

MINUTES OF THE SENATE WAYS AND MEANS COMMITTEE

The meeting was called to order by Chairman Dwayne Umbarger at 10:30 A.M. on March 7, 2008, in Room 123-S of the Capitol.

All members were present except:

Senator Carolyn McGinn - excused
Senator Chris Steineger - excused

Committee staff present:

Jill Wolters, Senior Assistant, Revisor of Statutes
Alan Conroy, Director, Kansas Legislative Research Department
Kristen Clarke Kellems, Assistant Revisor of Statutes
Amy Deckard, Kansas Legislative Research Department
Audrey Dunkel, Kansas Legislative Research Department
Reed Holwegner, Kansas Legislative Research Department
J. G. Scott, Kansas Legislative Research Department
Jarod Waltner, Kansas Legislative Research Department
Melinda Gaul, Chief of Staff, Senate Ways & Means
Mary Shaw, Committee Assistant

Conferees appearing before the committee:

Jane Rhys, Ph.D., Executive Director, Kansas Council on Developmental Disabilities
Gina Ervay, Chair fo the Kansas Respite Coalition
Jessica Smith
Austin Hansen
Beth Baldrige
Duane Smith
Mary Warren

Others attending:

See attached list.

Copies of the Kansas Legislative Research Department Budget Analysis Report for FY 2008 and FY 2009 were available to the committee.

Subcommittee reports on:

Kansas Department on Aging (Attachment 1)

Subcommittee Chairwoman Jean Schodorf reported that the subcommittee on the Kansas Department on Aging concurs with the Governor's recommendation in FY 2008 and concurs with the Governor's FY 2009 recommendation with adjustments. Additional information was provided by Staff titled, Kansas Department on Aging, FY 2009 Enhancements (Attachment 2).

Senator Taddiken moved, with a second by Senator Wysong, to amend the subcommittee report on the Kansas Department on Aging, in FY 2009, regarding Item No. 7, to draft a letter to the federal government regarding the Committee's concern related to targeted case management reimbursement, including the elimination of reimbursement for windshield time and request introduction of a resolution expressing the same concerns. Motion carried on a voice vote.

Senator Emler moved, with a second by Senator Teichman, to amend the subcommittee report on the Kansas Department on Aging, in FY 2009, regarding Item No. 2, to add \$174,000 from special revenue funds for eleven replacement vehicles and four additional vehicles. Motion carried on a voice vote.

Senator V. Schmidt moved, with a second by Senator Betts, to amend the subcommittee report on the Kansas Department on Aging, in FY 2009, regarding Item No. 4, to add \$2,495,000, including \$1.0 million from the

CONTINUATION SHEET

MINUTES OF THE Senate Ways and Means Committee at 10:30 A.M. on March 7, 2008, in Room 123-S of the Capitol.

State General Fund, to expand Home and Community Based Services for the Frail Elderly (HCBS/FE) waiver regarding attendant care services. Motion carried on a voice vote.

Senator V. Schmidt moved, with a second by Senator Emler, to amend the subcommittee report on the Kansas Department on Aging in FY 2009, regarding Item No. 9, to get the protected income level (PIL) numbers from the affected agencies to increase the PIL to that level and consider at Omnibus. Motion carried on a voice vote.

Senator Schodorf moved, with a second by Senator Betts, to adopt the subcommittee budget report on the Kansas Department on Aging in FY 2008 and FY 2009 as amended. Motion carried on a voice vote.

Kansas Department of Revenue (Attachment 3)

Subcommittee Chairwoman Jean Schodorf reported that the subcommittee on the Kansas Department of Revenue concurs with the Governor's recommendation in FY 2008 with notations and concurs with the Governor's FY 2009 recommendation with adjustments and notations.

Senator Schodorf moved, with a second by Senator Kelly, to amend the subcommittee report on the Kansas Department of Revenue to add language regarding thanking the agency for the services provided to East and Southeast Kansas concerning the flooding. Motion carried on a voice vote.

Senator Schodorf moved, with a second by Senator Kelly, to amend the subcommittee report on the Kansas Department of Revenue to consider Item No. 5, FY 2009, regarding Implementation of 2007 SB 9--Real I.D. at Omnibus. Motion carried on a voice vote.

Senator Schodorf moved, with a second by Senator Kelly, to amend the subcommittee report on the Kansas Department of Revenue and review the Fee Fund balances at Omnibus. Motion carried on a voice vote.

Senator Emler moved, with a second by Senator Wysong, to amend the subcommittee report on the Kansas Department of Revenue regarding Item No. 4, in FY 2009, and add the vehicles out of special revenue funds and consider the remainder at Omnibus. Motion carried on a voice vote.

Senator Schodorf moved, with a second by Senator V. Schmidt, to adopt the subcommittee budget report on the Kansas Department of Revenue in FY 2008 and FY 2009 as amended. Motion carried on a voice vote.

