

Approved

Thomas F. Walker
Date 1-25-90

MINUTES OF THE HOUSE COMMITTEE ON GOVERNMENTAL ORGANIZATION

The meeting was called to order by Representative Thomas F. Walker at
Chairperson

9:00 a.m./p.m. on Wednesday, January 24, 1990 in room 522-S of the Capitol.

All members were present except:

Committee staff present:

Avis Swartzman - Revisor
Carolyn Rampey - Legislative Research
Jackie Breymeyer - Committee Secretary

Conferees appearing before the committee:

Representative Joan Wagnon
Marilyn Greathouse - Regional Director, AAUW
Donna Umbarger - Kansas AAUW
Anne R. Kimmel - Public Policy Chairman, AAUW, Kansas Division
Jodie Van Meter - National Association of Women
Katherine Spiller - National Coordinator, Feminist Majority
Liz Hicks - State Coordinator, Kansas NOW
Janice Mauck - YWCA, Topeka
Representative Delbert Gross

Senator Norma Daniels
Dr. William Svoboda - Child Neurologist & Chairman, Task Force on Epilepsy
Bertha McDowell - Executive Director, Epilepsy Kansas
Mark D. Elmore, Olathe - Johnson County Mental Health Center
Jennifer Lattimore - Bureau of Child Research, University of Kansas
Cassie Lauver - Department of Health & Environment
Michael Lechnor - Kansas Commission on Disability Concerns

The meeting of the House Governmental Organization Committee was called to order by Representative Thomas F. Walker, Chairman. He stated the agenda for the day was the gender balance bill and epilepsy commission bill.

HB 2209 - gender balance

Representative Joan Wagnon, bill sponsor, distributed her attachment to the committee. She stated that gender balance would reflect the gender composition of the group that a particular board, commission, committee, etc. regulates. She used the example of 30% of barbers in the state being women, then the Barber Board must have one woman as one of its three members. Two states, Iowa and North Dakota, already have gender balance laws.

Representative Wagnon went through a long list of state boards, highlighting those such as Agriculture, Bank Commissioner, Capitol Area Plaza Authority, Civil Service Board, Corporation Commission, etc. to show the number of women, number of members and percentage of women.

Representative Wagnon stated this legislation is needed because while the number of elected women in office is rising, the number of appointed women in office is increasing at a much slower rate.

Representative Wagnon also had a copy of North Dakota Legislation. (See Attachment 1) Representative answered several committee questions and said she had no problem with tightening up the bill, or making it better in any way.

Marilyn Greathouse, Regional Director, AAUW, was next to address the bill. She asked the committee if this bill didn't seem fair. Shouldn't this be the way of operating. Fair is fair. Women are 52% of the population and should have the right to participate in the decision making that affects them just as men do. (See attachment 2)

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON GOVERNMENTAL ORGANIZATION

room 522-S, Statehouse, at 9:00 a.m./p.m. on Wednesday, January 24, 1990

Donna Umbarger was next on the agenda. She is President of the Kansas Division AAUW. She stated that women are under represented on policy-making state boards. This legislation will bring about state policy which will reflect a more balanced perspective of societal needs. It will also increase the pool of talented women who are experienced in state government. (See attachemnt 3)

Anne R. Kimmel, Public Policy Chairman, AAUW, addressed the committee. She said Kansas is falling behind in the role of women in government. In order to have more active women in government, more opportunities are needed. She urged support of the bill. (See Attachment 4)

Jodie Van Meter, National Association of Women, came to the podium not to speak to the bill, but to introduce Katherine Spiller, Feminist Majority National Coordinator.

Ms. Spillar cited several statistics. Women currently comprise only 5% of Congress and only 17% of state legislatures. At this rate, it will be over 50 years before women achieve parity in state legislatures and almost 350 years before parity in Congress. Women officeholders are more likely than their male counterparts to have held state appointed positions. According to one study 55% of women state senators, 42% state representatives and 41% of women county commissioners have held appointed positions. Increasing the number of women on appointive boards is essential because it will lead to more women getting elected. Also women holding elective or appointive office bring a different perspective to public policy issues. (See Attachment 5)

Liz Hicks, State Coordinator, Kansas NOW, brought her crochet needle with her and told the story of Clarinna Nichols who attended the Kansas Constitutional Convention as observers. Mrs. Nichols brought her knitting to the convention and periodically would query the speaker on issues such as allowing women to own their own property and allowing them equal rights with their husbands over their children. And again, "Mr. Speaker, if you want women to come to the State of Kansas, you must allow them the vote." Numerous women have contributed to the success of the State of Kansas. She added one last point of the bill not costing any money. (See Attachment 6)

Janice Browning Mauck, Topeka YWCA, addressed the bill. She stated she represents the 1990 Women's Agenda, who meet to prioritize and discuss social and political issues involving and affecting women and families. In November, 1989, the meeting was held at Washburn University. At this meeting many issues were raised. A consensus was reached that in order to get the attention of state administration and law makers, they must first get the right to propose and formulate policies and establish priorities by gaining access to state and local boards and commissions. This is not to steamroll over every objection, but to have an effective voice in decisions. Women comprise one-half the work force in the state and more than half of the state employees. (See Attachment 7)

Representative Delbert Gross, bill co-sponsor spoke briefly. He said he was proud to co-sponsor the bill. With the number of women in the Kansas workforce, they are in short supply as far as being appointed to boards, etc. This is a tremendous resource we as a state are ignoring. He urged the committee's serious consideration of the bill.

The Chairman asked for other conferees on HB 2209. Seeing none, he declared the hearing closed on the bill and thanked all who had attended and stated he appreciated everyone's testimony.

The committee turned to SB 371 - epilepsy commission

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON GOVERNMENTAL ORGANIZATION,

room 522-S, Statehouse, at 9:00 a.m./p.m. on Wednesday, January 24, 1990

Senator Norma Daniels was first to speak to the bill. She explained that epilepsy is a "short" in the nervous system. It can result in a brief loss of ability to hear or see, sometimes presented as a stare or some peculiar behavior. It can happen at any time. She asked the committee if they could imagine a math or science class wherein a person would hear a few sentences, lose a sentence or two, then pick up again. School, employment, and family life can be affected. Many agencies offer a tiny bit of service in this area, but there is no one coordinator to tie all together. An epilepsy task force was created to study needs, identify available resources and develop a plan of action for meeting these needs. The final report was submitted to the Governor and Legislature in December of 1988. It took a lot of hard work, but was very well done. Senator Daniels directed attention to page 34, recommendation 62 where it is recommended that an Advisory Board on Epilepsy be established by 1990.

Senator Daniels was questioned about the sunset provision of the bill. The Senator replied that in order to gain support in an atmosphere of too many commissions, the accountability factor was put in. She would be delighted if it was removed. Senator Daniels testimony was taken from the book she distributed entitled, "Kansas Task Force on Epilepsy and Other Seizure-Related Disorders". (See attachment 8)

William Svoboda, M.D., Child Neurologist and Chairman, Task Force on Epilepsy & Other Seizure-Related Disorders, spoke next to the bill. He said the main problem has been that any information or help with regard to epilepsy is not getting out to the general public. The planning by the task force has been done and now it is time to take action. He stated recommendation #62 is the essence and backbone of the bill. Experts from various disciplines will work with and advise various state agencies and organizations with regard to the needs and advances in services and in program development. Those benefitting will be those with epilepsy, parents, teachers employers, spouses and children. (See Attachment 9)

The Chairman said any committee members could leave who wished to do so. Bertha McDowall, Executive Director, Epilepsy Kansas, gave her testimony. Ms. McDowall gave history on how the bill came to be, including the interim committee, task force, etc. She stated that what is being asked for is an investment in making the quality of life better for approximately 49,000 state citizens. (See attachment 10) Ms. McDowall stated that it has been a tremendous and exhausting activity. In answer to a question, Ms. McDowall said that Epilepsy Kansas is the only recognized associated in Kansas.

Mark Elmore, Olathe, spoke of the ignorance of the general populace which needs to be corrected. His testimony contained the struggles he and his wife have had coping with the struggles their daughter has had over many years. (See attachment 11)

Jennifer Lattimore, Bureau of Child Research at the University of Kansas, gave task force information and stated that once armed with the right tools much will be accomplished. Sometimes in looking at the professional perspective, we forget the human perspective. (See attachment 12)

Cassie Lauver, Department of Health & Environment, stated that the Department supports in concept the establishment of a Commission on Epilepsy, however, does not support this bill, as funding was not included in the Governor's budget. (Attachment 13)

An attachment was distributed from R.C. Loux, Chairperson, Kansas Advocacy and Protective Services, Inc. (Attachment 14)

Mike Lechnor, Kansas Commission on Disability Concerns gave a brief statement in support of SB 371.

The Chairman thanked the conferees and adjourned the meeting. Page 3 of 3

STATE OF KANSAS

JOAN WAGNON

REPRESENTATIVE, FIFTY-FIFTH DISTRICT
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TOPEKA

HOUSE OF
REPRESENTATIVES

DEMOCRAT AGENDA CHAIR

COMMITTEE ASSIGNMENTS
RANKING MINORITY MEMBER: TAXATION
MEMBER: FEDERAL AND STATE AFFAIRS

January 23, 1990

Testimony to Governmental Organization Committee
Re: HB 2209 Gender Balance Legislation

What is Gender Balance?

Legislation to require that appointments to boards, commissions, committees, councils or other statutorily created bodies reflect the gender composition of the group that board regulates. For example, if 30% of the barbers in the state are women, the Barber Board must have one woman as one of its three members.

Currently in Kansas, about 25% of appointed positions are filled by women.

Where did this idea come from?

Two states already have Gender Balance laws--Iowa and North Dakota; Montana has a gender balance resolution. Minnesota, Ohio, New York will be considering such legislation in their 1990 sessions.

Two national Women's Agenda conferences (Des Moines, 1988; Kansas City, 1989) have caused the idea to spread among mainstream women's groups; a local Women's Agenda conference in Topeka was the genesis for this particular bill in 1989.

Why is this legislation needed?

While the number of women in elected office is rising, the number of women in appointive office is increasing at a much slower rate. Gender balance legislation gives states an objective yardstick by which to measure their good intentions.

Even in states where gubernatorial appointments of women have been excellent, close examination reveals that women tend to be clustered in boards with small budgets and little influence, while men are usually appointed to those with more power and influence on state policy or to those with larger salaries for service.

A uniform gender balance policy will utilize the talents of women which are now being lost, and will result in state policy which will more closely reflect societal view.

Attachment 1
Y.O.
1/24/90

State Board Name	# Women	# Members	Percent Women
Abst for Board Examinors	1	3	33.
Accountancy	0	7	0.00
Adjutant General	0	24	0.00
Administration	1	11	9.09
Adult Care	3	7	42.86
Aging Advisory	6	14	42.86
Aging Dept.	1	1	100.00
Agriculture Labor Relations	0	2	0.00
XAgriculture State Board	1	21	4.76
Alcohol - Drug Abuse	11	24	45.83
All Sports Hall Of Fame Board	0	7	0.00
Animal Health Board	0	7	0.00
Animal Health Dept.	0	3	0.00
Antiquities Comm.	1	5	20.00
Apprenticeship Council	0	11	0.00
Arkansas River Commission	0	3	0.00
Arkansas River Compact Admin	0	3	0.00
Arts Advisory Council	17	31	54.84
Arts Commission	10	12	83.33
Assesment Sales Ratio	0	3	0.00
Attorneys, Kansas Brd Disp.	1	15	6.67
XBank Commissioner	1	3	33.33
Banking Board	0	9	0.00
Barber Examiners Board	1	3	33.33
Behavioral Sciences Reg. Board	2	7	28.57
Bicentennial of US Consx, Comm. KS	7	23	30.43
Big Blue River Compact	0	3	0.00
Biological Survey	0	8	0.00
Building Advisory	0	8	0.00
Building Construction Joint Comm.	0	6	0.00
XCapitol Area Plaza Authority	2	11	18.18
Capitol Dome Committee	1	6	16.67
Capitol Murals	1	6	16.67
Cntrl. Inter. Low Lvl. Radioact. Wa	0	2	0.00
Child Research Bureau	3	11	27.27
Child Support Committee	8	20	40.00
Children And Youth Advisory	8	17	47.06
Civil Rights	2	7	28.57
XCivil Service Board	0	5	0.00
Citizens Utility Rate Payer	2	4	50.00
Coal Commission	0	13	0.00
Commerce KS Dept.	1	6	16.67
Community College Adv.	2	11	18.18
Conservation Comm.	0	8	0.00
Corn Comm.	0	10	0.00
XCorporation Comm.	1	3	33.33
Correctional Ind. Adv.	1	14	7.14
Corrporate Farming, Sel. Comm.	3	9	33.33
Corrections Dept.	1	7	14.29
Corrections Ombudsman Board	5	10	50.00
Cosmetology Board	4	5	80.00
Court Reporters Board Examiner	0	5	0.00
Credit Union Council	1	7	14.29
Credit Union Dept.	0	1	0.00
Crime Prevention	4	15	26.67

Crime Victims Reparation	1	3	33.33
Crim Justice Coord. Council	1	6	16.7
Crip Childrens advisory Comm.	2	5	40.0
Deaf and Hearing Impaired	3	7	42.86
Dealer Review Board	0	8	0.00
Delta Dental Plan Inc.	1	10	10.00
Dental Board	1	5	20.00
Development \ Finance	0	5	0.00
Developmental Disabilities Srvs.	6	13	46.15
Early Childhood Devl. Srvs. Council	2	7	28.57
Education Commission	2	6	33.33
Education, State Dept.	1	5	20.00
Eisenhower Centennial Comm.	3	5	60.00
Eisenhower Cent. Advisory Comm.	4	24	16.67
Election Commissioners	4	4	100.00
Emergency Medical Serv. Board	4	14	28.57
Emergency Responce Comm.	1	5	20.00
Employee Award Board	2	5	40.00
Employment Security Adv. Council	1	13	7.69
Employment Security Review Board	0	3	0.00
Employment training council	14	34	41.18
Environment Adv. Comm.	4	7	57.14
XFilm Commission	6	22	27.27
Fire Marshall	0	2	0.00
Geological Survey	3	12	25.00
Governor,s Cabinet	1	11	9.09
Governor"s Residence Advisory	0	6	0.00
Grain Advisory	0	6	0.00
Grain Sorghum	0	2	0.00
Hazard.Waste Disposal Facil.	0	5	0.00
Healing Arts Board	1	15	6.67
XHealth &Enviornment Adv.	3	13	23.08
Hearing Aids Examiners	2	5	40.00
Hiway Adv. Comm.	1	12	8.33
Hiway Patrol	0	2	0.00
Hispanic Affairs	3	7	42.86
Historic Sites Board Review	2	10	20.00
Historical Records Adv.	1	10	10.00
Historical Society	5	15	33.33
Human Resources Dept.	4	16	25.00
Humanities Committee	4	5	80.00
Indigents Defence Services	2	9	22.22
Independent Living Council	6	13	46.15
Information Systems Policy	0	3	0.00
Insurance, Office & Comm.	3	18	16.67
Interstate Cooperation Comm.	1	18	5.56
Interstate Oil Compact	0	1	0.00
Judicial Council	1	10	10.00
Judicial Qualifications Comm.	1	9	11.11
Juvenile Offender Adv. Prog.	7	14	50.00
KS Advocacy/Protective Serv.	2	4	50.00
XKS Inc.	0	14	0.00
KS Technology Enterprise	3	15	20.00
Law Enforcement & Civil Def. Comm.	0	3	0.00
Law Enforcement Training Comm.	0	12	0.00
Legislative Administrative Serv.	0	1	0.00
Legislative Coordinating Council	0	7	0.00

Legislative Educational Planning	3	13	23.08
Legis' tive Post Audit Com	2	10	20.
Leg. tive Research Dept.	0	0	0.
Libraries, Regional - Northeast	7	12	58.00
Libraries, Regional - Northwest	6	8	75.00
Libraries, Regional - Northcentral	6	7	85.71
Libraries, Regional - Southeast	14	14	100.00
Libraries, Regional - Southwest	6	6	100.00
Libraries, Regional - S. Central	12	12	100.00
Libraries, Regional - Central	11	11	100.00
Library Adv. Comm.	4	9	44.44
Library Kansas State	3	7	42.86
Library Network	5	10	50.00
Lottery Kansas	5	13	38.46
Lottery Commission	1	5	20.00
Low-level Radioactive Waste Adv.	0	12	0.00
Medically Indigent/Homeless Comm.	2	9	22.22
Mental Health/Retardation Serv.	3	13	23.08
Midwest Nuclear Board	0	1	0.00
Military Adv. Board	0	10	0.00
Military Disability	1	5	20.00
Milk Adv. Comm.	0	5	0.00
Mined-Land Conservation & Recl.	0	13	0.00
Mortuary Arts	1	5	20.00
Natural & Scientific Areas Adv.	2	13	15.38
Non Profit Medical Services	0	2	0.00
Nursing Board	8	11	72.73
Nursing Scholarship Review Comm.	1	5	20.00
Oil & Gas Activities Adv. Comm.	0	1	0.00
Ombudsman for Corrections Office	0	4	0.00
Optometry Board & Examiners	1	4	25.00
Parole Board	1	4	25.00
Pharmacy Board	4	5	80.00
Physical Therapy Exam. Comm.	4	6	66.67
Podiatry Adv. Comm.	0	3	0.00
Poligraphist, KS Board	1	3	33.33
Pooled Money Investment Board	1	3	33.33
Proffecional Practices Comm.	6	9	66.67
Proprietary Schools Adv. Comm.	4	9	44.44
Public Broadcasting Comm.	1	6	16.67
X Public Disclosure Comm.	1	5	20.00
Public employee Relations Board	1	5	20.00
Public Employee Retirement System	1	7	14.29
Racing Comm.	1	5	20.00
Real State Comm.	1	5	20.00
Records Board	0	4	0.00
X Regents	1	9	11.11
Republican River Compact Adm.	0	1	0.00
Revenue	0	8	0.00
Revision of Statues	3	13	23.08
Rules & Regulations	1	4	25.00
Savings & Loan Board	0	5	0.00
Secretary of State Office	3	9	33.33
Securities Comm.	0	1	0.00
Social Rehab Serv. (SRS)	15	52	28.85
Soybean Comm.	0	8	0.00
Special Education Adv. Council	4	8	50.00

