

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Carlos Mayans, at 1:30 p.m. on January 20, 1998 in Room 423-S-of the State Capitol.

All members were present except: Representative Becky Hutchins - excused

Committee staff present: Norman Furse, Revisor of Statutes
Emalene Correll, Legislative Research Department
Robin Kempf, Legislative Research Departmen
Lois Hedrick, Committee Secretary

Conferees appearing before the committee:
Sandra Strand, Kansas Advocates for Better Care
John Federico, Sterling House
Stacy Allen, Education Director, Wichita Chapter, Alzheimer's Association

Others attending: See Guest List (Attachment 1)

The minutes of the meetings held on January 14 and 15, 1998 were distributed for review and, by policy, will be approved as read if no changes are reported to the Chairperson by 5:00 p.m. January 20.

The Chairperson asked if anyone was present to recommend introduction of legislation. There was none.

Chairperson Mayans then opened the hearing on **SCR 1613** - Establishing a task force on long-term care services, saying that the resolution was referred to the committee in last year's session and that several states have established similar task forces. He then introduced Sandra Strand, Legislative Coordinator, Kansas Advocates for Better Care, who testified in support of the resolution and offered a list of issues for possible coordination by such a group. (See testimony, Attachment 2.) Mr. Furse asked if **HB 2607** (state long-term care ombudsman; powers, duties and functions) is enacted, could the task force serve as an advisory committee for the provisions of **HB 2607** or to the ombudsman's responsibilities.

Representative Henry asked if **SCR 1613** covers any long-term care services for any adult. Mr. Furse answered that he believed the task force would have flexibility and that the adult care homes, referred to in the resolution, would be those defined in existing statutes and may exclude some by definition.

John Federico, representing Sterling House, testified in support of the resolution and offered his assistance in the establishment of the task force. Mr. Federico noted concerns about the make up of the task force; and recommended that among the four provider members authorized, that owners of free-standing care homes be included. He indicated he did not mean that his client, Sterling House, should necessarily be one of the members, but that a free-standing facility should be included as those operators have special insight into the needs of their residents. Representative Horst questioned Mr. Federico's suggestion for inclusion; and Mr. Federico answered that he believed profit and non-profit nursing homes should be represented also.

Representative Wells asked what was the definition of a "consumer," and Mr. Federico answered that residents of assisted living facilities (as an advocacy group), as well as home health patients and residents of other care facilities should be included in that definition.

The Chairperson then introduced Stacy Allen, Education Director of the Wichita Chapter, Alzheimer's Association, who testified in support of **SCR 1613**. Ms. Allen outlined the work of the Association, and described the growing number of Alzheimer's patients and their increasing need for care facilities, trained health care providers, and financial support. She suggested some issues for consideration by the task force: housing alternatives for those with the disease, specialized training for dementia care, and financial support issues for such patients. (See testimony, Attachment 3.)

There being no other present to testify on the resolution, the hearing on **SCR 1613** was closed. Chairperson Mayans suggested that some amendments may be appropriate--such as amending the date on page 2, line 21, to January 11, 1999. He suggested the resolution may be considered at the committee meeting on Thursday, January 22. The Chairperson then closed the hearing on the resolution.

Chairperson Mayans noted that at he next meeting, the committee will consider introduction of bills and **HB 2622** - concerning dental practices act; services for indigent persons.

The meeting was adjourned at 2:15 p.m.

The next meeting is scheduled for January 21, 1998.

HOUSE COMMITTEE ON
HEALTH AND HUMAN SERVICES COMMITTEE
GUEST LIST
JANUARY 20, 1998

NAME	REPRESENTING
Jill Hiron	The Hiron Group
Carrie Reech	Shoob
Mary M. Allen	The Alzheimer's Assoc. -
KEITH R LANDIS	CHRISTIAN SCIENCE COMM ON PUBLICATION FOR KS
Susan Anderson	Hein & Weir
John Federico	Sterling House
Mary Lisa Pilce	Ks Advocates for Better Care
Sandra Strand	"
LARRY HENDERSON	DOA/DPS
Myron Dimarwan	LTCO Prog KDOA
JEAN KRAHW	KBP
Jan Maxwell	KDOA
Natalie Regan	Federico Consulting
Carolyn Muddindot	KSNH
Carol Quins	KDHE
Michelle Peterson	Peterson Public Affairs
Kathy Keleron	Prudential Insurance
David B. Dallam	DOB

Sunflower
Chapter.