Chairman Umbarger welcomed Jane Rhys and Gina Ervay who presented a briefing and background on Lifespan Respite Care:

Jane Rhys, Ph.D., Executive Director, Kansas Council on Developmental Disabilities, mentioned that they support **SB 657** because they see the need for families to have access to a few hours a week of respite care (Attachment 4). Ms. Rhys explained that last Fall she had a former Nebraska State Senator contact her about a lifespan respite care bill that was introduced and passed in Nebraska.

Gina Ervay, Chair of the Kansas Lifespan Respite Coalition, mentioned that they support **SB 657** to fund a statewide respite study as a first step toward the development of a coordinated lifespan respite program for caregivers (Attachment 5). Ms. Ervay addressed the impact on caregivers across Kansas, respite benefits families and is cost saving, the need for respite care and described how the lifespan respite care program would help.

Chairman Umbarger opened the public hearing on:

SB 657--Creating the Lifespan Respite Care Program

Staff briefed the committee on the bill.

CONTINUATION SHEET

MINUTES OF THE Senate Ways and Means Committee at 10:30 A.M. on March 7, 2008, in Room 123-S of the Capitol.

The Chairman welcomed the following conferees:

Jessica Smith, caregiver from El Dorado, Kansas, testified as a proponent on **SB 657** ([Attachment 6](#)). She explained her life experiences in being young parents and having a disabled child.

Austin Hansen, testified in support of **SB 657** and on behalf of the many disabled Kansas that do not have a voice ([Attachment 7](#)). Mr. Hansen explained that he has Cerebral Palsy and has been totally dependent twenty-four hours a day Attendant Care for thirty-four years. Mr. Hansen noted that he was asking for help to improve lives because you never know when it may be part of your life.

Beth Baldrige spoke in support of **SB 657** ([Attachment 8](#)). Ms. Baldrige spoke as a caregiver to her 55 year old sister-in-law who has lupus and is a two-time stroke survivor with limited speech and cognitive abilities. This would provide Ms. Baldrige, as a caregiver, some normalcy and freedom to nourish the other relationships left behind (grandchildren, husband, children) when life changed so suddenly and unexpectedly.

Duane Smith, Wichita, testified as a proponent of **SB 657** ([Attachment 9](#)). Mr. Smith has been caring for his wife with Alzheimer's for ten years and he noted that he is a 24/7 caregiver, but is able to put his full strength into the job because he gets respite care. Caregivers are able to keep their loved one at home longer, if they do have respite care and urged passage of the bill.

Mary Warren, Wichita, spoke in support of **SB 657** ([Attachment 10](#)). Ms. Warren described her caregiving experiences with adopting two sibling children with the youngest child having mental health needs. She urged passage of the bill so that someday they and other families will have the respite relief they need so they can keep their child at home where the child belongs.

Written testimony was submitted by:

Connie Zienkewica, Executive Director, Families Together, Inc. ([Attachment 11](#))

Judy Weigel, Executive Director, Independent Living Resource Center ([Attachment 12](#))

Rebecca Kimbell, National Multiple Sclerosis Society ([Attachment 13](#))

Chad VonAhnen, Dir., Sedgwick County Developmental Disability Organization ([Attachment 14](#))

Kelly Evans, Executive Director, Trinity In-Home Care ([Attachment 15](#))

Rachel Mendoza Banning, Wichita ([Attachment 16](#))

Matt Fletcher, Associate Director, InterHab ([Attachment 17](#))

Questions and discussion followed with concluding remarks by Gina Ervay.

The Chairman closed the public hearing on **SB 657**.

The meeting adjourned at 12:25 p.m. The next meeting was scheduled for March 10, 2008.

**SENATE WAYS AND MEANS
GUEST LIST**


Date March 7, 2008

NAME	REPRESENTING
Katy Seensler	KDOA
Barb Coxart	KDOA
Jim Coxart	KDOR
Julie Sergeant	Univ of KS / School of Social Welfare
JESSICA SCHWARTZ	\$
Jennifer DeYoung	KACIL
Ace Maria Hyslop	SKIL
Connie Huesels	KMC
Mary Warren	ROCKO
Jessica Smith	ROCKO
Gina Ervay	Kansas Lifespan Respite Coalition
Jane Rhys	KLDD
Pat Coakley	KCOE
Prudy A. Miller	Alzheimer's Association
Marion Knappinberger	Alzheimer's Association
Marilyn E. Thomas	Jayhawk Area Agency on Aging
Celia Keedel	Alzheimer's Assoc. of Central-Western KS
Suane Smith	Alzheimer's people / caregivers
Pete Baldridge	KS Lifespan Respite Coalition
Kelly Evans	KS Lifespan Respite Coalition
Austin Hanson	KS Lifespan Respite Coalition
Kathy Perron	
John Petersen	Capital Strategies