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State Employees Health Care	0	3	0.00
Stat Air Managers Board	1	14	6.7
Supr Court Nominating Comm.	3	11	27.
Tax Appeals Board	0	5	0.00
Teaching and School Adm. Prof. Stds	9	18	50.00
Technical Professions Board	1	9	11.11
Transportation Dept.	3	32	9.38
Travel & Tourism	2	19	10.53
Turnpike Authority	1	15	6.67
Uniform State Laws Adv. Comm.	0	7	0.00
Veterans Affairs Govs. Comm.	0	15	0.00
Veterans Affairs Comm.	0	5	0.00
Veterinary Medical Exam Board	0	5	0.00
Vision Service Plan of Kansas	1	2	50.00
Vocational Education Council	6	13	46.15
Washburn Univ. Board Regents	1	3	33.33
Water Authority	1	17	5.88
Water Office	0	3	0.00
Wheat Comm.	0	9	0.00
WSU Board Trustees	2	9	22.22
Wildlife Arts Council	1	5	20.00
Wildlife & Parks Comm.	1	7	14.29
Wildlife & Parks Dept.	0	9	0.00
SRS	0	0	0.00
Directors / Administration	0	0	0.00
Total	424	1705	24.87

Fifty-first Legislative Assembly, State of North Dakota, begun and held
the Capitol in the City of Bismarck, on Wednesday, the fourth day of
January, one thousand nine hundred and eighty-nine

SENATE BILL NO. 2410
(Senators Waldera, Mushik, Holmberg)
(Representatives Scherber, Rydell, Wentz)

AN ACT to provide gender balance in the appointment of members of state boards, commissions, committees, and councils; and to amend and reenact sections 15-39.1-05 and 23-14-04 of the North Dakota Century Code, relating to the appointment of members of the board of trustees of the teachers' fund for retirement and district boards of health.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. Appointive boards, commissions, committees, and councils - Gender balance. Appointments to boards, commissions, committees, and councils of the state established by this code, if not otherwise provided by law, should be gender balanced to the extent possible and to the extent that appointees are qualified to serve on those boards, commissions, committees, and councils. Any appointment in accordance with this section should be made in a manner that strives to seek gender balance based on the numbers of each gender belonging to the group from which appointments are made. Ex officio members are not to be included in determining gender balance under this section.

SECTION 2. AMENDMENT. Section 15-39.1-05 of the North Dakota Century Code is hereby amended and reenacted to read as follows:

15-39.1-05. Management of fund. The fund ~~shall~~ must be managed by a board of trustees, which shall consist of the state treasurer, the superintendent of public instruction, and three persons ~~to be~~ appointed by the governor. ~~One of the appointees shall be a woman and a~~ A majority of the board ~~shall~~ must at all times consist of persons who are members of the fund. The term of the office of the appointees ~~shall be~~ is three years with ~~said~~ those terms fixed to terminate on June thirtieth of alternate years. The term of each appointee shall commence on July first next succeeding ~~his~~ the appointee's appointment.

SECTION 3. AMENDMENT. Section 23-14-04 of the 1987 Supplement to the North Dakota Century Code is hereby amended and reenacted to read as follows:

23-14-04. District board of health. A district health unit ~~shall~~ must be organized by the appointment of a district board of health to consist of not less than five members, one of whom ~~shall~~ must be a physician, one a dentist, one a business or professional person, one a farmer, and one additional person, who ~~shall~~ must be appointed for terms as follows: One for one year, one for two years, one for three years, one for four years, and one for five years. All ~~appointments shall~~ must be for a term of five years. ~~In no instance shall the board be either all male or all female.~~ Each appointee shall serve until ~~his~~ the appointee's successor is appointed

256

and qualified and if a vacancy occurs, the vacancy ~~shall~~ must be filled by appointing for the remainder of the unexpired term. Each appointee shall qualify by filing the constitutional oath of office, and in case of a district health unit, such oath ~~shall~~ must be filed in the office of the county auditor of the county having the larger population according to the most recent state or federal census. Each county in the district shall have at least one representative on the district board of health and counties of over fifteen thousand population shall have an additional representative for each fifteen thousand population or fraction thereof. In district units of less than five counties, each county shall have at least one representative on the district board of health and the additional representatives selected to constitute the minimum five-member board ~~shall~~ must be equitably apportioned among the counties on a population basis. In a city-county health district comprised of only one county and having a city or cities of fifteen thousand population or more, each city having a population of fifteen thousand or more shall have a representative on the district board of health for each fifteen thousand population or fraction thereof and the remaining population of the county, exclusive of the populations of cities with fifteen thousand population or more each, shall have a representative on the district board of health for each fifteen thousand population or fraction thereof. Members of the board may be compensated at the rate not to exceed forty-five dollars per day and not to exceed twenty-five days in any one year. ~~They~~ shall and must be reimbursed for expenses incurred in the manner and to the extent provided for state officers.

For more information on Pay Equity or
Gender Balance issues contact:

Alice League
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Dickinson, N.D. 58601

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pg 7

Testimony before the House Governmental Organization
Committee- January 24, 1990.

To: Chairman Tom Walker, Vice-Chairperson Ramirez, Members
of the committee.

From: Marilyn R. Greathouse, Colby, Kansas, Regional Director, AAUW

Re: Gender Balance, H. B. 2209

This bill simply states that it is the policy of the state of Kansas that appointments to boards, commissions, committees, etc. be made in such a manner that the gender of appointive members is representative of the gender of persons in the populations served by such body. Doesn't that sound fair? Shouldn't that be the way of operating? Fair is fair. Women are 52% of the population and should have the right to participate in the decision making that affects them just as men do.

Women in public office do make a difference. By their very presence in public life and by the different perspectives they bring to examining issues on the public agenda, elected and appointed women make a special contribution to the political process. Studies show that a gender gap on policy issues exists between women and men in office, just as it does in the general population. Women appointees positions on issues ranging from federal regulation and the death penalty to the ERA and a constitutional amendment prohibiting abortion are consistently more liberal than are those of men within the same offices. Being a majority of the population it would

Attachment 2
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1/24/90

seem those views should be reflected on the various boards, commissions, etc.

According to a study by the CENTER FOR WOMEN AND POLITICS of Rutgers University, women in office are as qualified and have as much political experience as their male counterparts. Political leaders sometimes point to a lack of qualifications or experience as a reason why women are so underrepresented in political office.

Yet, according to the research, a majority of women in state cabinet-level posts, like appointees overall, have advanced degrees. The women also have strong professional backgrounds. 16% of the women and 12% of appointees overall have law degrees. Many of the women have held high-level professional positions prior to their appointments. Although women were somewhat less likely to have previously held government jobs more of the women had worked as university administrators or professors or as executives in private sector or public affairs organizations. Although women appointees come into office with less prior government experience than do appointees overall, women are as likely than all appointees to have held political party positions, served as delegates to national party conventions, and worked in their governors' campaigns or had other types of political experience.

Kansas Division of the American Association of University Women received a grant from the AAUW Educational Foundation to create a directory of the talents and

expertise of their members in Kansas. Thirty of fifty branches responded and we have a long list of women with degrees, many of them advanced degrees and a range of expertise that would impress anyone. Working on the gathering of data for that grant made clear what I always suspected, that finding women who would be qualified for appointive positions in state government would simply not be a problem. There are legions of them in this state. I am sure, that in your own experience you have known many women who are very knowledgable in their field and should have the opportunity to use that expertise in policy making positions.

Finally, the recent opening up of the Berlin Wall points out the importance of freedom, democracy and representation in our world. With women being the majority in our society it is only fair and right that they should have equal representation on the various boards, commissions, committees and councils that help govern this state. With all the various and sundry problems we have in our society we need the help of all our citizens. It would be an unprecedented waste not to use the considerable talent and expertise of the women in this state to help us find those solutions. The passage of this bill would help insure that that would happen.

BRINGING MORE WOMEN INTO PUBLIC OFFICE

a project of

Center for the American Woman and Politics, Eagleton Institute of Politics, Rutgers—The State University of New Jersey
New Brunswick, New Jersey 08901
201/828-2210

WOMEN APPOINTED TO STATE GOVERNMENT

Women state cabinet-level appointees, like state appointees overall, have strong educational and professional backgrounds.

- A majority of women appointees, like appointees in general, have postgraduate degrees.
- Women appointees are more likely than appointees overall to have law degrees; 16% of the women and 12% of appointees overall have law degrees.
- Most women appointees, like appointees in general, held high-level professional positions prior to their appointments. While the largest proportions of both groups last held jobs in government, women are somewhat less likely than appointees overall to have previously held government jobs and are slightly more likely than appointees overall to have worked as university administrators or professors or as executives in private sector or public affairs organizations.
- A majority of women state appointees, like appointees in general, rate their professional reputations and credentials as the most important factors leading to their appointments.

Although women state cabinet-level appointees come into office with less prior government experience than do appointees overall, they are as or more likely than appointees overall to have had other types of political experience.

- Among appointees who belong to the same party as their governor, 34% of the women compared with 33% of all appointees have previously held elective or appointive positions in their political parties.
- Among appointees who belong to the same party as their governor, 13% of the women compared with 9% of appointees overall have previously served as delegates to national party conventions.
- A slightly larger proportion of women appointees (38%) than of appointees overall (34%) worked in their governor's campaign.
- 22% of women appointees compared with 19% of all appointees have previously held appointive or administrative positions at the federal level.
- Women appointees are less likely than appointees overall to have held appointive and administrative posts in state and local government or elective government offices.

Many women appointees were inspired and assisted by other women.

- Nearly one of every ten women appointees report that the person most influential in bringing about her appointment was a woman.
- Among women appointees who received assistance from an organization other than a political party in obtaining their appointments, 29% received assistance from women's groups.
- Among women appointees whose political involvement was inspired by role models, 27% had female role models.

Women state cabinet-level appointees are more likely than state cabinet-level appointees overall to take feminist stands on women's issues.

- 80% of women appointees compared with 60% of state appointees overall support ratification of the Equal Rights Amendment. Moreover, women are more likely to support the ERA strongly, with 57% of the women compared with 38% of all appointees voicing strong support for ratification of the ERA.
- Whether they are serving in the administrations of Democratic or Republican governors, nine out of every ten women appointees compared with three-fourths of appointees overall oppose a constitutional amendment prohibiting abortion.

While women appointees demographically resemble appointees overall, there are some notable differences.

- While a majority of women appointees and appointees overall are married, women are less likely to be married and are more likely than all appointees to be single, separated, or divorced; 67% of female appointees compared with 85% of appointees overall are married.
- Among appointees who were or are married, women are more likely than appointees overall to have no children or fewer children; 19% of the women compared with 10% of all appointees have no children, and 33% of the women compared with 50% of all appointees have three or more children.
- Women appointees are younger on the average than appointees in general; 46% of the women compared with 28% of appointees overall are under the age of forty.

This information is from Women Appointed to State Government: A Comparison with All State Appointees, a report based on a survey of state cabinet-level appointees serving in February 1981. Surveyed for the study were 112 women appointees and a sample of 110 appointees, including both women and men in proportion to their presence in the population of state cabinet-level appointees. The report is one of seven reports in a series entitled "Bringing More Women into Public Office." The report is available from the Center for the American Woman and Politics (CAWP).

pg 5



AMERICAN ASSOCIATION
OF UNIVERSITY WOMEN
KANSAS DIVISION

3

I am Donna Umbarger, President of the Kansas Division American Association of University Women. This organization represents 2500 men and women graduates in 65 Kansas communities. Our mission is to promote equity for women, positive societal change and education over the life span.

We are here today to testify in support of House Bill #2209 , presented by Representatives Joan Wagnon and Delbert Gross.

Women are underrepresented on policy-making State boards. The governmental appointments process has not adequately addressed equal representation of women in Kansas government.

- * Kansas has 193 State Boards. Only 23 have equal or in some cases more women than men. Sixty-five boards have NO women at all. Using a total body count, out of 2129 people on these boards, 424 are women... a representation of 24.87%. This is the inequity we address today.

In researching these numbers, women are clustered on boards with small budgets and little influence (social services, cultural and library boards) while men serve on boards with greater influence and power.

Women bring distinctive perspectives to public service since they are more likely to be sensitive to issues and decisions that affect women and children. They have been socialized differently from men because they are daughters, sisters, wives or mothers; because they frequently follow sex-segregated educational and career paths; because they have biological differences and because their collective histories are distinctly different from those of men. Thus, they may raise previously unaddressed questions, notice issues previously ignored, or see problems often not seen by men.

The talents of women are being underutilized, and Kansas currently suffers from a lack of balanced viewpoints.

State boards and commissions serve as training grounds for men and women in governmental service. An increase in opportunity to learn about state government through governmental appointments would increase the likely pool of candidates for elective office.

A society in which half of its numbers are excluded from the process by which it rules itself, will be governed in a manner which lacks a balanced viewpoint.

LEGISLATION TO REQUIRE A GENDER BALANCE ON ALL STATE BOARDS, COMMISSIONS , COUNCILS AND COMMITTEES WILL BRING ABOUT STATE POLICY WHICH REFLECTS A MORE BALANCED PERSPECTIVE OF SOCIETAL NEEDS. FURTHER, IT WILL INCREASE THE POOL OF TALENTED WOMEN WHO ARE EXPERIENCED IN STATE GOVERNMENT.

* Information supplied by the office of Rep. Joan Wagnon

Attachment 3
H.O.
1/24/90



AMERICAN ASSOCIATION
OF UNIVERSITY WOMEN
KANSAS DIVISION

Anne R. Kimmel
Public Policy Chairman

I appreciate the opportunity to testify in support of House Bill #2209 relating to gender balance of appointees to certain state government bodies.

Fourteen years ago when I came to Kansas, I was very impressed with the number of women in your legislature and the fact that Ks had passed the ERA amendment.

Now, however, I feel little progress has been made. Our numbers have not increased substantially, only 24.87%. However, we continue to have women better prepared to not only deal with the role of home-maker, but in many professions, careers, & occupations. The contributions to their communities, while serving in various capacities is noteworthy. Many of the innovative programs come from women who like the pioneer woman who first came to Ks were very frugal and learned to improvise and survive in spite of many hardships.

Ks is falling behind in the role of women in government. In checking with our national association, they indicate that Iowa, Montana, and North Dakota have passed a gender balance bill and a bill is now pending in 13 other states.

In order to have more women active in government, we need more opportunities and I, therefore, urge you to support this bill.

During this same period of time, progress has been made in other governmental positions: Senator Nancy Landon Kassebaum, Elizabeth Dole in a cabinet position formerly Transportation and now Labor, Sandra Day O'Connor, a Supreme Court Judge and even had a woman run for the office of Vice-President of the United States.

However, Ks has done nothing to improve the opportunities for women.

It is interesting to note that equal opportunities have been available to women in many other careers and professions. Since 1927, the motion picture academy awards have been presented equally to women and men--also the Emmy Awards from the Academy of Television Arts and Sciences. Women are co-anchors on the major networks. Many women have been successful authors including one here in Topeka, Harriet Lerner whose book has been on the best seller list.

But, still Ks legislature has done nothing to improve the opportunities for women.

Mother Teresa of Calcutta was awarded the Noble Prize for Peace. Margaret Mead, a noted anthropologist published her original research. Around the world, women have been allowed to rise to positions of authority: Margaret Thatcher, Mrs. Aquino, the President of Iceland, and Mrs. Ghandi of India.

But still Ks legislature has done nothing to improve the opportunities for women.

I need to ask "Do we want to lose our well qualified women legislators to opportunities available elsewhere?" I urge you to support this bill.

Attachment 4
H.O.
1/24/90

FUND FOR THE
**FEMINIST
MAJORITY**

1600 Wilson Blvd., #704, Arlington, VA 22209
(703) 522-2214

GENDER BALANCE LAWS

CAMPAIGN BRIEFING

I. What is a Gender Balance Law?

A state Gender Balance law requires the governor to appoint equal numbers of women and men to all appointive state boards, commissions, committees, and councils. As part of our ongoing Feminization of Power Campaign, the Feminist Majority is organizing for the adoption of Gender Balance laws across the nation.

