. CASEY
GOVERNOR

JOHN F. WHITE, JR.
SECRETARY

JULY 1988

PH+EE
6-E
1-23-9

6. E

PUB 95 11/87

TABLE OF CONTENTS

92 6-E 1-23-9

Pg. 4
6-E
1-23-9