FY 2008 and FY 2009

SENATE WAYS AND MEANS SUBCOMMITTEE

Department on Aging



Senator Jean Schodorf, Chair



Senator Donald Betts



Senator Vicki Schmidt

Senate Ways and Means
3-7-08
Attachment 1

Senate Subcommittee Report

Agency: Department on Aging

Bill No. SB 655

Bill Sec. 30

Analyst: Deckard

Analysis Pg. No. Vol.1-155

Budget Page No. 35

Expenditure Summary	Agency Estimate FY 08	Governor's Recommendation FY 08	Senate Subcommittee Adjustments
Operating Expenditures:			
State General Fund	\$ 188,451,958	\$ 187,378,162	\$ 0
Other Funds	<u>288,499,663</u>	<u>286,824,502</u>	<u>0</u>
Subtotal - Operating	<u>\$ 476,951,621</u>	<u>\$ 474,202,664</u>	<u>\$ 0</u>
Capital Improvements:			
State General Fund	\$ 0	\$ 0	\$ 0
Other Funds	<u>0</u>	<u>0</u>	<u>0</u>
Subtotal - Capital Improvements	<u>\$ 0</u>	<u>\$ 0</u>	<u>\$ 0</u>
 TOTAL	 <u><u>\$ 476,951,621</u></u>	 <u><u>\$ 474,202,664</u></u>	 <u><u>\$ 0</u></u>
 FTE Positions	 209.0	 209.0	 0.0
Non FTE Uncl. Perm. Pos.	<u>10.5</u>	<u>10.5</u>	<u>0.0</u>
TOTAL	<u><u>219.5</u></u>	<u><u>219.5</u></u>	<u><u>0.0</u></u>

Agency Estimate

The **agency** requests a revised FY 2008 budget totaling \$477.0 million, an increase of \$1.6 million, or 0.3 percent, above the amount approved by the 2007 Legislature. Requested State General Fund expenditures total \$188.5 million, an increase of \$612,515, or 0.3 percent, above the approved amount. The request would fund 209.0 FTE positions and 10.5 non-FTE positions. This is an increase of 1.0 non-FTE position from the approved amount. Major adjustments to the FY 2007 approved budget include:

- The request to transfer the balance of the Adult Care Licensure Revolving Fund of \$290,408 to the State Licensure Fee Fund, which was established by the 2007 Legislature.
- An increase of \$139,076, including \$49,539 from the State Licensure Fee Fund and the remainder from federal funds to fund two existing Health Facility Surveyor I positions, including salaries and travel.
- \$941,427 in State General Fund reappropriations from FY 2007 into FY 2008.
- \$289,519 in KSIP expenditures for technology purchases.

The remainder of the increase is attributable to changes in federal funding, including a supplemental federal Medicare appropriation of \$225,000.

Governor's Recommendation

The **Governor** recommends FY 2008 expenditures of \$474.2 million, including \$187.4 million from the State General Fund. The recommendation is a decrease of \$2.7 million, or 0.6 percent, below the agency's estimate. The decrease is attributable to: increasing shrinkage by \$400,346, including \$127,156 from the State General Fund; decreasing other operating expenditures by \$288,550, including \$135,888 from the State General Fund; increasing nursing facility expenditures by \$10,528 from all funding sources, but reducing State General Fund expenditures by \$31,000, to what was agreed to at the fall 2007 consensus caseload meeting; and decreasing expenditures for Home and Community Based Services for the Frail Elderly (HCBS/FE) waiver by \$1,931,513, including \$779,752 from the State General Fund, to reflect revised caseload estimates.

Senate Subcommittee Recommendation

The Senate Subcommittee concurs with the Governor's recommendation.

Senate Subcommittee Report

Agency: Department on Aging

Bill No. SB 658

Bill Sec. 31

Analyst: Deckard

Analysis Pg. No. Vol.1-155

Budget Page No. 35

Expenditure Summary	Agency Request FY 09	Governor's Recommendation FY 09	Senate Subcommittee Adjustments*
Operating Expenditures:			
State General Fund	\$ 197,812,264	\$ 194,735,313	\$ (1,349,172)
Other Funds	292,212,010	298,170,096	(2,503,064)
Subtotal - Operating	<u>\$ 490,024,274</u>	<u>\$ 492,905,409</u>	<u>\$ (3,852,236)</u>
Capital Improvements:			
State General Fund	\$ 0	\$ 0	\$ 0
Other Funds	0	0	0
Subtotal - Capital Improvements	<u>\$ 0</u>	<u>\$ 0</u>	<u>\$ 0</u>
TOTAL	<u><u>\$ 490,024,274</u></u>	<u><u>\$ 492,905,409</u></u>	<u><u>\$ (3,852,236)</u></u>
FTE Positions	209.0	209.0	0.0
Non FTE Uncl. Perm. Pos.	10.5	10.5	0.0
TOTAL	<u><u>219.5</u></u>	<u><u>219.5</u></u>	<u><u>0.0</u></u>

* Of the Subcommittee's recommended reductions, \$423,215, including \$279,429 from the State General Fund, is related to pay plan adjustments.