II. Why a Gender Balance Law?

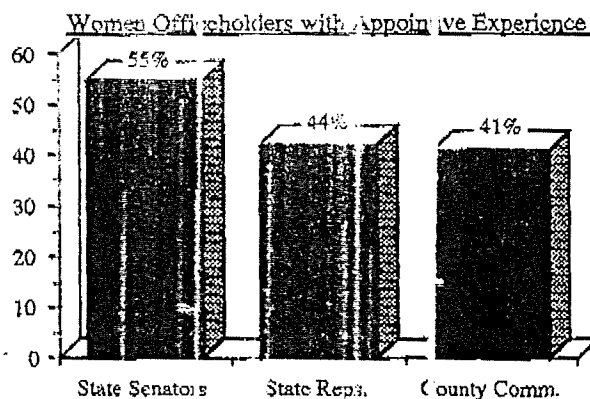
Women currently comprise only 5% of Congress and only 17% of state legislatures. At the current rate of gain, it will be over 50 years before women achieve parity in the state legislatures and almost 350 years before parity in Congress.

Feminization of Power

Since appointive office is frequently a route to elected office, Gender Balance laws that require 50% of state-appointed positions be filled by women would lead to a dramatic increase in the number of women running for and winning elected office. Appointive positions provide training for a wide variety of skills. The appointee gains experience, knowledge, exposure, and political and personal connections necessary to further their public leadership careers. These boards and commissions serve as stepping stones for women and men in governmental services and are especially important for women.

Women officeholders are more likely than their male counterparts to have held state appointed positions. According to a study by the Center

for the American Woman and Politics, 55% of women state senators, 42% of women state representatives, and 41% of women county commissioners have held appointed positions.



A Gender Balance law can also affect the number of women appointed as judges. In 16 states the governor appoints judges based on recommendations from a judicial nominating committee. Equal numbers of women on those commissions, experience shows, would increase the number of women judges.

Increasing the number of women on appointive boards is essential not only because it will lead to more women getting elected, but also because women holding elective or appointive office bring a different perspective to public policy issues -- a perspective that is largely missing today. Polls continually show a gender gap on attitudes on women's issues between women and men. A recent poll showed that 80% and 91% of women appointees support the Equal Rights Amendment and oppose a ban on abortions, respectively.

Attachment 5
H.O.
1/24/90

The Under-Representation of Women in Appointed Office: The California Study

Women across the nation are under-represented in appointed positions at all levels of government. A recent study of boards and commissions appointments in California -- one of the states with the largest number of appointed positions in the country -- illustrates women's under-representation. The 1988 study found that at the state level women held only 27.6% of appointed positions. Women fared only somewhat better at the county and city level with 34.3% and 35.5% respectively, serving on appointive boards.

The study found that women rarely reached parity on any boards and when they did it was limited to traditional "women's" areas such as health and social services or library boards. At all levels of government, the representation of women decreased dramatically on boards in areas of employment which are non-traditional for women. The California study also found that men are more likely to hold regulatory positions with decision-making power, while women were more likely to hold only advisory positions. In addition, women were less likely to be appointed to salaried positions, and more likely to serve on boards receiving expenses and/or per diem or no compensation at all.

Results of the California study are representative of the problem women face nationwide in achieving appointed office. The low percentage of women on state boards and commissions directly correlates with the small number of women in the state legislature. California is ranked 29th in the nation for the percentage of women state legislators with 15% of its legislative body comprised of women. Again, achieving parity in appointive positions will increase the number of women running for and holding office.

III. States With Gender Balance Measures

Already, two states have Gender Balance laws in effect -- Iowa and North Dakota. Two more states, Montana and Delaware, have passed Gender Balance resolutions which do not have the effect of a law because they are not binding but voluntary. However, they must be considered preliminary steps to adopting

a Gender Balance law. At least 12 states have introduced or have plans to introduce Gender Balance measures.

Iowa

Impact dramatic
Over the years, Iowa's Commission on the Status of Women has demonstrated active dedication to getting more women appointed to boards and commissions. As early as 1970 the Commission developed a roster of women qualified for appointments.

Constant monitoring by the Commission resulted in women's representation on state boards and commissions reaching 14% in 1974 and increasing to 29% in 1976. In 1980, the Commission reported that women comprised only 30% of state boards and commissions members.

Frustrated with the slow pace of progress, a Gender Balance statute was introduced by Rep. Minnette Boderer and stated, "all boards, commissions, committees, and councils shall reflect, as much as possible, a gender balance."

The statute was extended in 1987 to include Judicial Nomination Commissions and was amended to require gender balance on all boards, eliminating the discretion in appointments which was allowed by the "as much as possible" exception in the 1986 statute.

In 1983, the final amendment to the law clarified the requirement for boards with an even number of members. If the board is composed of an even number of members, not more than one-half of the membership shall be of one gender.

North Dakota

The passage of a Gender Balance measure has also been one of the top priorities for North Dakota's Commission on the Status of Women. In 1989, the Commission was successful in securing passage of a Gender Balance law; however, the language of the law is not as strong as that found in the Iowa legislation. It states that all "appointments to boards, commissions, committees, and councils of the state ... should be gender balanced to the extent possible." By contrast the Iowa law requires gender parity.

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Montana

In 1988, Montana passed a resolution calling for all appointive boards, commissions, committees, and councils of the state to be gender-balanced to the greatest extent possible. Although a resolution does not have the same weight as a law, its passage focused attention on the significant under-representation of women in appointive office.

Delaware

When a Gender Balance resolution was introduced in Delaware in 1989, women comprised 31% of appointive positions on boards and commissions, higher than most states. Delaware's Commission for Women pushed for Gender Balance legislation to increase women's access to public leadership and decision-making roles. The resolution calls for a gender balance on boards and commissions "as often as possible" and that all new appointments be made with the goal of achieving gender balance. Like Montana's resolution, Delaware's does not have the force of a law but is a step in the right direction towards gaining parity at this policy-making level.

Other States

The Feminist Majority has identified state legislators concerned with the Gender Balance issue. Several states legislatures have already introduced Gender Balance bills and will continue their debates in the upcoming sessions. Those states include: Delaware, Kansas, Minnesota, New Jersey, Ohio, and Rhode Island. Other states are in the process of introducing bills. They include: California, Hawaii, New York, Pennsylvania, and Wisconsin.

IV. What You Can Do

A. Know the Myths vs. the Facts

Myth: Women have made many strides in achieving equality. Gender-balanced boards and commissions will occur naturally without laws.

FACT: True, women have made great strides in gaining equality. Unfortunately, these gains have been slow, especially at policy-making levels. Women are still under-represented at all levels of government and will continue to be so unless some real changes are made. Equal access to appointive positions on boards and commissions can be one of these important changes.

Myth: Won't a Gender Balance law mean replacing qualified men with unqualified women?

FACT: Absolutely not! Increasing the recruitment of women to boards and commissions will in turn increase the total number of qualified people in the available talent pool. To deny women opportunities is to deny the state and nation of some of its best resources.

Myth: Requiring gender-balanced appointments is undemocratic. Women should make it on their own merits. After all, that's how men get appointed.

FACT: Don't we wish! There are plenty of qualified women to fill the small number of appointed positions available -- it is just that their names rarely come up in the recruiting process. That is because recruiting for appointees for public boards and commissions is most often done through the "old boy's networks" which of course generate small numbers of women's names. Requiring that half of all positions be filled with women will guarantee that women are actively sought for these jobs.

Myth: Some boards are comprised of members of a particular profession that have very few women members. There are not enough qualified women to serve on these boards.

FACT: The "qualified" women line is a rouse. There are always enough qualified women in any profession for the handful of positions to be filled in a whole state. In addition these committees include a number of laypeople. These laypeople are appointed by the governor to guarantee the presence of diverse perspectives during the decision-making process.

Myth: A Gender Balance law will prevent women from being the majority on certain commissions and potentially reduce the number of women appointments.

FACT: On the contrary, a Gender Balance law will mean a significant net increase in the total number of women serving in policy-making positions. There are a tiny percentage of boards that are comprised of a majority of women but the benefits of Gender Balance laws far outweigh the potential losses. Even in states where a governor's appointments of women have been excellent, women are too often appointed to boards with small budgets and little influence, while men are

appointed to those with more power and influence on state policy. We are so under-represented on most boards and commissions that to argue that a very few women-board majorities would be in jeopardy is to ignore creating significant opportunities for women.

B. Organize a Gender Balance Campaign

1. Do a study of women appointments to boards and commissions in your state. Seek information from the state's Commission on the Status of Women or a similar type of commission or go directly to the Governor's office.
2. Draft a bill using our model Gender Balance law as a guide.
3. Find legislators to co-sponsor the bill. Try to gain legislative leadership and bipartisan support as well as the support of all women legislators.
4. Have the Governor or gubernatorial candidates endorse the concept of a Gender Balance law.
5. Get organizations and community leaders to adopt the model resolution below adapted from the National Association of Commissions for Women's Gender Balance resolution of June, 1989.
6. Keep in touch with the Feminist Majority for further assistance.

C. Model Organizational Gender Balance Resolution

WHEREAS, The governmental appointments process has not adequately addressed the goal of equal representation of women in government; and

WHEREAS, A society in which half of its numbers are excluded from the process by which it rules itself, will be governed in a manner which lacks a balanced viewpoint; and

WHEREAS, The likelihood of passage of the Equal Rights Amendment will be enhanced by encouraging women to become candidates for state legislatures; and

WHEREAS, Currently women represent only 17% of

state elective legislative offices in the United States; and

WHEREAS, Women legislators are more likely than men legislators to have held appointive government positions; and

WHEREAS, 55% of elected women legislators have held one or more appointive governmental positions; and

WHEREAS, Historically the (name of organization) has been firmly in favor of increasing the number of women in elective and appointive office; and

WHEREAS, Women's organizations have played a major role in changing the laws that define women's status;

THEREFORE BE IT RESOLVED, That the (name of organization) encourages state legislatures to enact legislation which will require a gender balance on all state boards, commissions, and committees; and,

BE IT FURTHER RESOLVED, That the (name of organization) encourage leading organizations to join in a nationwide effort to attain a gender balance on state boards and commissions in order to increase substantially the number of women serving as policy makers in both appointive and elective office.

D. Resources

Fund for the Feminist Majority
1600 Wilson Blvd, Suite 704
Arlington, VA 22209
703/522-2214 or 213/651-0495 (Los Angeles office)

The Women's Network of the National Conference of State Legislatures
Sue Mullins - Executive Director
RR One, Box 49
Corwith, IA 50439
515/583-2156

Center for the American Woman and Politics
Lucy Baruch, Information Services Coordinator
Eagleton Institute of Politics, Rutgers University
New Brunswick, NJ 08901
201/823-2210

pg 4

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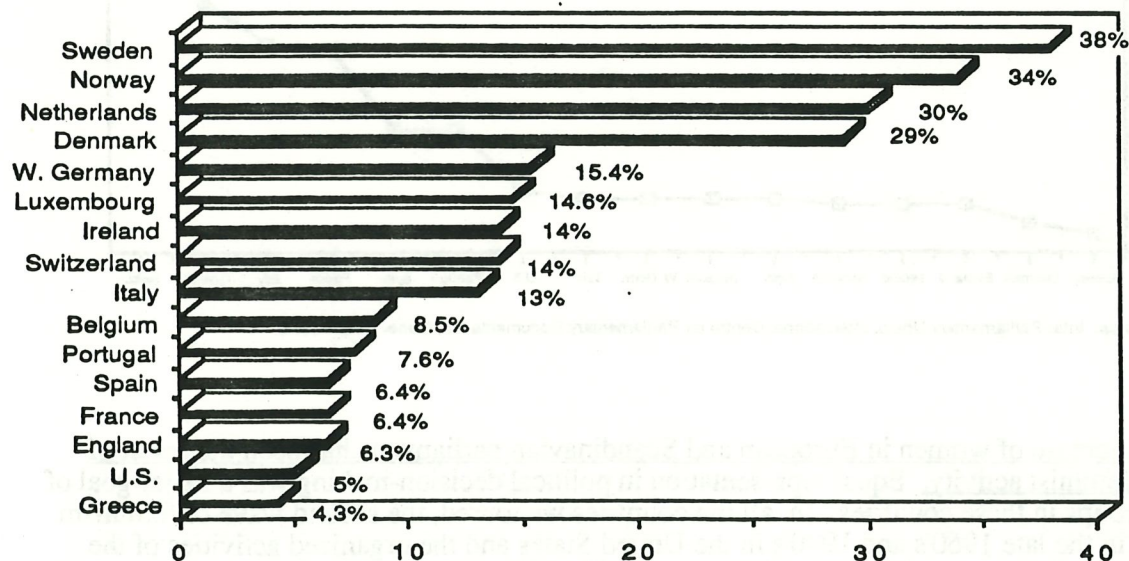
The Feminization of Power: An International Comparison

Fund for the Feminist Majority (FFM) activists led a fact-finding trip to European and Scandinavian countries on September 7-23. FFM President Ellie Smeal, FFM Board Chair Peg Yorkin and National Coordinator Katherine Spillar met with women's rights leaders and public officials to discuss strategies to put more women in power.

The feminist movement in Europe and Scandinavia has been more successful in obtaining political representation for women than we have been in the United States.

Currently the United States lags behind most of Europe in representation of women in the national congress or parliament. Since 1975, the average percentage of women in the various European parliaments has climbed from 5% to 13%. At present, the percentage of women in European and Scandinavian parliaments ranges from a low of 4.3% in Greece to highs of 30% in the Netherlands, 34% in Norway and 38% in Sweden as a result of the September 1988 election. Meanwhile, the U.S. still has less than 5% women in Congress. Belgium (8.5%), France (6.4%), Ireland (14%), Italy (13%), Denmark (29%), West Germany (15.4%), Luxembourg (14.6%), Portugal (7.6%), Spain (6.4%), U.K. (6.3%), and Switzerland (14%) all lead the U.S. in the percentage of women in their central national legislative bodies.

Percentage of Women in Parliaments and Congress



pg. 5

FFM activists and Patricia Ireland, NOW Vice President, attended an historic European Parliament debate on increasing the number of women in decision-making centers. The report, Women in Decision-Making Centers, prepared by the Committee on Women's Rights of the European Parliament found that voluntary measures to increase the number of women in positions of power in business, media, parliament, public administration, and universities proved to have very little success. Therefore, the committee proposed and the European Parliament passed a resolution endorsing: (1) quota systems and affirmative action programs for women in the internal structures of the political parties, and (2) called on political parties "when deciding on their candidates or lists of candidates, to operate a clear-cut and monitorable quota system aimed at achieving numerical equality between men and women in all representative political bodies within the foreseeable future."

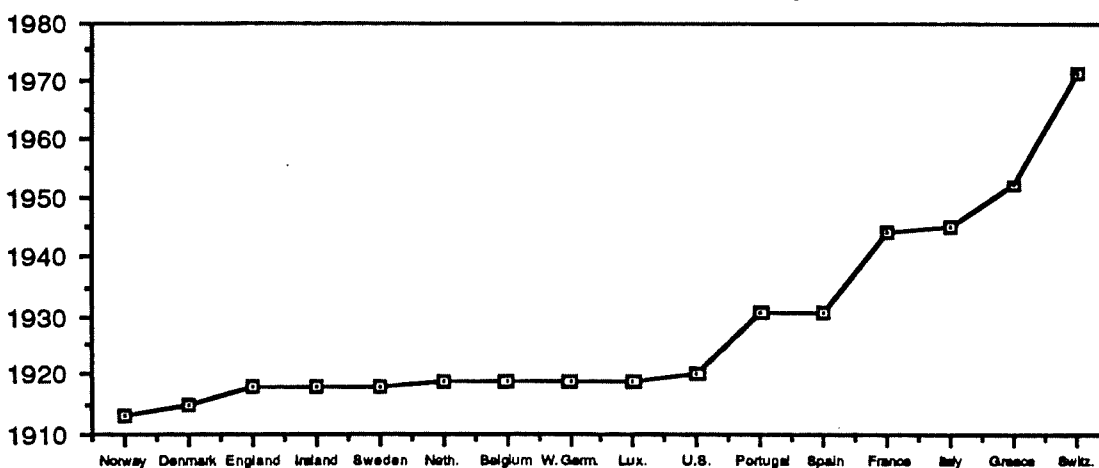
At the European Parliament (EP) in Strasbourg, France, we met with members of the EP Committee on Women's Rights from the United Kingdom, West Germany, Belgium, France, Denmark, Italy and the Netherlands. We also met with feminist organizational leaders, feminist researchers, women leaders from a wide variety of political parties, governmental officials working on women's equality and peace and union activists in Oslo, Norway, Stockholm, Sweden, Bonn, West Germany and London, England.

The following report highlights our observations and provides insights for future strategies.

I. The Importance of Organized Feminist Activity

The increase in the number of women in Scandinavian and European parliaments from 1975 to 1985 did not just evolve. There is no correlation between the date women won the vote or the date the first woman was elected to parliament in various countries and the number of women in parliament. For example, Italian women did not receive the vote until 1945, did not have their first woman in parliament until 1946 and have 12.8% women in parliament now. Swiss women won the vote in 1971 and elected the first woman to the parliament in 1971; today women are 14% of the Swiss parliament.