TESTIMONY

TO: House Committee on Health and Human Services
FROM: Sandra Strand, Legislative Coordinator
DATE: January 20, 1998
SUBJECT: SCR 1613

Kansas Advocates for Better Care appreciates the opportunity to speak in support of a task force on long-term care services. Since 1975, our organization has been the only private group in the state who has consistently advocated on behalf of long term care residents.

We support this resolution for a number of reasons:

- ♦ it clearly identifies the vital interest of the Legislature in the welfare of long-term care consumers;
- ♦ it clarifies the responsibility of providers and state government to provide services in a customer-friendly environment;
- ♦ it identifies areas of study which are important to consumer interests;
- ♦ it is structured in a way to provide consumer input.

We believe this task force could benefit residents by bringing together knowledgeable people from the public and from the long term care industry to recommend improvements in our state's long-term care system.

Issues which could be addressed by the task force:

- ♦ adequate staffing in adult care homes, including strategies to reduce the high rate of turnover of direct care staff;
- ♦ improved policies and practices to prevent abuse, neglect and exploitation of residents;
- ♦ improved consumer satisfaction with state survey and enforcement procedures, particularly the investigation of complaints.
- ♦ improved communication between families and providers;
- ♦ improved public education, including how to choose a care provider, how families can participate in resident care plans, and how to cope with care problems.

HOUSE HHS COMMITTEE
Attachment 2
1 - 20 - 98

TESTIMONY
HEALTH AND HUMAN SERVICES COMMITTEE
SENATE CONCURRENT RESOLUTION NO. 1613
ESTABLISHING A TASK FORCE ON LONG TERM CARE SERVICES

January 20, 1998

presented by

Stacy Allen, Education Director
Sunflower Chapter - Alzheimer's Association
5014 E. Central
Wichita, Kansas
(316) 688-1810

Hello, my name is Stacy Allen. I am the Education Director of the Sunflower Chapter of the Alzheimer's Association. There are three chapters which serve this state: The Sunflower Chapter in Wichita, The Topeka Chapter and The Heartland Chapter in Prairie Village, Kansas. I believe this presentation would be supported by the other chapters, but since we just found out about this hearing last Friday, it did not give us enough time to pull together our Coalition to discuss the issue formally. However, my Executive Director, Tina Lott, has been talking publicly about the need for a task force to work on health care and long term care issues for over a year now. So when we had this opportunity to be a part of this public hearing, we were excited to come up and talk with you. I know she wishes that she could be here, but today is also our Executive Board meeting, and as we are moving our offices, that is her priority today.

A little about my background: I have been an administrator in Kansas nursing homes for four years. I have been a volunteer with the Alzheimer's Association for a year and a half. And now I am the Education Director for the Sunflower Chapter. My own family has been touched by Alzheimer's disease. My experiences have given me the opportunity to look at the issues concerning long term care from many points of view. I also know that we must all work together to establish better communication and services for our families that are touched by this disease and other long term care issues.

POINTS TO PONDER:

- ❖ There are 51,000 people with Alzheimer's disease in Kansas. More than 200,000 people have a family member with the disease. Almost 400,000 know someone with the disease.