Agency Request

The **agency** requests an FY 2009 budget of \$490.0 million, an increase of \$13.1 million, or 2.7 percent, above the revised current year estimate. The request includes State General Fund expenditures of \$197.8 million, an increase of \$9.4 million, or 5.0 percent, above the revised current year estimate. The request would fund 219.5 positions, the same as the revised current year estimate. The request includes enhancement funding of \$16.5 million, including \$9.0 million from the State General Fund. Absent the enhancement requests, the request would be a decrease in FY 2009 of \$3.4 million, or 0.7 percent, from all funding sources and an increase of \$350,887, or 0.2 percent, from the State General Fund. The majority of the decrease is attributable to decreases in nursing facility expenditures, salaries and wages costs due to a one time bonus for state employees in FY 2008 that were not budgeted in FY 2009, capital outlay expenditures and grants which do not reoccur in FY 2009, partially offset by increases in Home and Community Based Services for the Frail Elderly (HCBS/FE) waiver expenditures.

Governor's Recommendation

The **Governor** recommends FY 2009 operating expenditures of \$492.9 million, including \$194.7 million from the State General Fund. The recommendation is an increase of \$18.7 million, including \$7.4 million from the State General Fund, above the Governor's FY 2008 recommendation.

The recommendation is an increase of \$2.8 million above the agency's FY 2009 request, however it is a decrease of \$3.1 million below the agency's request for State General Fund moneys.

The Governor's recommendation includes a portion of the agency's enhancement requests, specifically: the addition of \$2.5 million, including \$1.0 million from the State General Fund, to expand attendant care services and to begin providing companion services; \$1.0 million from the State General Fund to increase funding for the nutrition program; \$1.2 million, including \$461,722 from the State General Fund, to expand the Topeka Program of All Inclusive Care for the Elderly ; \$312,008 to fund surveyor positions; \$361,370, including \$232,650 from the State General Fund, for licensure and certification funding; and \$174,000 for eleven replacement vehicles and four additional vehicles. Additionally, the Governor's recommendation includes the addition of \$328,894, including \$244,810 from the State General Fund, for the recommended pay plan adjustment, the addition of \$15.5 million, including \$4.0 million from the State General Fund, for revised nursing facility caseload estimate agreed to at the fall 2007 consensus caseload meeting and makes adjustments for Federal Medical Assistance Percentages (FMAP) calculations.

Senate Subcommittee Recommendation

The Senate Subcommittee concurs with the Governor's recommendation with the following adjustments:

1. **Pay Plan Adjustments.** Delete \$423,215, including \$279,429 from the State General Fund (or all from the State General Fund, or all from special revenue funds), to remove the following pay plan adjustments recommended by the Governor. Pay plan adjustments will be considered in a separate bill.
 - a. **State Employee Pay Increases.** Delete \$ 245,384, including \$182,653 from the State General Fund, to remove the amount recommended by the Governor for the 2.5 percent base salary adjustment.
 - b. **Classified Employee Pay Plan.** Delete \$83,510, including \$62,157 from the State General Fund, to remove the amount recommended by the Governor for FY 2009 pay increases for basic vocational classes and for those employees identified as having the most disparity relative to market rate.
 - c. **Longevity Pay.** Delete \$94,321, including \$34,619 from the State General Fund to remove the amount recommended by the Governor for longevity bonus payments.
2. Delete \$174,000, all from the special revenue funds, to remove funding for eleven replacement vehicles and four additional vehicles for review at Omnibus.
3. Delete \$1,152,000, including \$461,722 from the State General Fund, for the expansion of the Topeka Program of All Inclusive Care for the Elderly by 75 slots. The Subcommittee recommends that the expansion be reviewed at Omnibus. The Subcommittee notes its support for the program and requests information regarding current year usage of this program. The Subcommittee notes that the Topeka program has not yet filled the current allotment for the program. The Subcommittee notes that this is a relatively young program and recommends review of the projected caseload for this location.

In addition, the Subcommittee requests that the addition of \$66,240, all from the State General Fund, for 24 slots to be located at a new PACE location in Kansas City, Kansas be considered at Omnibus. The funding would provide for partial year funding for the slots, which would be opened in late FY 2009. The Subcommittee notes testimony that indicates the Kansas City PACE program could eventually have enrollment of 240 in FY 2014.

4. Delete \$2,495,000, including \$1.0 million from the State General Fund, to expand Home and Community Based Services for the Frail Elderly (HCBS/FE) waiver attendant care services and begin providing companion services. The Subcommittee recommends a review of this funding at Omnibus. The Subcommittee notes testimony received indicated the addition of \$581,758, including \$236,892 would allow individuals to receive twelve hours of attendant care services per day. The HCBS/FE waiver currently limits the number of attendant care hours to eight per day. The twelve hours of attendant care and twelve hours of sleep cycle support would allow 24 hours of care per day. This action would create consistency with the home and community based services for the physically disabled and for individuals with developmental disabilities waivers.