Year Women Won the Vote by Nation



Source: Inter-Parliamentary Union, International Centre for Parliamentary Documentation, Geneva, April 1988

The increase of women in European and Scandinavian parliaments has been the result of organized feminist activity. Equal representation in political decision-making was a major goal of feminist groups in these countries. In all the countries we toured, the second wave of feminism kicked off in the late 1960's and 1970's in the United States and the organized activities of the United Nations International Decade of Women (1975-1985) were cited as giving impetus to this equal representation movement. **Having easily won equal rights under the law in many**

ajg/b

of these countries, the feminists were able to concentrate more on the goal of equal representation.

The longest sustained drive, and the most successful thus far, for equal representation is in Norway. (Norwegian women are 34% of the parliament, 8 of the 18 Cabinet members including the Prime Minister, and 40% of local governmental bodies). Norwegian women's groups waged organized campaigns to increase the number of women in their parliaments every four years from 1967 on -- except in 1975 because of the United Nations International Women's Year observations and activities in Norway.

The Equal Status Council of Norway, established in 1972, helped lead the fight to increase women's representation and has already begun its 1989 campaign. The campaign is sponsored not only by the Equal Status Council, which is publicly funded, but also by some 12 women's and feminist groups together with the women's associations of the various political parties.

The Norwegian feminists stressed that it is crucial to have outside, independent feminist groups, women's associations within the parties and the government all pushing for the goal of equal representation.

II. The Importance of Changing the Rules of Political Parties and Election Systems.

The Importance of timetables, goals and quotas.

The first Norwegian campaigns to increase the number of women in parliament were aimed at the voters -- encouraging them to vote for women. Results were modest. In later Norwegian campaigns the focus was on the political parties -- demanding they place women candidates in "winnable" or "safe" seats not "throwaway" seats. Again results were modest until the Social Democrats, the largest party, adopted after an elaborate organized campaign of its women's association, a 40% minimum gender rule, i.e. neither gender could have less than 40% of the party's parliamentary seats. Then and only then did a significant increase occur.

In Sweden, the women pointed to the "Norwegian Experience" with the quota system to help their efforts. Although debated, the parties have not adopted quotas in Sweden. Instead they have goals -- although the women's association of the Swedish Social Democrats are for the quota system, the women's associations of the Moderate, Liberal and Center Parties are not. But all would agree that the push from the Social Democrats and the example of Norway helped them to increase the numbers of women in power.

The women's associations of the various parties in Norway and Sweden are very strong, very dedicated to women's equality and are a key reason for the increase in the number of women in political parties. The women's leaders in Norway and Sweden warn that as the number of women in the parliament increases, the power moves from the Parliament, itself, to the parliamentary committees. Women are only 17% of the parliamentary committees in Norway while 34.4% of the parliament. To plug this loophole, the Social Democrats have just passed a 40% rule for the parliamentary committees and all public boards and commissions.

The European Parliament research shows that increasing the number of women in simple majority election systems, as in the United Kingdom and the United States, is more difficult than in proportional representation systems such as in Sweden and Norway. But some parliaments with proportional representation systems such as Greece, France and Luxembourg, still have small numbers of women. The key ingredients appeared not to be the system but an organized women's campaign with real goals and timetables aimed at the political parties.

III. The Gender Gap, Small Parties and the Increase in Women's Representation

The first party to adopt positive quotas for women was a small, new Socialist Left party which had feminist women in its organizing core in Norway in 1975. When the Green Party was formed during 1979-1980 in West Germany by feminist, peace, and environmental activists led by Petra Kelly, it adopted a "50-50" rule. The Green Party list for election, with a woman every other name, starts with a woman and ends with a woman.

At the beginning of the 80's parties left of center had more men voting for them than women while women were voting more conservatively. They were concerned that other left parties with positive quotas would attract women's votes away from them. The Social Democrats had this added incentive to consider quotas.

The West German Social Democrats (SDP), determined to attract more women's votes and prodded by the examples of Norway and the Greens in West Germany, just adopted a quota of a minimum of 30% representation for women.

The Social Democrats throughout Europe and Scandinavia are aligned with labor unions which are dominated by male leadership. Traditionally they have had a gender gap of more men's support but less women's support. In Norway one of the incentives for adopting the 40% minimum rule was to improve the image of the party with women. Moreover, the selection of Gro Harlem Brundtland as their leader was partially to help change the image of a party of old men to attract women's votes.

IV. U.S. Needs, Goals and Timetables for Women

Right now the U.S. lags behind the Western democracies of Europe and Scandinavia in representation of women in their national congress or parliament. At the present rate of growth, it will take until the year 2333 for women to have equality in the U.S. Congress. And it is not much better at our local levels. It will take until the year 2038 for women to achieve equality in the state legislatures. And it is even worse at the county levels. Meanwhile in Norway, 40% of the local governmental councils are women.

Some of the political parties of these countries made a decision to open up candidacies to women in both their safe seats and the more competitive seats. This occurred only after the women's associations of their parties and outside feminist groups waged long campaigns for equal representation aimed at the parties.

Some parties adopted positive quotas for women's representation. The women argued successfully that without a positive quota for women, there is a quota for men. For example the largest party in Norway adopted a 40% minimum gender rule. Other parties throughout Europe have adopted similar quotas or voluntary affirmative action goals and timetables.

U.S. politicians have adopted affirmative action timetables and goals in other sectors but have carefully avoided, until recently, passing similar guidelines for themselves. In 1980, the Democratic party adopted an equal gender representation rule in all internal decision-making bodies. The Republicans followed with a voluntary system but still are far from equality.

The U.S. parties must go beyond these internal decision-making rules and adopt equal gender rules for candidacies in both safe and competitive seats. Moreover, we must have affirmative action for racial and ethnic minorities. Note there is just one black woman, no Hispanic women and less than 5% Blacks in congress.

Does it matter? No question about it. Today in congress, bills concerning pay equity for women, child care, and family and medical leave languish; access to abortion is being curbed for the poor and the vulnerable; and the Equal Rights Amendment has not passed either house since it was reintroduced in 1983.

You don't need a poll to tell you that although both women and men want child care and women's rights -- women care more about these issues.

We need to take bold steps to eradicate the under-representation of women and minorities. It's time to end the foot dragging and to take the movement for women's equality the next step. We must work to build the groundwork of the Feminization of Power by changing the rules, and by inspiring thousands of feminists to seek and gain leadership positions. We deserve and must be equally at the tables of power.

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KANSAS



7

Liz Hicks
State Coordinator
Kansas NOW
Jan. 24, 1990

I am testifying for the passage of the Gender Balance Bill #2209. First let me set a perspective: women comprise 51% (1980 census) of our population, but only 23% (see addendum) of people appointed to state boards and commissions. Some boards require members to have special knowledge or skills. For example the board of pharmacy has 6 members of which 5 must be pharmacists and the 6th a member of the general public. Women pharmacists have served proudly on that board, but not always in equal numbers with the men. As more women move into various professions, there are more of us to draw on to fill those slots.

But more to the point are the numerous seats that could be filled by any citizen who has an interest in the subject of that board or commission. It is sometimes said that there aren't enough qualified women to appoint to boards. Isn't that silly? Shall we ask if there are enough qualified men? Of course there are both men and women qualified to serve our state. All it takes is a change of mind set to realize that we all benefit when a larger pool of citizens is drawn from.

Kansas has a proud history of women serving our state, beginning with Clarinna Nichols and other Douglas County women who attended the Kansas Constitutional Convention as observers. They could not vote (it was 1859) and could not be delegates but they could speak to the needs of the new state. Mrs. Nichols brought her knitting. Periodically she put it down and motioned to the Speaker of the House.

"Mr. Speaker?" she queried. "Mrs. Nichols," he acknowledged. "Mr. Speaker, if you want women to come to the State of Kansas you must allow them to own property in their own names." Across the United States women could not own property - it was held by their fathers or husbands.

And again, "Mr. Speaker, if you want women to come to the State of Kansas, you must allow them equal rights with their husbands over their children". Across the U.S. men could disinherit their children or indenture them but their wives had no legal say in those decisions.

And again, "Mr. Speaker, if you want women to come to the State of Kansas , you must allow them the vote."

*Attachment 6
D. O.
1/24/90*

When the Kansas Constitution was ratified, it was the most radical document since the Declaration of Independence. The laws allowed partnership of parenting, women's ownership of property and business, and granted suffrage in school board elections. And women flocked to Kansas where they could participate more equitably in their society and government. And note that it was Kansas in 1860 that was the first state to allow women to vote at all!

I could name numerous women who have contributed to Kansas' success: Susanna Salter, Argonia, first woman elected mayor ever (1887); Mary Elizabeth Lease, leader of the Populist Party; Margaret Hill McCarter, appointed to the boards of illiteracy at the state, national and international levels; Georgia Neese Gray, United States Treasurer; Anne Laughlin, Director of the National Youth Administration and Unicef Mission Chief. And that doesn't touch the women who built our society but didn't have well known positions.

But somewhere along the line, we have neglected to use the knowledge and skills of many of our citizens. This bill is a simple solution.

One last point for this troublesome financial session. This bill doesn't cost any money!

Addendum

The 1989 list of state boards and commissions contained the following data. 191 boards were counted. No elected or ex officio members were included in the numbers.

66 boards (35%) no women 18 boards (9%) 1-10% women
36 boards (19%) 11-25% women 40 boards (21%) 26-49% women
31 boards (16%) 50% or more women but when you exclude the regional library boards, there are 23 (12%) in this group.

Pg 2



January 24, 1990

225 West 12th
Topeka, KS 66612
913-233-1750

TO: Government Organization Committee

FROM: Janice Browning Mauck, PhD

SUBJECT: House Bill No. 2209

My name is Jan⁸ Mauck, and my home address is 421 Woodlawn, Topeka, KS 66606.

I come before you today to speak in support of House Bill No. 2209. I represent the 1990 Women's Agenda, which is formulated at an annual gathering of delegates of various women's organizations who meet to discuss and prioritize social and political issues involving and affecting women and families. Our last meeting was held in November, 1989; at Washburn University and was sponsored by the YWCA. More than 80 delegates representing 14 women's organizations were at that meeting.

The issues that were raised by the delegates included child care, pay equity, abortion rights, pensions, education, health care, and housing. In short, the very topics that concern all of us - men, women, and children - at every level of society. The feeling of frustration mounted as the day wore on because we soon realized that our deep concerns are often lost in the bureaucracy or trivialized by insensitive boards and commissions that are not tuned into the basic problems that affect women and children on a daily basis.

As our session drew to a close, we came to a consensus that in order to get the attention of the state administration and law makers, we must first get the right to propose and formulate policies and establish priorities by gaining access to state and local boards and commissions.

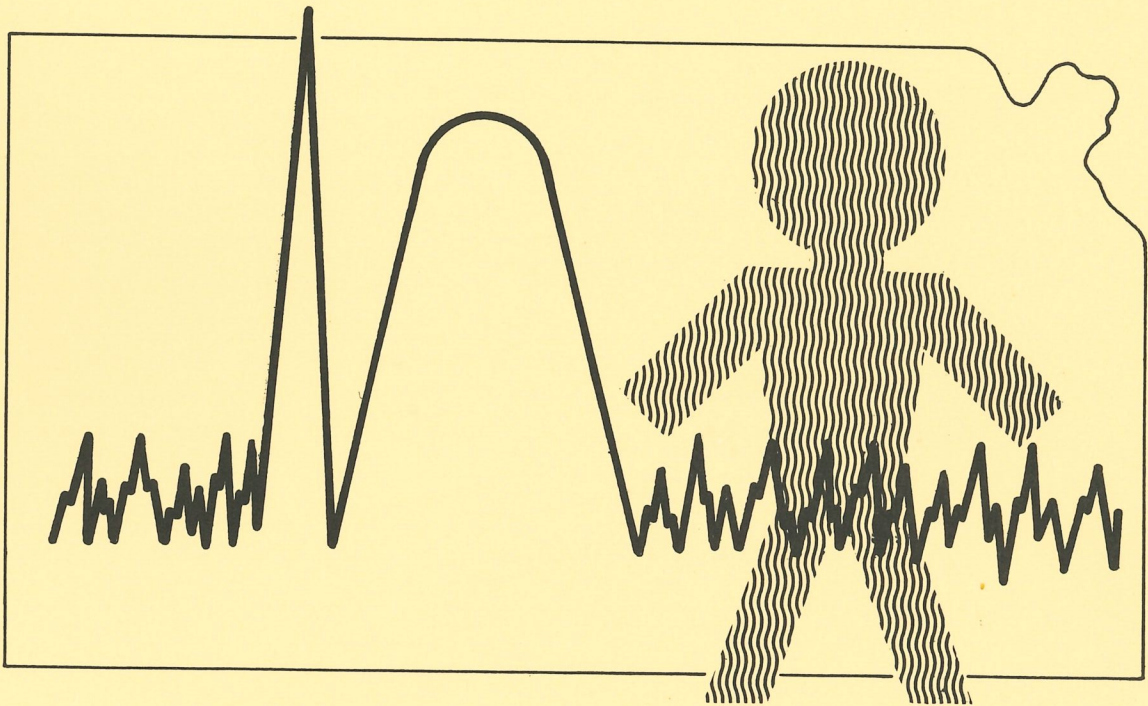
We are very serious about achieving gender balance on governing and regulating bodies at all levels of government, not because we wish to steamroll over every objection to our needs and concerns, but so that we can have an effective voice in decisions that affect us. How fair is it for one segment of our society (in this case, women) to be excluded from the decision-making process in such areas as pensions, insurance, banking, and economic development? Surely it should not need to be pointed out that women are one-half the work force in this state, and more than half of state employees.

We ask only for fairness in being given the right to realize our vision for Kansas, and in return for this fairness we pledge to make our state a model of cooperation for the improvement in all areas of our common concerns.

Thank you for your attention and consideration.

Attachment 7
G.O.
1/24/90

**KANSAS TASK FORCE
ON EPILEPSY AND OTHER
SEIZURE-RELATED
DISORDERS**



Presented to the Kansas Legislature

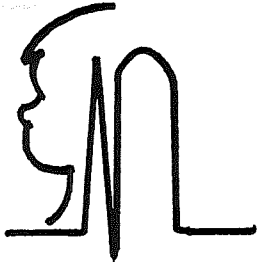
December, 1988

*Attachment 8
Y. O.
1/24/90*

TASK FORCE ON EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS

FINAL REPORT

**Presented to Governor Mike Hayden
and the
Kansas Legislature
December, 1988**



NEUROLOGY & EPILEPTOLOGY

PEDIATRIC & ADOLESCENT

WILLIAM B. SVOBODA, M.D.
PEDIATRIC NEUROLOGIST

ST. FRANCIS MEDICAL PARK PLAZA
1035 N. EMPORIA, SUITE 270
WICHITA, KANSAS 67214

TEL. (316) 267-5215

December 31, 1988

The Honorable Mike Hayden, Governor of Kansas
The Honorable Jack D. Walker, M.D., Lieutenant Governor of Kansas
The Honorable Paul "Bud" Burke, President of the Kansas Senate
The Honorable Jim Braden, Speaker of the Kansas House
Members of the 73rd Legislature

Dear Ladies and Gentlemen:

On behalf of the Task Force on Epilepsy and Other Seizure-Related Disorders, we are pleased to submit the final report and recommendations of the Task Force as specified in Senate Bill 461.

First, we would like to thank you for having the concern and sensitivity to establish a task force of this nature. Second, we want to commend you for your appointment of individuals selected to serve on the Task Force. The quality and commitment of the individuals that you appointed and those appointed by the Secretary of the Department of Health and Environment, Stanley C. Grant, made my job as Chair most gratifying.

In the following pages The Task Force has identified some of the critical needs of individuals with epilepsy and other seizure-related disorders in the areas of medical and mental health, education, employment, and daily living. Effective strategies to address these identified needs will be brought about through positive action taken by each of you, as Governor of Kansas, members of the 73rd Legislature and interested citizens throughout the state.

Finally, we are grateful for the support and helpful suggestions offered by consumers, state agencies, providers and interested persons in the state. We hope that the 73rd Legislature and all relevant state agencies will give serious consideration to the Task Force recommendations and the ongoing needs of individuals in Kansas with epilepsy and other seizure related disorders.

Sincerely,

William Svoboda, M.D.

Chairman, Task Force on Epilepsy and
Other Seizure-Related Disorders

TASK FORCE ON EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS

Members Appointed by Secretary Stanley C. Grant, Kansas Department of Health and Environment

William B. Svoboda, M.D.
Comprehensive Epilepsy Center
St. Francis Regional Medical Center
Wichita, Kansas

Health Care Provider/
Medical Director
(Chairman)

Azzie Young, Ph.D.
Bureau of Maternal & Child Health
Kansas Department of Health & Environment
Topeka, Kansas

State Government
(Staff Director of Task Force)

Lillian Pardo, M.D.
Department of Pediatrics
University of Kansas Medical Center
Kansas City, Kansas

Health Care Provider/
Pediatric Neurologist
(Section Leader)

Virginia Tucker, M.D.
Bureau of Maternal & Child Health
Kansas Department of Health & Environment
Topeka, Kansas

State Government

Lawrence J. Faflick
Boeing Military Airplane Co.
Wichita, Kansas

Employer
(Section Leader)

Stephen Schiffelbein
Rehabilitation Services
Kansas Department of Social &
Rehabilitation Services
Topeka, Kansas

State Government

Mark Elmore
Johnson County Mental Retardation Center
Olathe, Kansas

Educational Professional and
Parent of a Child with Epilepsy
(Vice Chairman)

Ms. Bertha McDowall
Epilepsy Kansas Inc.
Wichita, Kansas

Private Organization
Executive Director
(Section Leader)

Members Appointed by the Legislative Leadership

Senator Norma Daniels
Valley Center, Kansas

Legislator and Parent of a Child
with Epilepsy

Jennifer Lattimore, Ph.D.
University of Kansas
Research & Training Center on
Independent Living
Lawrence, Kansas

Educational Professional

Representative Elaine Hassler
Abilene, Kansas

Legislator (Vice Chair of the
Public Health and Welfare
Committee) and Former Teacher

Joyce E. Barrett
Graduate Student
University of Kansas
Oskaloosa, Kansas

Educational Professional

ACKNOWLEDGEMENTS

The Task Force on Epilepsy and Other Seizure-Related Disorders wishes to gratefully acknowledge the contribution of the many individuals, state agencies and other public and private organizations that contributed to this effort. The list is far too great to enumerate.