HOUSE HHS COMMITTEE
Attachment 3-1
1 - 20 - 98

- ❖ One in ten people over the age of 65 will have Alzheimer's disease. Over the age of 75, nearly 25 percent will have Alzheimer's. Over the age of 85, over 50 percent will have Alzheimer's. How many of us have a family member in these age categories? In some rural areas of Kansas, forty percent of the population is over 55 years of age. And when you have a number of counties with populations of 5,000 or below, how are we going to help those families? The babyboom generation is quickly coming upon the age when Alzheimer's will touch that population.
- ❖ At the present time Alzheimer's disease is the fourth leading cause of death. One researcher has told us this will jump to number three, passing cancer, by the year 2000. The funding for research is much lower for Alzheimer's disease, then cancer and others, yet this is fastly becoming the most costly. For every \$321 we spend on the disease, only one dollar goes to research. The Federal investment in heart disease, cancer, and AIDS is four to seven times higher.
- ❖ In Kansas there are approximately 32,000 licensed nursing home beds. Out of 32,000 beds approximately 6,400 (20%) are specialized dementia care beds. According to national statistics seven out of ten patients with Alzheimer's disease are being taken care of at home. Meaning of the 51,000 people afflicted, 15,300 with Alzheimer's disease need specialized care in a long term care facility. Currently, we are only meeting the needs of 42% of the patients who have been diagnosed with Alzheimer's in Kansas. While, 60-80% of our current population in nursing homes are **at least** in the early stage of dementia.
- ❖ Kansas has many assisted living facilities which are accepting early stage dementia patients. A family may want to maintain independence for as long as possible for their loved one, but there is a concern about safety and training. I will mention that there are now several assisted living facilities being developed for Alzheimer's patients in that State as we speak. As well as some other housing alternatives that have been developed over the last few years. So, families who **can afford** these alternatives have a few choice, but no definite answer as to the longevity of their loved ones stay.
- ❖ There is no specific training that has been established or required by regulations for dementia care. Only to our knowledge, facilities with Alzheimer's units need to have specialized training which is continuous. Along with assisted living facilities, adult daycare programs, respite (short term stay) care, home health, and private duty nursing are also alternatives, but there again, no set guidelines have been established for the training of the professionals performing the specialized care. **Quality of care** is a big issue.

- ❖ Our Kansas families are proud, and we want to take care of our families by ourselves. Putting someone in a nursing home is generally the last resort. The cost is between \$35,000 and \$50,000 a year, so it can be financially devastating. A loved one who have saved \$200,000 for their care will spend that in approximately 5 years (the average life expectancy for a person afflicted with Alzheimer's is 8 years). When a patient runs out of money, they will then qualify for the state Medicaid Program, possibly leaving the family with the choice of a new residence. High health care costs, Medicare, Medicaid (Home and Community Based Services for the frail elderly), and our methods of evaluating the effective use of dollars spent must be addressed.
- ❖ Many families don't know what the options or resources are available to them, such as adult day care and other respite care programs. Education is the key to helping families, long term care facilities, and the general public to plan and deal the disease better.

This is a disease that is scary, even to our professionals whom we rely on. Yet, it continues to grow in number and in cause of death, we are only meeting 42% of the need for specialized nursing home beds, there are no solid training regulations, it is an expensive disease, and education is needed for the entire state to insure proper care.