The remaining \$1,913,242, including \$763,108 from the State General Fund, would allow companion services to be provided under the HCBS/FE waiver. The Subcommittee notes testimony that indicated that providing this service, especially for individuals who are in the beginning stages of dementia, allows individuals to remain in their homes.

5. Add \$391,979, all from the State General Fund, to fund two grants to the Kansas Foundation for Medical Care, Inc.
 - \$224,640 for Community Collaboratives which would develop and facilitate community collaborative/coalitions focused on healthcare quality improvement through increased continuity and coordination of care; and
 - \$167,339 for individualized nursing home technical assistance program to operate in select nursing facilities on a voluntary basis to improve the quality of care.

The Subcommittee notes that this would provide a second year of funding and recommends the continuation of these grants. The Subcommittee notes that the data gathered in these activities will be very useful in studies of the long-term care system in Kansas.

6. Recommend that the Subcommittee on the Department of Social and Rehabilitation Services delete the current proviso in the appropriations bill that limits the number of individuals to 80, that transition into the community under the money follows the person program. The Subcommittee notes that Kansas received a five-year \$37.0 million, money follows the person demonstration federal grant to transition individuals from institutional settings to the community, which is located in the Department of Social and Rehabilitation Services budget.

7. Review at Omnibus the addition of \$1,569,674, all from the State General Fund, to increase funding for the Area Agencies on Aging (AAAs) for services not reimbursed by either state or federal programs. This would be completed in two steps. Each of the eleven AAAs would receive a base allocation of \$60,000, for a total of \$660,000. Additionally, a formula based on \$2 per Kansan, aged 60 years or older, will be distributed to each AAA for a total of \$909,674.

The Budget Committee notes testimony that if the funding for the AAAs core services is not increased it will likely result in an increase for individuals case managers and a limited ability to reach seniors within the appropriate timeframe to prevent premature institutionalization.

The Budget Committee notes that the AAA are faced with other funding issues at the current time, including reimbursement of targeted case management services. The Subcommittee received testimony that the federal Centers for Medicare and Medicaid Services (CMS) indicated that the previous method of operation used by Kansas to provide targeted case management services was not going to be allowed in the future, and failure to change methodologies might result in federal deferrals.

Two components of this decision directly impact the AAAs, windshield time and any qualified provider. The time that employees of AAAs travel to visit elderly clients in their homes, windshield time, is no longer allowed to be submitted for reimbursement. This change is most acutely impacting AAAs operating in the rural areas of the state. In addition, the state may no longer limit targeted case management services to AAAs, instead must allow any qualified provider to perform the services. Testimony indicated that the changes to targeted case management reimbursement could potentially have a large negative impact on AAAs revenues.

The Subcommittee notes that the Secretary on Aging sent a letter to the federal Department of Health and Human Services expressing concern at the implementation of single point of entry as well as other issues with the new federal rules. This letter is included as Attachment A.

The Subcommittee requests an interim study to review the effects of the implementation of the new targeted case management rules. In addition, the Subcommittee requests that the interim study review when case management services for individuals in hospitals are reimbursed. The Subcommittee notes its concern that the current system does not support adequate coordination of care. The Subcommittee notes that this failure has the potential to require elderly individuals to enter nursing facilities if home and community based services are not organized for them prior to their return home from the hospital.

8. Review at Omnibus the addition of \$125,000, all from the State General Fund, for the United Cerebral Palsy of Kansas Assistive Technology Initiative. The Subcommittee notes that United Cerebral Palsy indicated it would be able to leverage this funding with additional private funds. Testimony received by the Subcommittee noted that the funds would allow United Cerebral Palsy to expand its services specifically for the aging population, including funding for power mobility, home modifications, lift chairs, and other technology to assist in maintaining independence.

9. The Subcommittee requests an interim study of long term care reform, including the potential for global funding of long term care, by which no one is denied service in the manner they choose. Additionally, the interim study would review states that have implemented this method, specifically Washington, Vermont, and New Jersey. Additionally, the interim study should consider implementation of a global home and community based service waiver, that provides service regardless of labels.

The Subcommittee also requests an interim study of increasing the protected income level (PIL) and review automatically increasing the PIL when the federal Social Security Administration grants a cost of living adjustment. The Subcommittee notes that this increase would affect three separate agencies and should be reviewed in its totality.

10. The Subcommittee notes its support of the request in the Department of Administration's budget to add funding and two additional FTE positions for the Long Term Care Ombudsman's office.
11. The Subcommittee notes that as of January 31, 2008 there were 148 individuals waiting for services through the Senior Care Act. The Senior Care Act is a state only funded program which provides home and community based services for those individuals over the age of 60 who have not yet exhausted their financial resources. The Budget Committee requests a review of the waiting list at Omnibus.