We are grateful for the information supplied by the Epilepsy Foundation of America's National Office and State Affiliates including Kansas City Affiliate, and Epilepsy Kansas, Inc. The Task Force members found the Legislative Interim Committee on Epilepsy of the Special Committee on Public Health and Welfare Report invaluable in completing their work. We acknowledge the contributions of the Comprehensive Epilepsy Center, St. Francis Regional Medical Center in Wichita, Kansas and Kansas University Medical Center in Kansas City, Kansas.

Special appreciation for the efforts of Opal Becker and Paula Dollmann is also noted.

pg 6

TABLE OF CONTENTS

Letter of Transmittal.....	i
Task Force Members.....	ii
Acknowledgements.....	iv
SUMMARY OF TASK FORCE FINDINGS.....	1
SECTIONS:	
MEDICAL & MENTAL HEALTH.....	4
Identified Needs and Recommendations.....	5
Attachments.....	11
EDUCATION & EMPLOYMENT.....	15
Identified Needs and Recommendations.....	16
Attachments.....	19
PROBLEMS OF DAILY LIVING.....	24
Identified Needs and Recommendations.....	25
Attachments.....	30
CONCLUSION.....	34
REFLECTIONS BY THE CHAIR.....	34
REFERENCES.....	36
APPENDIX.....	38
1. Senate Bill 461	
2. State Agency Survey	
3. Summary of State Agency Survey	

SUMMARY OF TASK FORCE FINDINGS

Epilepsy is a seizure disorder that can happen to anyone at any age at any time. A seizure is a brief, involuntary disturbance of brain function due to a sudden, uncontrolled burst of energy from a cluster of brain cells, presented as a brief stare or impaired consciousness, a disturbed movement, or a peculiar behavior. The seizure may be due to an irritation of some part of the brain (as with a scar, a tumor, a malformation or a blood vessel abnormality). Epilepsy is a symptom of a brain disorder. It is a treatable condition but one surrounded by misunderstanding and sometimes improper diagnosis and management.

The Task Force on Epilepsy and Other Seizure-Related Disorders was established by Senate Bill 461 that was passed by the 1988 Legislature. Members of the Task Force included consumers and providers and were drawn from public and private organizations. Some members were persons with epilepsy and parents of children with epilepsy. The Task Force was authorized to study needs, identify available resources and develop a plan of action for meeting the identified needs. In addition, the Task Force was instructed to submit a report and plan to the Governor and the Legislature by December 31, 1988.

To fulfill the legislative mandate, the Task Force added two goals: (1) to address rural as well as urban needs, and (2) to seek practical and economic solutions to identified problems. Needs and recommendations are presented according to the following sections: Medical and Mental Health; Education and Employment; and Problems of Daily Living. The recommended plan of action attempts to identify the type of action required, the implementing agency, and a suggested timeline for implementation. This report and plan is a concentrated effort to address some of the problems experienced by many citizens of Kansas with epilepsy and other seizure-related disorders. It is by no means the final word.

pg 8

STATE PLANNING BASED ON THE FEDERAL MODEL. For many centuries epilepsy has been spoken of in terms of magic and mysticism, demons and dreads, fears and fads. Even in the first half of this century, epilepsy, idiocy and insanity were linked in the public mind. The pendulum then swung to the other extreme with a complete denial of any epilepsy-related problems except for the brief interruption of normal functions when the person had a seizure. Only with the publication of the report of the Federal Commission on Epilepsy and Its Consequences in 1978 did epilepsy enter into the modern age of "complete person care."

This Federal Commission report identified needs, available services, and recommended approaches toward improving assistance to individuals with epilepsy. States such as Florida, Louisiana, Texas, and Michigan initiated planning efforts that were modeled after the Federal Plan for Action on Epilepsy.

The shaping of the Kansas plan began with a conference on Epilepsy held in Wichita in 1984. Prior to 1984, outreach clinics to provide secondary/intermediate medical and education evaluations and consultations for youth with special health care needs were established. To address the needs of children with complex problems including seizures, these Special Child Clinics were initiated by the Department of Health and Environment and the State Department of Education in cooperation with local community agencies. Team members typically have included a pediatric neurologist, behavioral psychologist and a perceptual motor or learning disabilities specialist. These Special Child Clinics are currently held at six sites with an annual average of four clinics per site. The Kansas Comprehensive Epilepsy Center was established in Wichita in 1985. During the same year, the Legislature approved seizures as a medically diagnosed condition for children participating in the Services for Children with Special Health Care Needs Program (formerly the Crippled and Chronically Ill Children's Program) of the Kansas Department of Health and Environment. A Special Legislative Interim Study on Epilepsy was undertaken in 1987. The Task Force on Epilepsy and Other Seizure-Related Disorders was established in 1988.

THE APPROACH. The Task Force had seven months to complete its work. The twelve members were assigned to three sections according to their area of expertise. The sections were: Medical and Mental Health; Education and Employment; and Problems of Daily Living. Section leaders were appointed by the Chairman. Each section included members of public and private organizations including one consumer and at least one state agency representative. The Task Force held monthly meetings that were open to the public. Extra section meetings were scheduled as needed.

The Task Force reviewed: the Federal Commission Report; all available plans from other states; data from the 1984 State Conference Planning and Prioritizing Report; the Legislative Interim Study; and other related information. A survey of current and planned programs and services of state agencies was completed. A statewide survey of medical, mental health, educational, employment and other service providers was completed that identified current services and needs. Consumer and provider testimony was invited to be presented at the monthly Task Force meetings. Information was received concerning auto licensure, insurance and advocacy. Specific position papers were obtained as needed to educate the



Task Force membership. Comments and complaints from various consumers were collected for each area.

THE REPORT AND PLAN. The Task Force report and plan has been divided into three sections according to the working groups. In each of these sections, a general problem statement is presented followed by identified needs and specific recommendations. For each identified need, at least one recommendation is given. The type of action is suggested i.e., administrative, fiscal and/or statutory. The agency or organization considered most able to enact the recommendation is identified. A reasonable time schedule to achieve each recommendation is suggested. Within the limited time available, the Task Force was not able to project the price tag for each recommendation.

The Task Force presents this Plan of Action to citizens of Kansas. This is not a completed wish list but hopefully it is a new beginning to attain more comprehensive care for individuals with epilepsy and other seizure-related disorders. This effort was best described by Task Force member, Senator Norma Daniels:

"Now people with epilepsy are lost in the maze of services. The services may be out there, but no one knows they're there. Each agency has a little part of the picture, but no one has the whole picture. Our goal is to help people with epilepsy reach their full potential by educating the public and employer about epilepsy."

MEDICAL AND MENTAL HEALTH

Too often epilepsy is thought of as a medical problem and no more. This section identified the major needs for more comprehensive and modern care of the whole person beyond mere pills and tests. Specifically, the medical area identifies the need for minimal standards of care including reliable diagnostic approaches, appropriate anticonvulsant selection and monitoring, and coordination of comprehensive services in both urban and rural Kansas. The Task Force discovered both an unawareness of the needs for an availability of appropriate mental health services by counselors knowledgeable about epilepsy. One area of research open to many disciplines is determining the relationships between seizures, the medications, and the consequences. The other major area is the study of improved service delivery. Lessening the chances of epilepsy from various conditions may be achieved through genetic counseling and improved prenatal care. Improved management of the neonate with seizures may reduce later handicaps. Efforts to reduce the risks and frequency of head injuries can address major causes of epilepsy. In terms of comprehensive care, the main effort must be to develop teams drawn from various disciplines to provide a statewide system of whole-person management.

pg 11

IDENTIFIED NEEDS AND RECOMMENDATIONS

I. THE NEED TO ESTABLISH MINIMAL CARE STANDARDS REGARDING THE DIAGNOSIS AND TREATMENT OF EPILEPSY.

RECOMMENDATION 1: The Task Force recommends that by 1990, the Department of Health and Environment should develop and adopt minimum standards for medical evaluation and care of persons with epilepsy, based on the report by the Federal Commission on Epilepsy and Its Consequences to be used by private and state agencies. (ADMINISTRATIVE)

RECOMMENDATION 2: The Task Force recommends that by 1990, the Department of Health and Environment should develop protocols regarding acute seizure management for medical personnel in emergency rooms, operating rooms, ambulatory care facilities, and emergency medical services. (ADMINISTRATIVE)

RECOMMENDATION 3: The Task Force recommends that by 1991, the Department of Health and Environment should assure that all state institutions adopt the minimum standards of care for all patients with epilepsy. (ADMINISTRATIVE)

II. THE NEED TO ESTABLISH AND MAKE AVAILABLE QUALITY DIAGNOSTIC SERVICES TO PROVIDERS. The two major areas of need are: (a) quality control in laboratories conducting blood tests for medication concentrations; and (b) EEG laboratories.

RECOMMENDATION 4: The Task Force recommends that by 1990, state agencies should utilize and fund only EEG laboratories that adhere to the standards of the American EEG Society. Also, state agencies and third party payers should establish funding for EEG monitoring services according to the EEG Society standards for patients with uncontrolled seizures. (ADMINISTRATIVE and FISCAL)

RECOMMENDATION 5: The Task Force recommends that by 1990, state agencies should increase funding magnetic resonance imaging services for patients with epilepsy who require financial assistance. (FISCAL)

RECOMMENDATION 6: The Task Force recommends that by 1990, the Department of Health and Environment and the Board of Pharmacy should provide accurate and up-to-date information on side effects and cost of anticonvulsant drugs available to individuals with epilepsy and their families. In addition, information about

3/12

anticonvulsant drugs should be disseminated to professionals, consumers, counselors and other appropriate persons. This information should be reviewed periodically. Also, information relative to new drugs, changes in drug use and difficulties with existent drugs should be distributed to health care units, mental health centers, and to other local care givers. (ADMINISTRATIVE)

RECOMMENDATION 7: The Task Force recommends that by 1990, the Department of Social and Rehabilitation Services should develop a mechanism to provide funding for the distribution of anticonvulsant drugs, blood level monitoring and related laboratory work for individuals who are unable to pay for these services. Also, financial support should be provided for all recognized primary and adjunctive anticonvulsant medications on the basis of need. In addition, the Board of Pharmacy should encourage pharmacists to prescribe brand name drugs instead of substituting generic drugs for patients with completely controlled seizures or episodic toxicity. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 8: The Task Force recommends that by 1990, the Department of Health and Environment and other state agencies should develop an educational package and adopt standards for the use and methods of anticonvulsant blood testing based on recommendations by a panel of neurologic consultants or by an Advisory Committee on Epilepsy. (ADMINISTRATIVE)

III. **THE NEED TO PROVIDE EDUCATION/TRAINING TO PHYSICIANS AND RELATED HEALTH CARE PROVIDERS ESPECIALLY THOSE IN PRIMARY CARE, IN THE MODERN DIAGNOSIS AND TREATMENT OF EPILEPSY.**

RECOMMENDATION 9: The Task Force recommends that by 1990, the Advisory Board on Epilepsy (or a similar group), in cooperation with the University of Kansas Medical Center at Kansas City and the Comprehensive Epilepsy Center in Wichita should provide educational information to physicians and develop professional continuing education courses and in-service workshops dealing with the comprehensive management of individuals with epilepsy. (ADMINISTRATIVE)

RECOMMENDATION 10: The Task Force recommends that by 1990, the Dental Board should provide training materials to dentists regarding epilepsy that include the effects of anticonvulsant medication. (ADMINISTRATIVE)

RECOMMENDATION 11: The Task Force recommends that by 1991, the Department of Health and Environment should educate providers of medical services about the use of emergency medical

identification bracelets and/or chains, protective helmets, and pill containers. (ADMINISTRATIVE)

RECOMMENDATION 12: The Task Force recommends that by 1990, the Department of Health and Environment should assure that every school nurse throughout the state has access to information on epilepsy, including an epilepsy School Alert Kit. Also, the State Nurses Association should make available a continuing program of inservice training to all personnel. These sessions shall be tailored to meet local needs. (ADMINISTRATIVE)

RECOMMENDATION 13: The Task Force recommends that by 1990, the Department of Social and Rehabilitation Services should develop and present in-service training programs and materials for mental health workers and counselors regarding the special needs of persons with epilepsy and their families. (ADMINISTRATIVE and FISCAL)

RECOMMENDATION 14: The Task Force recommends that by 1990, Community Mental Health Centers should develop services for persons with epilepsy and their families. A workshop on epilepsy addressing mental health problems should be held in at least one region of the state. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 15: The Task Force recommends that by 1990, schools training students in psychology, social work, and rehabilitation counseling should increase training regarding epilepsy. To the degree possible, this should include experience in a medical clinic serving those with epilepsy. (ADMINISTRATIVE)

IV. **THE NEED TO PROVIDE COMPREHENSIVE EPILEPSY SERVICES AND COORDINATION OF EXISTING RESOURCES.**

RECOMMENDATION 16: The Task Force recommends that by 1994, the Department of Social and Rehabilitation Services, and the Department of Health and Environment in coordination with the Advisory Committee on Epilepsy, the University of Kansas Medical Center in Kansas City and Wichita, should establish regional comprehensive epilepsy clinics. The clinic staff should include representatives of the local health department, Mental Health Centers, Vocational Rehabilitation Centers, the local and/or regional school system and support cooperatives, and other pertinent groups. Technical assistance will be provided by the Comprehensive Epilepsy program in Wichita and the University of Kansas Medical Center in Kansas City. The Department of Health and Environment should continue Special Child Clinics with multidisciplinary care for children with handicaps complicated by seizures. These clinics should identify children with

epilepsy and provide basic medical standards of care.
(ADMINISTRATIVE OR FISCAL)

RECOMMENDATION 17: The Task Force recommends that by 1991, the Department of Health and Environment should develop a community-based tracking and follow-up system for individuals with epilepsy. (ADMINISTRATIVE)

RECOMMENDATION 18: The Task Force recommends that by 1990, the Department of Health and Environment and the Department of Social and Rehabilitation Services should provide dental care for problems related to epilepsy for individuals who are unable to pay for such services. (ADMINISTRATIVE AND FISCAL)

V. **THE NEED TO INCREASE GENETIC COUNSELING SERVICES.**

RECOMMENDATION 19: The Task Force recommends that by 1990, the Department of Health and Environment, the Comprehensive Epilepsy Center in Wichita and the University of Kansas Medical Center in Kansas City should support counseling services that address the inheritance potentials of specific epilepsy syndromes and other disorders often accompanied by seizures. (ADMINISTRATIVE AND FISCAL)

VI. **THE NEED TO PROMOTE MATERNAL SERVICES FOR PREGNANT WOMEN WITH EPILEPSY AND THEIR CHILDREN.**

RECOMMENDATION 20: The Task Force recommends that by 1990, the Regional Perinatal Care Program and the Department of Health and Environment should develop medical guidelines regarding comprehensive standards of care for women of child-bearing age with epilepsy both pre-conception and prenatal. The Department of Health and Environment should continue its support of neonatal Level III perinatal centers in the management of neonatal epilepsy. (ADMINISTRATIVE)

RECOMMENDATION 21: The Task Force recommends that by 1990, the Department of Health and Environment should designate the pregnancy of a woman having epilepsy as a "high risk" condition and disseminate this information to contracting agencies. (ADMINISTRATIVE)

VII. THE NEED FOR EARLY IDENTIFICATION OF CHILDREN WITH EPILEPSY.

RECOMMENDATION 22: The Task Force recommends that by 1991, the Department of Social and Rehabilitation Services should revise the state guidelines for the KAN BE HEALTHY Program, as to the detection of possible seizure conditions. It is further recommended that the Department of Health and Environment should instruct contracting agencies to screen uniformly for epilepsy through pediatric neurologic evaluations and thorough histories to detect all possible seizure conditions. (ADMINISTRATIVE)

VIII. THE NEED TO ENHANCE MENTAL HEALTH SERVICES AND COUNSELING SERVICES.

RECOMMENDATION 23: The Task Force recommends that by 1990, the Department of Social and Rehabilitation Services, local mental health programs, and the State Department of Education should develop a counseling referral system and should provide access to these services for individuals with epilepsy and their families. (ADMINISTRATIVE)

RECOMMENDATION 24: The Task Force recommends that by 1991, the Department of Social and Rehabilitation Services should submit a budget request for a mental health specialist to provide consultation and training to mental health centers and other mental health personnel regarding epilepsy. (ADMINISTRATIVE AND FISCAL)

IX. THE NEED TO REDUCE HEAD INJURIES.

RECOMMENDATION 25: The Task Force recommends that by 1991, the State Department of Education and the Department of Health and Environment in cooperation with the State Affiliates of the Epilepsy Foundation of America and/or the Comprehensive Epilepsy Center should develop a safety education program aimed at reducing head injuries and promoting safe sports participation and play equipment. (ADMINISTRATIVE)

RECOMMENDATION 26: The Task Force recommends that they 1991, the Governor, Legislature, the Department of Revenue, the Kansas Highway Patrol and local police departments should develop, promote and enforce laws that: (a) require full use of front and back seat restraints in all types of motor vehicles including school buses; (b) require the use of helmets by motorcycle and moped drivers and passengers; and (c) continue enforcement of driving under the influence restrictions. (ADMINISTRATIVE and STATUTORY)

X. THE NEED FOR RESEARCH IN KANSAS.

RECOMMENDATION 27. The Task Force recommends that by 1991, the Department of Aging shall undertake a study concerning the special problems faced by elderly persons with epilepsy.