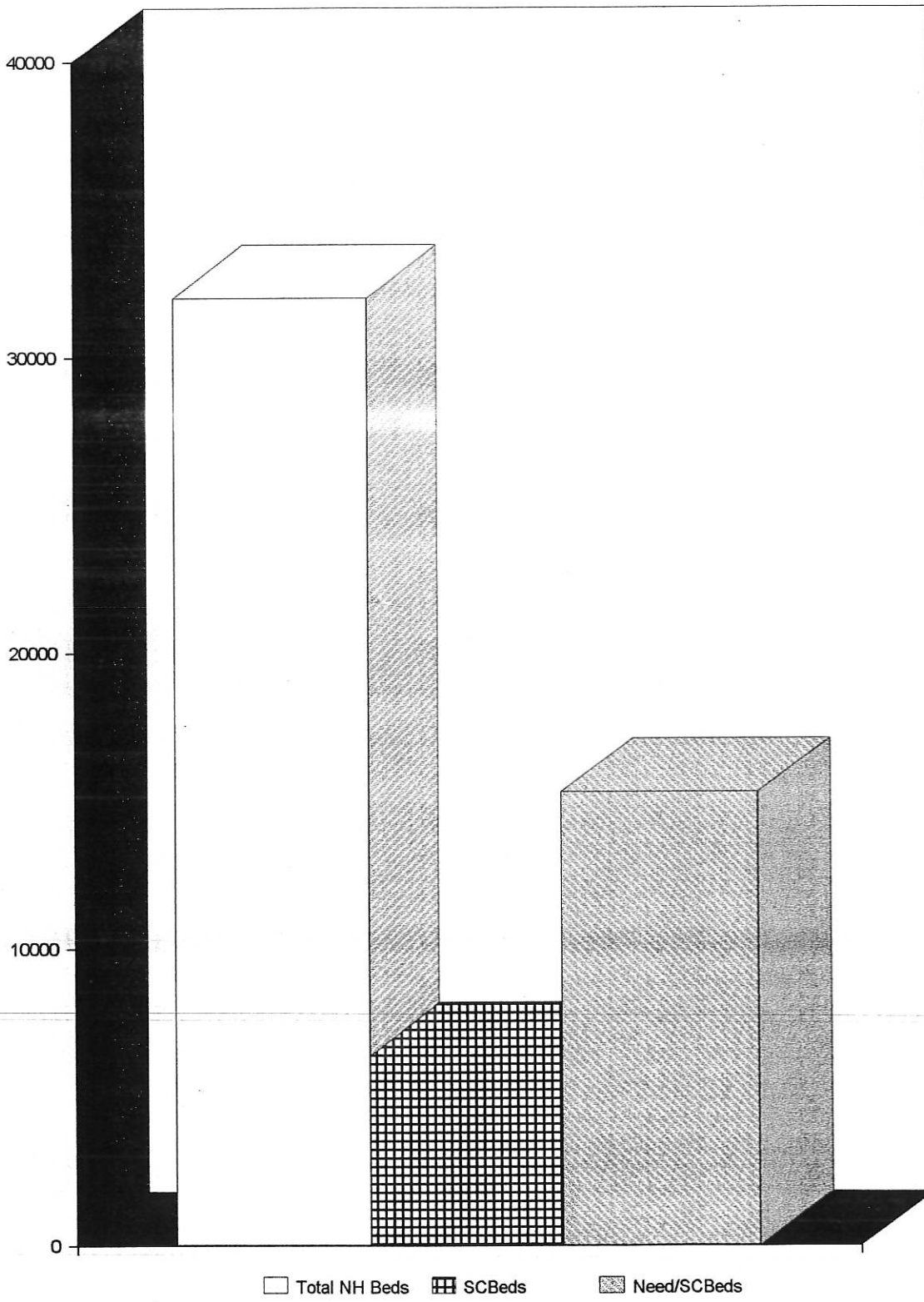
The Sunflower Chapter of the Alzheimer's Association is dedicated to providing support and assistance to afflicted patients and to their families through education, advocacy and service. In the past 18 months we have gone from formally serving eight counties to 48 counties. We have a big job ahead of us. There are still many counties that are not receiving the help they need, but the Alzheimer's Association is aggressively trying to meet the needs of everyone in our state.

Based on the issues mentioned here today, The Alzheimer's Association hopes that you will establish this task force, and involve us in the recommendations that will be presented to the Governor and the Legislature.

On February 4, The Kansas Coalition of Chapters of the Alzheimer's Association will be here at the state capitol. Volunteers and staff want to have an opportunity to sit down and talk with you about the issues concerning our Kansas families. We hope that you will take a few minutes and visit with them.

I would like to thank you for giving me this opportunity to speak to you today, and I would be happy to answer any questions you may have.