Kathleen Sebelius, Governor
Kathy Greenlee, Secretary
www.agingkansas.org

Via e-mail

February 1, 2008

Mr. Dennis Smith
Director of the Centers for Medicaid State Operations
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention – CMS-2237-IFC
P.O. Box 8016
Baltimore, MD 21244-8016

Attention CMS-2237-IFC

Dear Mr. Smith,

The following comments by the Kansas Department on Aging (KDOA) are in response to the Centers for Medicare and Medicaid Services' (CMS) Interim Final Rule (IFR) for Optional State Plan Case Management Services. The IFR was published in the *Federal Register* on December 4, 2007.

The KDOA is the designated state unit on aging for Kansas. In addition to administering programs under the Older Americans Act, KDOA is responsible for the administration of certain long-term care programs including the home and community based – frail elderly waiver (HCBS/FE) and the Money Follows the Person grant as it relates to institutionalized persons age 65 and older.

Section 441.18(a) – Single Point of Entry

One of the purposes of the Older Americans Act (OAA) is to encourage and assist state agencies and area agencies on aging to concentrate resources in order to develop greater capacity and foster the development and implementation of comprehensive and coordinated systems to serve older individuals. This includes facilitating access to all supportive services through a single point of entry.

The eleven area agencies on aging (AAAs) in Kansas provide comprehensive and coordinated services, including Medicaid services, by being the single point of entry and gatekeepers in their respective geographic regions for providing information, care and services to seniors. Over the past ten years, the AAAs have provided targeted case management (TCM) services to the state's HCBS/FE waiver population. Our HCBS/FE waiver is specifically designed for individuals aged 65 and older who would otherwise utilize institutionalized care to meet their long-term care needs. Having the AAAs act as the single point of entry for seniors seeking services and

providing TCM services helps reduce system fragmentation by providing excellent coordination and access to services. Moreover, the AAAs have the knowledge and expertise necessary to understand and meet the needs that are specific to older Kansans in their geographic area. Since the AAAs typically do not provide direct care services, the potential for a conflict of interest in providing TCM is not an issue. This system has served Kansas seniors very well for the past ten years.

The IFR, however, will create problems for a system that is designed to focus solely on the specific needs of the frail elderly. Gatekeeping and single points of entry do not restrict access to services. Rather, gatekeeping and single points of entry are an effective way for case managers to coordinate the services that are necessary to ensure that individuals do have access to needed services. The changes in the IFR would break down this system and create fragmentation resulting in individuals not receiving the services they need.

Section 440.169(c) – Limitations on Community Transition Programs

The IFR proposes to severely limit the amount of TCM service an individual can receive to 60 consecutive days for a covered, long-term, institutional stay of 180 days or longer and a mere 14 days for a covered institutional stay of less than 180 days. This arbitrary and unrealistic limitation on TCM will have a severe negative impact on community transition programs such as Money Follows the Person (MFP). MFP was specifically designed to assist individuals who have been in nursing facilities transition back into their communities. Individuals who have been in facilities for a long period of time will need substantial assistance to successfully transition to the community. Just finding appropriate housing is a major barrier. Many individuals no longer have homes to which they may return. Discharge planning to locate appropriate housing and home-based services for individuals with many and varied types of illnesses and disabilities could take well over 60 days. This is particularly true in more rural communities. Placing such limitations on the very service that is key to a successful transition to the community is counterproductive.

Section 441.18(c) – Restriction on Administrative Costs

Likewise, limiting the state's ability to charge TCM as an administrative cost will have a detrimental effect on all MFP transition programs. If TCM services are provided to a nursing home resident for potential discharge to the community and the resident remains in the nursing home, these services will not be reimbursed by Medicaid. It is possible that a resident can suffer an unforeseen illness or accident that will prevent the resident from transitioning as planned. The case management service that was provided nevertheless is still a medical assistance service. This places a financial burden on the TCM providers when services are delivered but not reimbursed. The restriction on billing Medicaid administrative costs along with the unrealistic limitation on TCM for community transition planning will put the states and TCM providers at risk of not being reimbursed for services rendered.

Dennis Smith
February 1, 2008
Page 3 of 3

Section 441.18(a)(5) – Single Case Manager

The IFR limiting case management services to a single Medicaid case management provider will also impair an individual's ability to receive comprehensive assessments and care planning.

Waiver participants have varied and complex needs. Case managers can not be expected to possess the broad base of knowledge that would be necessary to meet all the potential needs of all waiver participants. Limiting case management to one case manager will have the effect of limiting access to services.

The single case manager limitation is also unworkable for situations where certain services, such as mental health, are provided through managed care organizations and selective contracts. In Kansas, most individuals eligible for Title XIX services are automatically enrolled in the state's Pre-paid Ambulatory Health Plan (PAHP). Targeted Case Management is a service contained in the PAHP. Duplication may occur when a person who is enrolled in the frail elderly waiver program and working with a case manager is also auto-enrolled in the PAHP and assigned another case manager through the PAHP.