RECOMMENDATION 28. The Task Force recommends that by 1991, the Department of Social and Rehabilitation Services should conduct a study on the specific problems preventing successful vocational rehabilitation of clients with epilepsy and fund model programs. In addition, the State Developmental Disabilities Council should fund a study of the service delivery system for individuals with epilepsy. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 29: The Task Force recommends that by 1990, the Department of Health and Environment should explore methods of obtaining statistics on the cause of death in individuals with epilepsy. (ADMINISTRATIVE)

XI. THE NEED FOR HEALTH INSURANCE COVERAGE.

RECOMMENDATION 30: The Task Force recommends that by 1990, the State Insurance Commissioner should develop an uninsurable pooled health insurance program and/or mandate that epilepsy not be used as an exclusion rider for insurance issuance. (ADMINISTRATIVE)



MEDICAL AND MENTAL HEALTH SECTION ATTACHMENTS

A. Sample Survey

B. Survey Results

MEDICAL AND MENTAL HEALTH SERVICES FOR PATIENTS WITH EPILEPSY

A. ACCESSIBILITY OF MEDICAL SERVICES (Circle the appropriate answer/answers)

1. Who follows persons with epilepsy in your community?
 Family Practitioners General Practitioners Pediatricians
 Internists Osteopaths Other _____

2. Where are patients referred for diagnosis and treatment?
 Private Clinics Local Hospitals Tertiary Care Centers
 Location of above: Instate (Kansas) _____ Out of state (name state) _____

3. Once the diagnosis of epilepsy is made, who does follow-up care and treatment?

4. Are emergency medical services available in your community? Yes No
 If yes, is the training and performance adequate to handle seizures? Yes No Unknown
 If not, explain:

B. MINIMUM STANDARDS OF CARE - DIAGNOSTIC/LABORATORY SERVICES

1. Is EEG (electroencephalograph) available in your community? Yes No
 If yes, who interprets the EEG record? _____
 Is the EEG record sent or transmitted to remote consultation or interpreter? Yes No
 How soon are the interpretation results sent back to the person/facility who requested it?
 (State number of days) _____

2. Is CT scanning available in your community? Yes No
 If yes, hospital equipment? or by mobile van?

3. Is MRI available in your community? Yes No
 If not, where would you send a patient who in your opinion could benefit from the test?
 (name place) _____

4. Can any physician order any of the above tests? Yes No Don't Know

5. Are anticonvulsant drug level determinations available in your community? Yes No
 If yes, how soon are results available to you? _____ (number of days)

C. MENTAL HEALTH ISSUES

1. Is social, emotional and educational counselling available for patients who are diagnosed with epilepsy? Yes No
 If yes, who provides the counselling? Physician Nurse Social Worker Psychologist
 School Counselor Educator Other (Specify) _____

2. Do you refer patients and their families with epilepsy experiencing emotional and social adjustment problems to mental health clinics? Yes No
 If not, where would you refer them? _____ (name)

3. Would you refer patients with epilepsy to a multidisciplinary outreach clinic if it were made available to your community? Yes NO

4. What kind of support services are available? _____

D. EDUCATIONAL PROGRAMS/SERVICES

1. Would your community be interested in a seminar or educational presentation about epilepsy?
 Yes No
 If yes, indicate by circling names of target groups that might be interested: Physicians Nurses
 School Personnel (psychologists, administrators, educators, therapists, OT, PT, speech)
 Others, providers of service, and the public

2. Would your community be interested in consultative services for patients with epilepsy?
 Yes No
 If yes, state nature of consultation (medical, educational, mental health issue, other)

pg 19

SURVEY: MEDICAL/MENTAL HEALTH NEEDS OF PATIENTS WITH EPILEPSY
IN KANSAS - 1988

	East	Central	West	Total
No of counties	33	39	34	106
No. of responses	103	120	65	288
Access or medical care				
Family Practice	78	98	40	216
Internists	45	54	10	109
General Practice	62	64	24	150
Osteopaths	35	41	5	81
Pediatrician	41	45	10	96
Others	13	6	3	22
Location of Medical care				
Private Clinic	47	59	27	133
Local Hospitals	62	56	18	136
Tertiary Care Hosp.	40	61	26	127
EEG Access				
Yes	67	63	31	161
Local Interp.	31	52	6	89
Outside Interp.	39	29	16	84
Transmittal EEG		4	24	28
CT Head Access				
Yes	81	71	24	176
Hospital	52	19	15	86
Van	27	25	6	58
MRI Access				
Yes	22	34	12	68
No	5	61	45	111
Lab Access for AED (Antiepileptic drugs)				
	81	89	54	224
Counselling Services				
Yes	86	103	50	240
MD	59	69	24	152
RN	54	49	14	97
SW	49	42	15	106
Psych	48	69	24	141
School	19	27	14	60

	<u>East</u>	<u>Central</u>	<u>West</u>	<u>Total</u>
Referral				
To Mental Health Clinic	76	100	50	225
To Outreach Clinic (if available)	53	20	43	108
Educational Program				
Interested (if offerrad)	46	71	37	154
Target Audience				
MD	46	58	20	124
RN	47	54	36	137
School	37	44	28	109
Public	15	7	8	30
Consultative Services	41	36	22	99

pg 21

EDUCATION AND EMPLOYMENT

The emphasis on epilepsy is more than just addressing the seizures. It is management of the life between the seizures. School problems are often mistakenly blamed on the seizures or medications. Major problems persist in the awareness of the needs of children with epilepsy and the proper management of children with seizures in the classroom. Such problems can only be approached through teaching the teachers. Even more important is the need to determine why many children with epilepsy are not achieving and special teaching techniques should be developed. Vocational counseling and preparation should be made available to teenagers with epilepsy. Employers also need to be informed about epilepsy.

IDENTIFIED NEEDS AND RECOMMENDATIONS

EDUCATION

XII. THE NEED FOR UPDATING STATE MANUALS AND GUIDELINES REGARDING THE MANAGEMENT OF ACUTE SEIZURES.

RECOMMENDATION 31: The Task Force recommends that by 1991, the two State Epilepsy Foundations of America Affiliates, the Kansas Association for School Health, the Department of Health and Environment, and the Kansas Planning Council on Developmental Disabilities collaborate in the revisions of first aid procedures for persons with epilepsy and other seizure-related disorders. (ADMINISTRATIVE)

XIII. THE NEED TO EDUCATE/TRAIN TEACHERS, STUDENTS AND OTHER SCHOOL PERSONNEL ABOUT EPILEPSY.

RECOMMENDATION 32: The Task Force recommends that by the 1990-91 school year, the State Department of Education, the Board of Regents, and all local school boards should develop a teacher training plan on epilepsy and other seizure-related disorders. This plan should utilize existing videotapes and materials whenever possible. (ADMINISTRATIVE)

RECOMMENDATION 33: The Task Force recommends that beginning with the 1989-1990 school year, the State Department of Education, the Department of Health and Environment, the two state Affiliates of the Epilepsy Foundation of America, the Comprehensive Epilepsy Center, and the Kansas University Medical Center should work cooperatively on presentations regarding epilepsy at statewide meetings and conferences of school personnel. (ADMINISTRATIVE)

RECOMMENDATION 34: The Task Force recommends that the state Affiliates of the Epilepsy Foundation of America should provide regularly scheduled presentations of school children and in-service training to clergy, community living providers, government mental personnel, law enforcement workers, school bus drivers, and others. (ADMINISTRATIVE)

07/23

RECOMMENDATION 35: The Task Force recommends that by 1991, the state colleges and universities, State Department of Education, the Department of Health and Environment, and Kansas University Medical Center should develop a curriculum aimed at elementary and secondary school students on seizure disorders that emphasizes the importance of peer and teacher understanding in the educational achievement of students with epilepsy. (ADMINISTRATIVE)

XIV. THE NEED TO ADDRESS THE SPECIAL EDUCATION NEEDS OF CHILDREN WITH EPILEPSY.

RECOMMENDATION 36: The Task Force recommends that by 1990, the State Department of Education should review and revise the state guidelines for Special Education. A child suspected and/or verified as having epilepsy who is underachieving in school should be formally evaluated. (ADMINISTRATIVE)

XV. THE NEED TO DEVELOP SUMMER MAKE-UP EDUCATIONAL OPPORTUNITIES FOR STUDENTS WHO FALL BEHIND BECAUSE OF SEIZURES.

RECOMMENDATION 37: The Task Force recommends that by 1990, local education agencies should make available special summer educational opportunities in cases where students need remedial efforts to help compensate for the interruption of their studies due to epilepsy or other seizure-related disorders. (ADMINISTRATIVE)

XVI. THE NEED TO PROVIDE SAFE TRANSPORTATION TO SCHOOL PROGRAMS FOR THOSE WITH SEIZURES.

RECOMMENDATION 38: The Task Force recommends that by 1990, the State Department of Education should assure that seizure-prone children will have safe transportation to school. Such transportation services should be operated by trained personnel that know first-aid techniques for students who have seizures. (ADMINISTRATIVE)

Og 24

EMPLOYMENT

XVII. THE NEED TO PROVIDE VOCATIONAL COUNSELING SERVICES TO STUDENTS WITH EPILEPSY.

RECOMMENDATION 39: The Task Force recommends that by 1990, the State Department of Education and the Department of Social and Rehabilitation Services assure that seizure-prone children will receive appropriate vocational counseling during high school years. (ADMINISTRATIVE)

XVIII. THE NEED TO PROVIDE INFORMATION ABOUT EPILEPSY TO POTENTIAL EMPLOYERS.

RECOMMENDATION 40: The Task Force recommends that by 1991, the State Department of Commerce, in cooperation with other governmental agencies and private organizations should establish an annual mailing list of employers to encourage employment opportunities for persons with epilepsy and other seizure-related disorders. (ADMINISTRATIVE)

XIX. THE NEED TO TRAIN JOB PREPARATION AND PLACEMENT PROVIDERS REGARDING NEEDS AND SERVICES FOR INDIVIDUALS WITH EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS.

RECOMMENDATION 41: The Task Force recommends that by 1990, the Department of Human Resources designate and train at least one worker in each of the Kansas Job Service Offices. The Department of Social and Rehabilitation Services should conduct in-service training, with the cooperation of appropriate medical consultants, to improve services provided to persons with disabilities including epilepsy. (ADMINISTRATIVE AND FISCAL)

0725

EDUCATION AND EMPLOYMENT SECTION ATTACHMENTS

C. Sample Survey

D. Survey Results

TASK FORCE ON EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS SURVEY

EDUCATION AND EMPLOYMENT

Employment

1. How many employees/students/members do you have?
2. If you are self-employed and have a seizure-related disorder, did you have any difficulty starting your own business? _____ If yes, please describe, and you may omit the balance of the questions:
3. How many of these individuals have epilepsy/seizure-related disorders? _____
4. What concerns would you have if a qualified person applied for a job who had a seizure-related disorder?

Why?

5. Do you have any policies restricting the activity of these individuals? _____
If yes, please provide copies if these are written policies.
6. Do you provide health insurance coverage to your employees? _____ Are seizure-related disorders included in the coverage? _____
7. What awareness, training, education does your staff have in the handling of epilepsy/seizure-related disorders?
8. Describe your experience with individuals having seizure type disorders:

Education

9. What is your policy if any, on students taking medication?
If written, please attach a copy.
10. What is your policy on students with epilepsy/seizure-type disorders participating in:
 - a. Vocational education
 - b. Physical education (including sports)
 - c. Driver's education
 - d. Field trips
11. What concerns would you have in teaching a student with a seizure-related disability?
12. Do you have any programs for students whose epilepsy and/or medication may interfere with the regular classroom setting? Yes _____ No _____
If yes, what kind?

ATTACHMENT D

Survey: Education and Employment Needs in Kansas - 1988

The Education and Employment Section surveyed the educational system and employers in Kansas.

EDUCATION. Of the surveys returned, 187 responses (44%) out of the 444 mailed were from educational facilities. A recap of survey responses, sorted by numbers of students, is as follows:

QUESTIONS ASKED	SCHOOLS 500 AND UNDER	SCHOOLS OVER 500
Size of school	41	45
No policies	54%	51%
Minimal policies	46%	49%

pg 28

QUESTIONS ASKED

ALL SCHOOLS

MEDICATION

No policies	38%
State policies used	34%
Doctor directed	23%
Student reported	8%
State regulations	6%
Nurse supervised	5%

PARTICIPATION

No policies in any area below	78%
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VOCATIONAL EDUCATION

No policies	87%
Physician approved	12%

PHYSICAL EDUCATION

Physician advice	24%
No restrictions	12%
Other restructures	6%

DRIVERS EDUCATION

Physician statement	22%
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FIELD TRIPS

No policies	86%
No restrictions	17%
Participation encouraged	9%

CONCERNS

None	44%
Information lack about student	21%
Specific health, emotional care, awareness needs	26%
Miscellaneous concerns	9%

SPECIAL PROGRAMS

No programs	82%
Specialized services	18%
Special Education classes	7%
Individualized services	5%

MEDICATION POLICIES: Twenty-nine schools submitted policies that were being used. The policies were often developed using the School Medication Administration Guidelines as published by the State Department of Education. These guidelines are reviewed by the State Board of Nursing as well as the Attorney General's Office in cooperation with the Department of Health and Environment. These guidelines were distributed to all school districts in Kansas.

PARTICIPATION POLICIES: Responses from the surveys relative to the areas of vocational education, physical education, driver education and field trips were much less specific than the medication areas. Nonetheless, they provided insight into the various organizations' policies and even more importantly, their awareness of the needs of persons with seizure disorders.

0929

TEACHER CONCERNS: Thirty responses noted concern for the health, safety, self-esteem, welfare, or care of the individual. Several noted the need for in-service or educational needs of the faculty. Ten responses covered a wide variety of concerns such as establishing lines of communication with the student's physician, information for other students and a concern for the tactful approach and care to avoid unnecessary stress that might cause seizures.

SPECIAL PROGRAMS: A total of 94 responses indicated that no special programs were in place. Twenty responses indicated that some type of specialized services were available.

EMPLOYMENT: There were a total of 73 responses to the employer's section of the survey. The larger the company, the fewer number of responses were received. Most respondents have had limited contact and knowledge of persons with seizure type disorders. In many cases, when contact had been made, it had been off rather than on the job. Those employers who expressed concern over the "hiring of epileptics" all cited safety of the worker (and others who might be impacted) as their primary concern. The medium-sized and larger companies also felt that they lacked knowledge of this particular medical condition. This is a potentially correctable area of concern.

A recap of survey responses, sorted by numbers of employees, is as follows:

QUESTIONS ASKED	SMALL-SIZE EMPLOYER	MEDIUM-SIZE EMPLOYER	LARGE-SIZE EMPLOYER
Number of employees	1-19	20-50	51-550
Number of responses	48	17	8
Number of epilepsy Concerns	0-2	0-1	0-2
	Safety Driving	Safety Lack of knowledge Medication	Safety Lack of knowledge
Epilepsy policies	8%	0	0
No insurance	40%	29%	0%
Staff training	-----Generally no training-----		
	Uses EMT	Some have staff RNs	13% with file information
Seizure experiences	4%	0-12%	0-50%
Management experience		Off job experience	Refer to the hospital

The smaller companies less frequently offered health insurance coverage. Medical coverage is available with 60% of the small employers, 71% of the mid-sized employers and 100% of all larger companies from which a response was received.

Og 30

PROBLEMS OF DAILY LIVING

Survival on a day-to-day basis with the restrictions and stigma posed by epilepsy could be more painful than the task of seizure control. The major barrier to obtaining good care is often the inability to pay for needed services. Alternative resources are needed. Existing public and private agencies and organizations should be encouraged to assist individuals with epilepsy. Another barrier to care is transportation. Also, the adult with active seizures often is unable to find a place to live. The family with a child who has seizures may not be able to find respite care. There is a great need for public education about the needs of individuals with epilepsy.