Nursing Home Beds/Special Care Beds Compared to Need for Special Care Beds



ALZHEIMER'S DISEASE IN KANSAS

- There are over 51,000 people in Kansas with Alzheimer's disease. Over 200,000 say they have a family member with the disease, and 393,000 know someone with the disease.
- Incidence of Alzheimer's disease is seen equally in all economic, social, ethnic, and national groups. It occurs almost equally in men and women.
- In America, approximately 4 million people have Alzheimer's disease. Unless a cure or prevention is found, by 2040, 14 million Americans will have Alzheimer's disease.
- Alzheimer's is the fourth leading cause of death among adults after heart disease, cancer, and stroke. Over 100,000 die annually in the United States.
- People now over 65 will have a 1 in 10 chance of developing Alzheimer's disease. Increasingly, it is found in people in their 40s and 50s.
- People now over 85 will have a 50-50 chance of developing Alzheimer's. And, people who are 85 and older form the fastest growing population segment.
- Time from the onset of symptoms to death can range from 3 to 20 years; the average is 8 years.
- More than 7 of 10 people with Alzheimer's disease live at home. Almost 75% of the care of Alzheimer's patients is provided at home by families—the remainder is "paid" care costing an average of \$12,500 per year. Most expenses are paid out-of-pocket by the family.
- The economic cost of Alzheimer care is estimated to be \$80-100 billion each year with approximately \$71.5 billion in costs borne directly by the patients and their families. The average lifetime cost per patient is \$174,000. Neither Medicare nor private health insurance covers the type of care most patients require.

We are here to help Kansas patients, families, and caregivers

Support Groups

Caregiver Training for Families

Promotion of Research

Current Disease Information

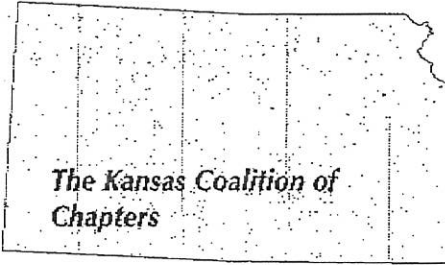
Assistance Programs

Community Resource Information

Training for Health Care and Social Service Professionals

Community Speaking Programs

Newsletters



ALZHEIMER'S ASSOCIATION

Representing:

The Heartland Chapter

The Sunflower Chapter

The Topeka Chapter

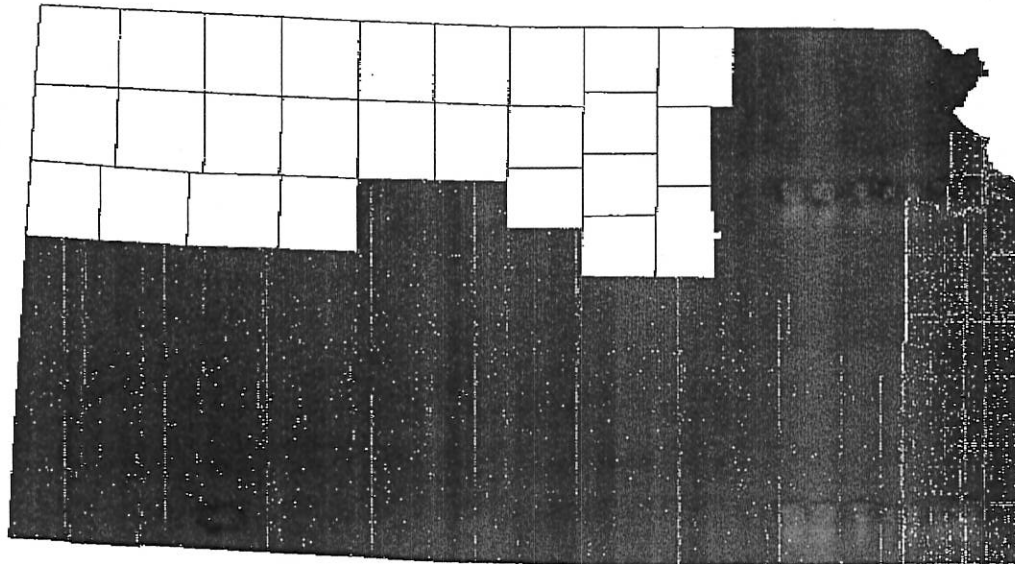


The Kansas Coalition of Alzheimer's Association Chapters

Chapter Service Areas

#4:

A branch office is being considered to cover this area; in the meantime, residents are encouraged to call the Topeka Chapter for information.



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Topeka Chapter
P.O. Box 1427
Topeka, Kansas 66601-1427
(785) 234-2523
FAX (785) 234-0919
marcene.grimes@alz.org

2

Heartland Chapter
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(913) 831-3888
(800) 733-1981
FAX (913) 831-1916
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(888) 688-1010
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