Prevention of duplication will require enormous effort on the part of the State as well as by providers. CMS has not provided states any practical suggestions on how to de-duplicate TCM services to comply with the IFR. CMS has not demonstrated that their directive can be implemented in today's health care marketplace without significant cost, disruption and negative impact on beneficiaries. At a minimum, we know that our claims payment system will need to be reprogrammed. In addition, community providers will need significant re-training and also stand to lose revenue.

We appreciate this opportunity to comment on the IFR and look forward to working with CMS on devising a manageable solution to TCM.

Sincerely,



Kathy Greenlee
Secretary

c: Frank Burns, AoA
AAA Directors
Senator Brownback
Senator Roberts
Congresswoman Boyda
Congressman Moran
Congressman Moore
Congressman Tiahrt

Kansas Department on Aging FY 2009 Enhancements

Enhancement	Agency Request			Governor's Recommendation			Senate Subcommittee Adjustments		
	SGF	All Funds	FTE	SGF	All Funds	FTE	SGF	All Funds	FTE
Expand Attendant Care Services/ Companion Services	\$ 2,414,394	\$ 5,929,258	0.0	\$ 1,000,000	\$ 2,495,000	0.0	(1,000,000)	(2,495,000)	0.0
Nutrition Program increase for federal minimum wage	1,007,672	1,007,672	0.0	1,007,672	1,007,672	0.0	-	-	0.0
Core funding for AAAs	1,569,674	1,569,674	0.0	-	-	0.0	Consider at Omnibus		
HCBS/FE rate increase	519,950	1,276,891	0.0	-	-	0.0	-	-	0.0
HCBS/FE maintainance of effort	1,597,932	3,924,195	0.0	-	-	0.0	-	-	0.0
Senior Care Act caseload funding	726,000	726,000	0.0	-	-	0.0	-	-	-
PACE expansion	792,818	1,947,000	0.0	461,722	1,152,000	0.0	(461,722)	(1,152,000)	-
Funding for health facility surveyor positions	-	312,008	0.0	-	312,008	0.0	-	-	0.0
Licensure and Certification program funding	232,650	361,370	0.0	232,650	361,370	0.0	-	-	0.0
Purchase of Vehicles	148,329	232,000	0.0	-	174,000	0.0	-	(174,000)	-
Grant to Kansas Foundation for Medical Care, Inc	-	-	0.0	-	-	0.0	391,979	391,979	0.0
Grant to United Cebra Palsy	-	-	0.0	-	-	0.0	Consider at Omnibus		
TOTAL	\$ 9,009,419	\$ 17,286,068	0.0	\$ 2,702,044	\$ 5,502,050	0.0	\$ (1,069,743)	\$ (3,429,021)	0.0

Senate Subcommittee
 3/1/09
 Attachment d

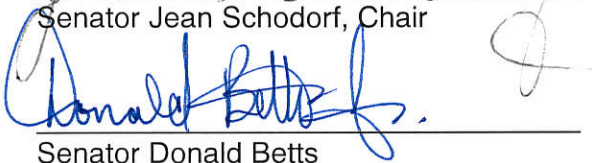
FY 2008 and FY 2009

SENATE WAYS AND MEANS SUBCOMMITTEE

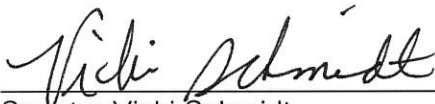
Department of Revenue



Senator Jean Schodorf, Chair



Senator Donald Betts



Senator Vicki Schmidt



Senator Ruth Teichman

Senate Ways and Means
3-7-08
Attachment 3

Senate Subcommittee Report

Agency: Department of Revenue **Bill No.** SB 655

Bill Sec. 10

Analyst: Holwegner

Analysis Pg. No. Vol. II-1170

Budget Page No. 335

Expenditure Summary	Agency Estimate FY 08	Governor's Recommendation FY 08	Senate Subcommittee Adjustments
Operating Expenditures:			
State General Fund	\$ 21,572,916	\$ 21,572,916	\$ 0
Other Funds	75,774,001	78,216,001	0
Subtotal - Operating	\$ 97,346,917	\$ 99,788,917	\$ 0
Capital Improvements:			
State General Fund	\$ 0	\$ 0	\$ 0
Other Funds	0	0	0
Subtotal - Capital Improvements	\$ 0	\$ 0	\$ 0
TOTAL	\$ 97,346,917	\$ 99,788,917	\$ 0
FTE Positions	1,146.0	1,146.0	0.0
Non FTE Uncl. Perm. Pos.	15.5	15.5	0.0
TOTAL	1,161.5	1,161.5	0.0

Agency Estimate

The Department of Revenue requests a revised FY 2008 budget totaling \$97,346,917. This includes \$21,572,916 from the State General Fund, \$2,077,619 from federal funds, and \$73,696,382 from other funds. The revised budget request is an increase of \$1,887,152, or 2.0 percent, above the amount approved by the 2007 Legislature. Most of the increase can be attributed to moneys either re-appropriated or additional funds made available to the agency since the last legislative session. No supplementals have been requested. The request would fund 1,161.5 positions including 1,146.0 FTE positions and 15.5 non-FTE unclassified permanent positions, the same level as the 2007 Legislature approved.