IDENTIFIED NEEDS AND RECOMMENDATIONS

XX. THE NEED TO PROMOTE FAMILY SUPPORT SERVICES FOR INDIVIDUALS WITH EPILEPSY.

RECOMMENDATION 42: The Task Force recommends that on an ongoing basis, the State Affiliates of the Epilepsy Foundation of America, the University of Kansas Medical Center in Kansas City and the Comprehensive Epilepsy center in Wichita should insure that consumer and family education and consultation are available. Also by 1991, support groups should be developed to assist individuals with epilepsy in identifying recreational activities and in developing social skills. In addition, organizations of parents of children with epilepsy should be established to discuss mutual epilepsy-related problems. (ADMINISTRATIVE)

XXI. THE NEED TO PROVIDE BILINGUAL SERVICES.

RECOMMENDATION 43: The Task Force recommends that by 1990, the State Affiliates of the Epilepsy Foundation of America should provide specifically designed bilingual materials, programs and outreach services. (ADMINISTRATIVE)

XXII. THE NEED TO DEVELOP LEGISLATIVE INITIATIVES TO ASSIST THOSE WITH EPILEPSY.

RECOMMENDATION 44: The Task Force recommends that by 1991, the State Affiliates of the Epilepsy Foundation of America and the Kansas Advocacy and Protection Services should develop a mechanism for suggesting, developing, and publicizing legislation pertaining to epilepsy. (ADMINISTRATIVE)

RECOMMENDATION 45: The Task Force recommends that by 1991, appropriate Legislative Committees should develop legislation and/or administrative regulations to require law enforcement officials to check with the prescribing doctor(s) before taking medications away from an individual who claims to have epilepsy or who shows symptoms of epilepsy; and to erase any arrest record resulting from false arrest due to an epileptic seizure. (ADMINISTRATIVE)

pg 32

XXIII. **THE NEED TO ASSIST INDIVIDUALS WITH EPILEPSY WITH TRANSPORTATION PROBLEMS.**

RECOMMENDATION 46: The Task Force recommends that by 1990, the Department of Revenue should revise driver license guidelines and policies used by the Medical Advisory Board such as:

- a) Revise reporting forms used by physicians;
- b) Educate physicians as to form completion and policies of the Medical Advisory Board;
- c) Educate field workers of the Division of Motor Vehicles regarding driver license policies; and
- d) Educate consumers regarding the licensing process and appeal procedures. (ADMINISTRATIVE)

RECOMMENDATION 47: The Task Force recommends that by 1990, the Department of Revenue should seek legislation to change the one-year seizure-free period of restricted driving to 3 months or less according to national data. (ADMINISTRATIVE AND STATUTORY)

RECOMMENDATION 48: The Task Force recommends that by 1990, the Department of Revenue should issue identification cards automatically to persons whose license becomes suspended for medical reasons. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 49: The Task Force recommends that by 1990, the Department of Revenue should seek legislation to change the wording in the law relative to driver licensing from "revocation" to another term such as medical suspension, in order to eliminate the need for retesting an individual with epilepsy. (ADMINISTRATIVE AND STATUTORY)

RECOMMENDATION 50: The Task Force recommends that by 1992, the Department of Transportation should develop an accessible transportation network to enable individuals with epilepsy to have the same mobility as the general public (utilizing federal funds). (ADMINISTRATIVE AND FISCAL)

XXIV. **THE NEED TO DEVELOP ALTERNATIVE LIVING ARRANGEMENTS.**

RECOMMENDATION 51: The Task Force recommends that by 1992, the Department of Social and Rehabilitation Services should work to increase the number of alternative community-based living arrangements for persons with epilepsy. (ADMINISTRATIVE AND FISCAL)

33

RECOMMENDATION 52: The Task Force recommends that by 1992, the Department of Social and Rehabilitation Services, Department of Health and Environment and the State Affiliates of the Epilepsy Foundation of America should develop follow-up procedures to re-allocate resources from institutions to alternative community living arrangements. These arrangements should be based on a working model program to assure the continuity of care for persons with epilepsy moving from a state residential facility to the community. (ADMINISTRATIVE, FISCAL AND STATUTORY)

XXV. THE NEED TO IMPROVE THE MANAGEMENT OF INDIVIDUALS WITH EPILEPSY IN PRISONS.

RECOMMENDATION 53: The Task Force recommends that by 1990, the Department of Corrections should review the status and implementation of medical care for prisoners with epilepsy. (ADMINISTRATIVE)

XXVI. THE NEED FOR RESPITE CARE SERVICES FOR PARENTS OF CHILDREN WITH EPILEPSY.

RECOMMENDATION 54: The Task Force recommends that by 1992, the Department of Health and Environment and the Department of Social and Rehabilitation Services should develop a plan of respite care services for families of children and adults with special health care needs including epilepsy. (ADMINISTRATIVE AND FISCAL)

XXVII. THE NEED FOR PUBLIC AWARENESS OF EPILEPSY.

RECOMMENDATION 55: The Task Force recommends that on an ongoing basis, the State Epilepsy Foundation of American Affiliates in cooperation with the University of Kansas Medical Center in Kansas City, the Comprehensive Epilepsy Program in Wichita, the Department of Health and Environment and the Department of Social and Rehabilitation Services should make information on epilepsy more available to individuals with epilepsy and their families. In addition, the Department of Health and Environment and other agencies should continue to support and maintain a statewide 24-hour general information phone number (1-800-332-6262) that lists medical-clinical facilities, local chapter services, and special education programs. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 56: The Task Force recommends that by 1991, the Department of Social and Rehabilitation Services in cooperation with the State Affiliates of the Epilepsy Foundation of America

should develop and disseminate resource directories of services available for persons with epilepsy. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 57: The Task Force recommends that the State Affiliates of the Epilepsy Foundation of America, the University of Kansas Medical Center in Kansas City, the Comprehensive Epilepsy Program in Wichita should develop and implement a comprehensive program of community education in order to increase knowledge about epilepsy and the needs of people with epilepsy and to improve attitudes among the public by: 1) developing and distributing public service announcements; 2) expanding the use of the Speaker's Bureau; 3) providing conferences and workshops on epilepsy for the general public; 4) preparing and executing programs for use during Epilepsy Month (November); and 5) using all forms of the mass media to disseminate epilepsy information. (ADMINISTRATIVE)

RECOMMENDATION 58: The Task Force recommends that by 1991, the State Affiliates of the Epilepsy Foundation of America and the University of Kansas Medical Center in Kansas City, the Comprehensive Epilepsy Program in Wichita, the Department of Health and Environment and the Department of Social and Rehabilitation Services should develop and maintain a library for the collection and dissemination of public education materials on epilepsy. By 1992, at least one book about epilepsy, published within the last three years, should be available through every public library in the state. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 59: The Task Force recommends that by 1992, the Insurance Commissioner, working with the State Affiliates of the Epilepsy Foundation of America, should survey and distribute health insurance for persons with epilepsy, e.g., riders, cautions, and appeal procedures. (ADMINISTRATIVE AND FISCAL)

XXVIII. THE NEED TO PROVIDE FINANCIAL ASSISTANCE TO INDIVIDUALS WITH EPILEPSY WHO ARE UNABLE TO PAY FOR NEEDED SERVICES.

RECOMMENDATION 60: The Task Force recommends that by 1990, the Department of Social and Rehabilitation Services should seek expansion of Medicaid eligibility requirements to cover medical and seizure control medication services. (ADMINISTRATIVE AND FISCAL)

RECOMMENDATION 61: The Task Force recommends that by 1991, the State Affiliates of the Epilepsy Foundation of America, the University of Kansas Medical Center in Kansas City, the Comprehensive Epilepsy Program in Wichita, the Department of Health and Environment and the Department of Social and

pg 35

Rehabilitation Services should provide staff to assist persons with epilepsy who are eligible for Supplemental Security Insurance and Social Disability Insurance to fill out appropriate application forms. (ADMINISTRATIVE AND FISCAL)

DAILY LIVING SECTION ATTACHMENTS

E. Sample Survey

F. Survey Results

TASK FORCE ON EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS SURVEY

INDEPENDENCE AND EQUALITY

1. List the estimated unduplicated number of individuals with epilepsy and/or other seizure-related disorders served: _____.

2. Types of services provided: (for each applicable area, enter approximate number of people with epilepsy served annually--same individual can be counted in multiple areas)

Consumer Advocacy _____	Peer/Other Counseling _____
Systems Advocacy _____	Respite Care _____
Information and Referral _____	Public Education _____
Housing _____	Independent Living Skills Training _____
Transportation _____	Recreational Programs _____
Financial Assistance (general) _____	Employment _____
Legal Assistance _____	Rehabilitation _____
Community, Professional/Technical Assistance _____	Insurance (specify) _____
Other (specify) _____	Day Care _____

3. Eligibility requirements for services: (please specify)

Age _____	Residence _____
Sex _____	Adaptive Behavior Level _____
Income Level _____	Mental Development Level _____
Education Level _____	Other (specify) _____

4. Fees charged: Yes _____ No _____

5. Types of Financial Arrangements Accepted: (please specify)

Insurance Plans _____
Public Assistance Programs _____
Other (specify) _____

6. Please estimate the percentage of your services budget that is expended for epilepsy-related services:

Public Funding Source _____	Private Funding Source _____
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7. Is referral required for your agency to provide services: Yes _____ No _____
 If yes, by whom: _____

8. Specify Limits on Services Provided:

Monetary Limit _____	Time Limit _____
Frequency Limit _____	

9. What difficulties have you experienced in the delivery of service to individuals who have epilepsy or other seizure-related disorders? _____

10. What recommendations do you have to address these seizure-related difficulties?

11. General Description of Service indicated in Number 2 Above: (use additional pages if necessary) _____

38

ATTACHMENT F

Survey: Daily Living Needs in Kansas - 1988

Surveys were sent to agencies across the state to determine the availability of services for individuals dealing with epilepsy provided through non-governmental agencies. Sixty-five surveys (36%) were returned and completed with nine of the respondents not currently serving persons with epilepsy and other seizure-related disorders.

Housing was one of the most frequently reported service areas cited by agencies surveyed. A total of 33% of the survey respondents indicated that some type of housing assistance was provided to persons with epilepsy. While respite care has been an area of need as reflected by consumer reports (Epilepsy-Kansas, 1987), it was reportedly provided by only 3% of survey respondents. In addition to living arrangements, more services are needed.

Many services are offered but this discussion will deal with public, provider and consumer awareness issues. Specifically, these include: information and referral; community and professional technical assistance; peer and other counseling; and public education. A summary of the data collected for these areas follows:

	TOTAL RESPONSES	RANGE IN # SERVED	MEAN # SERVED
	-----	-----	-----
INFORMATION & REFERRAL	38	1 - 375	42
COMMUNITY, PROFESSIONAL/ TECHNICAL ASSISTANCE	21	3 - 249	35
PEER/OTHER COUNSELING	29	1 - 249	23
PUBLIC EDUCATION	14	2 - 249	37

Other services mentioned included psychiatric treatment and counseling, educational services for persons with mental retardation and parent counseling.

As part of the same survey, agencies were asked what difficulties they have experienced in the delivery of services to individuals who have epilepsy or other seizure-related disorders. The responses were as follows: increased education; staff training; public ignorance; discrimination; patient acceptance of limitations; getting helpful and accurate medical information; parent acceptance; public acceptance; physician knowledge; support; and fear of or not understanding the disorder.

The following recommendations were suggested to address these seizure-related difficulties:

<u>CATEGORY</u>	<u>PERCENTAGE</u>
EDUCATION	17%
Education/information for:	
Public	7%
Teachers/educators/professionals	6%
Caregivers/staff	4%
Medical Personnel/doctors	3%
Employees	1%
EDUCATION/IN-SERVICE TRAINING, WORKSHOPS ON EPILEPSY	9%
PARENT SUPPORT GROUPS	3%

CONCLUSION AND BEGINNINGS

A final recommendation concludes this report.

RECOMMENDATION 62: The Task Force recommends that by 1990, an Advisory Board on Epilepsy should be established consisting of two neurologists, a mental health professional, two legislators (one from the House and one from the Senate), a consumer with epilepsy, a parent who has a child with epilepsy, and representatives from the Epilepsy Foundation of America in Kansas, an employer, the State Department of Education, local school districts (nurse or a counselor), the Department of Social and Rehabilitation Services (Vocational Rehabilitation), the Department of Health and Environment, and the Department of Revenue (Division of Motor Vehicles). (ADMINISTRATIVE)

This multidisciplinary Advisory Group of Experts on Epilepsy should work with state agencies and organizations to address the recommendations and to help translate this plan into action. This Advisory Board could be the focus of new beginnings in Epilepsy for Kansas.

REFLECTIONS BY THE CHAIR

Task Force members dedicated their own time and talents to the objectives of the legislative mandate. A decade of data accumulation toward such an effort was already available, including that developed by the Federal Commission and follow-up planning by the Epilepsy Foundation of America, numerous state plans, and the foresightedness of several groups and individuals actively involved in the state epilepsy programs. The support, assistance, and guidance of the Department of Health and Environment was invaluable in completing this report. The work of the Legislative Interim Committee and the State Affiliates of the Epilepsy Foundation of America essentially provided the framework upon which to build. The Task Force members were a model of cooperation, coordination, prioritizing and planning despite personal hardships. This was a unique group, a unique cooperation and a unique coordination. State agencies were prompt and thorough in the provision of requested information with an amazingly high response rate.

Surveys were returned with far more information than could possibly be included in this report. The amazing fact is that there was a readily apparent consensus as to needs and program approaches. Everything fell together suggesting that the time was ripe for this effort.

It was the fortunate combination of individuals and events that enabled the Task Force to accomplish its goals. Many would not have been able to accomplish as much within the existing restraints. Kansas had awareness and dedication. This report stands as a tribute to the efforts of all involved and as a witness to the many potentially solvable needs.

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APPENDIX

SENATE BILL No.

AN ACT creating the task force on epilepsy and other seizure-related disorders; providing for the powers, duties and functions thereof.

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

Section 1. (a) There is hereby created the task force on epilepsy and other seizure-related disorders, hereinafter referred to as the task force, which shall consist of the following members: (1) Not more than eight members appointed by the secretary of health and environment; (2) one member appointed by the president of the senate; (3) one member appointed by the speaker of the house of representatives; (4) one member appointed by the minority leader of the senate; and (5) one member appointed by the minority leader of the house of representatives. Individuals appointed to the task force shall include representatives of private organizations involved in assisting epileptic persons or persons suffering from other seizure-related disorders and their families, persons licensed to practice medicine and surgery who have expertise in the field of epilepsy and other seizure-related disorders, educational professionals knowledgeable in the field of epilepsy or other seizure-related disorders, providers of services to epileptic individuals or individuals suffering from other seizure-related disorders, parents of epileptic individuals or individuals suffering from other seizure-related disorders and representatives of state and local government agencies. Of the members appointed by the secretary of health and environment, not more than two such members shall be providers of health care services.

(b) The members of the task force shall be appointed for terms which shall expire upon the date of expiration of this act under section 4. Upon the vacancy of a position on the task force, the person appointing the member whose position is vacant, or the successor to the position of the person appointing such member, shall appoint a person to fill such vacancy.

(c) The first person appointed by the secretary of health and environment shall call the first meeting of the task force and shall serve as temporary chairperson of the task force until a chairperson is elected. The task force shall elect a chairperson and vice-chairperson from among the members of the task force. The task force shall meet on the call of the chairperson or upon the request of a majority of all the members of the task force. A majority of all the members of the task force shall constitute a quorum.

Sec. 2. (a) The task force shall conduct a study of the needs of epileptic individuals and individuals suffering from other seizure-related disorders and the resources available to such persons and shall develop a plan for meeting the needs of such individuals and for coordinating the utilization of available resources in meeting these needs.

(b) The task force shall prepare and submit to the governor and the legislature its report and plan on or before December 31, 1988.

(c) The secretary of health and environment shall provide staff assistance and clerical services to the task force. Other state agencies shall cooperate with the task force by providing information and other assistance as may be helpful to the task force in carrying out its duties under this act.

Sec. 3. The members of the task force attending meetings of such task force, or attending a subcommittee meeting thereof authorized by such task force, shall be paid mileage as provided in subsection (c) of K.S.A. 75-3223 and amendments thereto but shall not be paid compensation, subsistence allowances or other expenses as otherwise may be authorized by law. Mileage allowances paid under this section shall be from appropriations to the department of health and environment upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the chairperson of the task force or a person designated by the chairperson and the secretary of health and environment or a person designated by the secretary.

SENATE BILL No. 461—page 2

Sec. 4. The provisions of sections 1 to 4, inclusive, shall expire on December 31, 1988.

Sec. 5. This act shall take effect and be in force from and after its publication in the Kansas register.

I hereby certify that the above BILL originated in the SENATE, and passed that body

SENATE concurred in
HOUSE amendments _____

President of the Senate.

Secretary of the Senate.

Passed the House
as amended _____

Speaker of the House.

Chief Clerk of the House.

APPROVED _____

Governor.

pg 47

TASK FORCE ON EPILEPSY AND OTHER SEIZURE-RELATED DISORDERS

SURVEY OF STATE AGENCIES

Name of Agency _____

Name of Person Responding _____

Title _____ Telephone No. _____

1. Please identify a contact person in your agency to work with the Task Force on Epilepsy and Seizure-Related Disorders if questions arise. (Include title, address, and telephone number.)

2. Does your agency have any of the following relative to individuals with epilepsy or other seizure-related disorders? Please attach a copy of any item you answer "yes."

	Yes	No	Date of Implementation	Comments
Policies				
Studies				
Reports				
Rules and Regulations				
Programs (Specify)				
Services (Specify)				
Other (Specify)				

3. Are you planning to develop any of the above? Yes _____ No _____

If yes, when? _____

If yes, attach a description of the initiative.

Please return no later than July 15, 1988, to:

Azzie Young, Ph.D., Director
 Bureau of Maternal and Child Health
 Kansas Dept. of Health and Environment
 Landon State Office Building, 10th Floor
 Topeka, KS 66612-1290

py 4/8

APPENDIX 3

SUMMARY OF STATE AGENCY SURVEY

- Fifty-eight surveys were mailed and 49 (84%) returned.
- Of the surveys returned, 26 (53%) indicated that the agency had no specific policies, programs, services, etc. for individuals with epilepsy.

SERVICES OFFERED

<u>Category</u>	<u>Number of Agencies</u>
Policies	16
Studies	4
Reports	4
Rules and Regulations	6
Programs	10
Services	15
Others	10

- Nine state agencies indicated plans to initiate at least one of the above in the future.

HISTORY OF LEGISLATIVE ACCOMPLISHMENTS

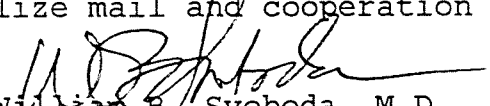
1. Two years ago, established Kansas Task Force on Epilepsy and Other Seizure-Related Disorders in order to:
 - a. Identify needs & existing services
 - b. Develop a plan of action
2. One year ago received THE PLAN and THE REFERENCE DOCUMENT
3. In the interim year, major advances in epilepsy have occurred:
 - a. Neonatal seizures differentiated from non-seizures.
 - b. Specific types of childhood epilepsy and associated learning and behavior needs, causes, diagnostics, treatments, and counseling identified, including knowledge of inheritance patterns.
 - c. Modern diagnostic techniques accepted by many insurers.
 - d. New anticonvulsant now available (Lomotrigin).
 - e. Better ways of using old anticonvulsants identified, including risks of generic forms.
 - f. Major advances in mental health approaches developing.
 - g. Major growth in surgical care of epilepsy for some. Yet for most of Kansas such knowledge services remain unknown, and unavailable. Why?

THE FINAL NEED In order to activate the facts of the Task Force Documents, the final recommendation was for the establishment of an Advisory Board on Epilepsy (recommendation 62), the key points being:

1. Consumer and provider experts from various pertinent disciplines;
2. To work with and advise various state agencies and organizations;
3. Relative to needs, potentials, and advances in services and in program development;
4. For those with epilepsy, their parents, their teachers, their employers, their spouses, their children, et. al., to include follow-up on the recommendations of the State Plan as well as subsequent developments;
5. Throughout all parts and populations of Kansas.

HOW?

1. Establish the Advisory Committee or Commission on Epilepsy administratively within one agency (such as Health and Environment) but serving all pertinent agencies;
2. Careful selection of an active and informed membership;
3. Seek to demonstrate economic approaches by:
 - a. Initially a few, efficient, meetings per year
 - b. Utilize mail and cooperation of agencies


William B. Svoboda, M.D., Child Neurologist
Chairman, Task Force on Epilepsy &
Other Seizure-Related Disorders

Attachment 9
4.0
1/24/90

January 24, 1990

Testimony Before the House Governmental Organization
Committee by Bertha McDowall Regarding
Senate Bill No. 371

Ladies and Gentlemen *

I am Bertha McDowall, Executive Director of Epilepsy*Kansas, the state affiliate of the Epilepsy* Foundation of America (EFA). I am also representing the Greater Kansas City Epilepsy League, which is the EFA affiliate serving Johnson and Wyandotte counties. Epilepsy*Kansas serves the remainder of the state.

While the bill and the cause it represents may be relatively new and unfamiliar to many of you, I can assure you that it has a long history behind it. In 1984, a major conference on epilepsy was held in Wichita to begin the process of developing a plan of action to promote and coordinate services for individuals with epilepsy and their families. A variety of needs were identified across a wide spectrum of service areas.

As the next step, representatives of Epilepsy*Kansas and the Greater Kansas City Epilepsy League met with individuals in various state departments to try to implement some changes recommended as a result of the conference. Time and time again, they were met with the comment "We would like to cooperate * we see the need, but you will have to go through the political channels before we can help * have the legislature mandate this service and we can do it * it has to be in our budget, etc." Taking this advice to heart and with the much appreciated help of Senator Daniels, an interim study was done in 1987.

After extensive testimony, The Interim Committee recommended the creation of a Task Force on Epilepsy and Related Seizure Disorders because they were convinced that while many different programs exist for persons with epilepsy and while a variety of governmental and private groups are attempting to provide services to this group, no statewide assessment of their needs had been attempted. Furthermore, no study of the availability of services had been done, no plan to address needs existed and no agency or department had been designated to coordinate or develop activities in the future.

It was the object of the Task Force to investigate the needs of and services for individuals with seizures and to develop a plan to meet these needs. I had the honor of serving on that Task Force which produced the Summary Report that each of you received.

Even a quick review of that Report should convince you that there is much to do covering a collection of governmental departments and private agencies. You will also notice that many of the recommendations are administrative in nature with little or no fiscal cost. It will not matter what the cost attached to any of the recommendations is if there is not a group to monitor and work towards their implementation. Without such a group, progress will be much slower and the momentum gathered over the last few years will be lost. That is why we strongly recommend the establishing of a commission on epilepsy to represent the needs of the estimated 24,500 to maybe 49,000 Kansans with seizure disorders.

*Attachment 10
X.O.
1/24/90*

Other states have traveled down the path that we are on * first establishing a Task Force and then developing a plan to meet the identified needs. For example, Florida has funded employment programs; Maryland has provided \$6.2 million in funding for epilepsy and other nonmental*retardation developmental disabilities; Illinois supports nine epilepsy agencies with appropriations totaling \$500,000; New York, nearly \$2 million appropriated; Ohio * \$700,000; North Carolina \$168,00; Alabama * \$73,000 and the list goes on.

We are not asking for appropriations anywhere near those that I've mentioned. We are asking for an investment of only \$15,000 for a chance to make the quality of life better for maybe 49,000 people * to help them be productive citizens. I firmly believe that by investing this \$15,000 now, we will be saving an amount many times that number as we help people become less dependent on government help.

When we were working toward the creation of the Task Force, a criticism we heard was "Just what we need, another Task Force Report to sit on the shelf to collect dust with no results * just taxpayer money wasted." You have it in your power to make that statement fact or fiction. It was never our intent to produce a report just to produce a report * the process was long and sometimes exhausting but the possibility of improving the lives of so many people made it worthwhile. Please let the process continue with the commission on epilepsy.

Thank you

Mark D. Elmore
13640 S. Locust Street
Olathe, Kansas 66062
913-764-5439

1/24/90

Chairman Walker and Committee Members,

Thank you for the opportunity to visit with your committee in regards to the efforts underway in trying to establish an Advisory Board on Epilepsy for the state of Kansas. I, like many others, for many years have been involved in efforts to educate and inform others of the difficulties persons with epilepsy face in their day to day lives. My involvement stems from a professional and personal awareness of these needs for over twenty years.

I am extremely pleased that your committee has brought this issue up for discussion and debate!

Over the past twenty three years, as a professional working in the field of service to persons with a variety of disabilities, I have witnessed the impact a seizure disorder can have on individuals and their families. On a much more personal note I have been by my daughter's side over the past sixteen years as she has gone through the many facets of growing up with a seizure disorder. I have witnessed many public reactions, both positive and negative of her having seizures in public places. My wife and I have experienced the struggle that not only our daughter Tracie has had in educational settings, but the struggles of many other students as well. We have been active advocates for our daughter and others in many areas.

It was my pleasure to serve on the Kansas Task Force On Epilepsy and other Seizure-Related Disorders group in 1988 in preparing the report that was submitted to the Governor and Legislature in April of 1989. The positive efforts of the task force are now starting to show beyond the valuable information generated to help families, children, and adults who are handicapped by epilepsy and the consequences of epilepsy. While on the task force my thoughts were reinforced that we in Kansas need to have some state coordination group to focus public attention to what can be done in a positive way to help these special Kansas citizens. The many complications of service delivery systems, complications of receiving appropriate medical care, and the complications of leading full and productive lives are generally not understood by those not directly affected.

In looking at the need for some coordination group in our state, it became obvious that many various state departments have an impact on the lives of persons with epilepsy. Yet, there is no central group that could help coordinate the provision of simple and cost effective links between agencies for the benefit of these persons. Kansans need your committee's help in recommending that a multidisciplinary Advisory Group of Experts on Epilepsy be established and funded to focus efforts towards new beginnings in Epilepsy for Kansas.

Cordially


Mark D. Elmore

Attachment 11
L. O.
1/24/90

House Governmental Organization Committee

January 24, 1990 - 9:00 a.m.

Madam or Mr. Chair:

My name is Jennifer Lattimore and I am a research associate with the Research & Training Center on Independent Living within the Bureau of Child Research at the University of Kansas in Lawrence. My background and specialty area is in setting up environments that facilitate the delivery of services to persons with developmental and other disabilities, including epilepsy. Over the past fifteen years, I have worked within numerous human service settings all over the country, including settings within the states of Alaska, West Virginia, North Carolina, Georgia, Oregon, and of course, Kansas.

Last year, I had the honor of being appointed to the State Task Force on Epilepsy and Other Seizure-Related Disorders. My participation on this Task Force included helping develop and summarize the results of a statewide survey on needs and services for persons with epilepsy and seizure-related disorders. I have had a chance to hear parent, provider, and consumer testimony on issues and concerns. Auto licensure, insurance, and advocacy issues have been reviewed in depth. My understanding of the issues and problems that face persons with epilepsy and seizure-related disorders in the state of Kansas has greatly increased. As a result of my task force participation and general background, I am here today to speak in support of Senate Bill 371.

The State Task Force was charged with: 1) conducting a study of needs, 2) identifying available resources, and 3) developing a plan of action. The task force identified 29 initial areas of need and made a total of 62 recommendations. Each of the 62 recommendations were summarized by: 1) primary agency, 2) timelines for implementation, and 3) type of enactment (i.e., administrative, fiscal or statutory change).

The task force's final report contains a well defined plan of action for implementing the 62 recommendations. However, this plan of action starts with Recommendation # 62:

"The task force recommends that by 1990, an Advisory Board on Epilepsy should be established consisting of two neurologists, a mental health professional, two legislators (one from the House and one from the Senate), a consumer with epilepsy, a parent who has a child with epilepsy, and representative from the Epilepsy Foundation of America in Kansas, an employer, the State Department of Education, local school districts (nurse or a counselor), the Department of Social and Rehabilitation Services (Vocational Rehabilitation), the Department of Health and Environment, and the Department of Revenue (Division of Motor Vehicles)."

Attachment 12
G.O.
1/24/90

Recommendation # 62 is addressed by Senate Bill No. 371. Senate Bill No. 371 proposes establishing a commission on epilepsy that would, "... make recommendations to the governor, secretary of health and environment and legislature concerning the implementation of the findings and recommendations of the task force on epilepsy and other seizure-related disorders..." This Bill is important for a number of reasons.

The primary importance of establishing a commission on epilepsy will be to identify a group of people responsible for implementing the task force's plan of action. This commission should consist of persons with an understanding of the state needs, state services, task force recommendations, specific issues related to seizure disorders (e.g., licensure, insurance, advocacy), and/or problems related to living with epilepsy. This commission can assist state agencies by: 1) interpreting task force recommendations, 2) pointing out areas of service need, 3) suggesting methods to eliminate duplication of effort or services, and 4) identifying additional resources. Further, the proposed composition of the commission ensures that recommendations are addressed from a consumer and consumer family perspective as well as the more traditional professional perspectives.

The State Task Force has developed an initial plan to address the varied needs of persons with epilepsy and seizure-related disorders. A State Commission on Epilepsy and Other Seizure-Related Disorders could put this plan into action.

I would be glad to answer any questions you might have.

pg 2



State of Kansas

Mike Hayden, Governor

Department of Health and Environment

Division of Health

Stanley C. Grant, Ph.D., Secretary

Landon State Office Bldg., Topeka, KS 66612-1290

(913) 296-1343
FAX (913) 296-6231

Testimony Presented to
Committee on House Governmental Organization

by

The Kansas Department of Health and Environment

SB 371

Services provided to the residents of Kansas under twenty-one years of age through Services for Children with Special Health Care Needs (SHS) focus on prior authorized medical specialty services. Diagnostic services are available for any individual under the age of twenty-one suspected to have a severe handicap, disability or chronic disease. Treatment services are limited to those individuals with a medically eligible condition and whose families meet the financial guidelines of the program. Medically eligible conditions, the method used to determine financial eligibility, and other information pertaining to the program activities are found in KAR 28-4-400 through 28-4-408. At this time, the diagnosis of seizures is medically eligible through SHS.

Seizures were added to the list of medically eligible conditions for SHS in 1978, but were deleted in 1980 because the budget was insufficient to absorb the cost associated with this coverage. The 1984 Legislature appropriated \$30,000 to reinstate seizure services and determine the future need. Legislative intent was that a pediatric seizure clinic be established in Wichita to augment the existing services in Kansas City. In FY 85, additional services were made available. These services included laboratory tests, x rays and medications.

A multidisciplinary team consisting of a pediatric neurologist, psychologist and nurse/coordinator began seeing patients at the University of Kansas School of Medicine-Wichita in December, 1984. Several meetings were held with members of the health care delivery team in Wichita to establish a permanent place for a multidisciplinary clinic. Beginning in the summer of 1986, the

Attachment 13
G.O.
1/24/90

Charles Konigsberg, Jr., M.D., M.P.H.,
Director of Health
(913) 296-1343

James Power, P.E.,
Director of Environment
(913) 296-1535

Lorne Phillips, Ph.D.,
Director of Information
Systems
(913) 296-1415

Roger Carlson, Ph.D.,
Director of the Kansas Health
and Environmental Laboratory
(913) 296-1619

SB 371

multidisciplinary clinic site was established at the private office of Dr William Svoboda in Wichita. This clinic is currently held one-half day per month. Other services are available as needed to meet the needs of the individual. Professionals, other than the team members, are paid on a fee for service basis.

In Kansas City, a contract was developed with the Department of Pediatrics, KUMC, to provide a multidisciplinary clinic which meets two half days per month. The professionals in the clinic include a pediatric neurologist, counselor/educator, social worker and clinic coordinator. Other services are available as needed to meet the needs of these individuals through the Children's Rehabilitation Unit at KUMC.

The following table shows the increase in expenditures for the seizure program from FY 85 to FY 87. FY 88 and 89 data is not currently available. Factors contributing to the increase in the average amount paid per child included the increased use of magnetic resonance imaging, increase in medical care costs, coverage of medications in FY 86 and FY 87 and the increase in the number of children without any other third-party payment source.

	FY 85	FY 86	FY 87
Unduplicated number of children	207	269	355
Total amount of dollars spent	\$9,550	\$31,008	\$44,596
Average amount per child	\$46	\$115	\$125

The Kansas Department of Health and Environment supports in concept the establishment of a Commission on Epilepsy, however, does not support this bill as funding was not included in the Governor's Budget for the Department of Health And Environment.

Testimony presented by Cassie Lauver, ACSW, Director
Services for Children with Special Health Care Needs
Kansas Department of Health and Environment
January 24, 1990

Kansas Advocacy & Protective Services, Inc.



Suite 2, the Denholm Bldg.
513 Leavenworth
Manhattan, KS 66502
(913) 776-1541

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Wichita

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Topeka

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Topeka

Liaison to the Governor
Jose A. de la Torre

Executive Director
Joan Strickler

TO: The House Committee on Governmental
Organization

Representative Thomas Walker, Chairperson

FROM: Kansas Advocacy and Protective Services, Inc.
R. C. Loux, Chairperson

RE: S. B. 371

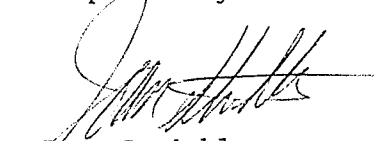
DATE: January 24, 1990

KAPS assists disabled children and adults in gaining access to the rights and services to which they are entitled. We fulfill the protection and advocacy requirements of P. L. 94-103, as amended, the Developmental Disabilities Act; and P. L. 99-319, as amended, the Protection and Advocacy for Mentally Ill Individuals Act. KAPS is a private, nonprofit corporation created specifically to serve this role in Kansas. We have been serving the state since 1977.

Through our work we became aware of many issues and problems that affect the lives of persons with disabilities - some affect most or many people and some are unique to specific handicapping conditions.

A Commission on Epilepsy can help to assure that the unique needs of persons with epilepsy and other seizure disorders are considered and addressed in Kansas. I support the establishment of such a Commission which could offer the information and recommendations needed to assist elected officials and public and private service providers to address problems and needs of Kansans with seizure disorders.

Respectfully Submitted,


Joan Strickler
Executive Director

KAPS has been charged with developing systems of advocacy and protective services in Kansas relevant to the provisions of Sec. 113 of P.L. 94-103, as amended; the Developmental Disabilities Services and Facilities Construction Act, and P.L. 99-319, the Protection and Advocacy for Mentally Ill Individuals Act.

Attachment 14
H.O.
1/24/90