Governor's Recommendation

The Governor recommends \$99,788,917, including \$21,572,916 from the State General Fund, for FY 2008 operating expenditures. The recommendation is an all funds increase of \$4,329,152, or 4.5 percent, above the approved amount. The recommendation is an all funds increase of \$2,442,000, or 2.5 percent, above the amount estimated by the agency. This difference between the agency's revised request and the Governor's recommendation is due to revised revenue estimates for the Special County Mineral Production Fund.

Senate Subcommittee Recommendation

The Senate Subcommittee concurs with the Governor's recommendation with the following notations:

1. The Subcommittee notes that collection and compliance activities for the Department of Revenue have improved over the last fiscal year. In particular:
 - a. **Alcohol and Tobacco.** The compliance rates for alcohol and tobacco sales were 72.0 percent and 88.0 percent, respectively, during FY 2007.
 - b. **Drug Tax Collections.** Tax collections due to the seizure of illegal drugs increased from \$800,000 to just over \$1,000,000 in FY 2007.
 - c. **Tax Collections.** In FY 2007, a total of approximately \$7.9 billion was collected by the agency, and over \$1.0 billion was distributed to local units of government.
2. The Subcommittee commends the agency for the service it provided Greensburg and Kiowa County. After the tornado's damage was incurred, the agency's fast response and presence in the community allowed people to obtain vehicle records and tax documents so that they could begin recovering from the disaster.

Senate Subcommittee Report

Agency: Department of Revenue **Bill No.** SB 658

Bill Sec. 21

Analyst: Holwegner

Analysis Pg. No. Vol. II-1170

Budget Page No. 335

Expenditure Summary	Agency Request FY 09	Governor's Recommendation FY 09	Senate Subcommittee Adjustments*
Operating Expenditures:			
State General Fund	\$ 21,363,340	\$ 21,367,861	\$ (1,171,562)
Other Funds	79,327,903	78,415,564	(1,783,676)
Subtotal - Operating	\$ 100,691,243	\$ 99,783,425	\$ (2,955,238)
Capital Improvements:			
State General Fund	\$ 0	\$ 0	0
Other Funds	0	0	0
Subtotal - Capital Improvements	\$ 0	\$ 0	\$ 0
 TOTAL	 \$ 100,691,243	 \$ 99,783,425	 \$ (2,955,238)
 FTE Positions	 1,146.0	 1,146.0	 0.0
Non FTE Uncl. Perm. Pos.	15.5	15.5	0.0
TOTAL	1,161.5	1,161.5	0.0

*Includes a reduction of \$2,457,666, including \$783,490 from the State General Fund, for the removal of the Governor's recommended pay plan adjustments.

Agency Request

The Department of Revenue requests an FY 2009 budget of \$100,691,243. This includes \$21,363,340 from the State General Fund and \$79,327,903 from all other funds. This is an increase of \$3,344,326, or 3.4 percent, above the revised current year estimate. Requested State General Fund expenditures are decreased by \$209,576, or 1.0 percent, below the revised budget. The request would finance 1,161.5 positions (including 15.5 non-FTE unclassified permanent positions), the same staffing level as approved for the current fiscal year. The request includes enhancement funding of \$4,948,556, with \$420,572 proposed to come from the State General Fund.

Governor's Recommendation

The Governor recommends FY 2009 operating expenditures of \$99,783,425, including \$21,367,861 from the State General Fund. This is a decrease of \$5,492 below the FY 2008 recommendation. The FY 2009 recommendation is a decrease of \$907,818, or 0.9 percent, below the amount requested by the agency. The Governor recommends \$1,497,572, including \$388,072 from the State General Fund, for enhancements. Additionally, the Governor recommends an increase of expenditures (\$2,239,000) from the Special County Mineral Production Fund. The

recommendation would finance 1,161.5 positions (including 15.5 non-FTE unclassified permanent positions), the same staffing level as approved for the current fiscal year.

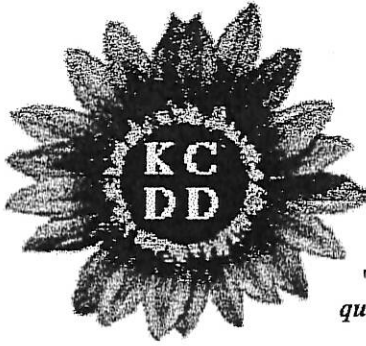
Senate Subcommittee Recommendation

The Senate Subcommittee concurs with the Governor's recommendation with the following adjustments and notations:

1. **Pay Plan Adjustments.** Delete \$2,457,666, including \$783,490 all from the State General Fund, to remove the following pay plan adjustments recommended by the Governor. Pay plan adjustments will be considered in a separate bill.
 - a. **State Employee Pay Increases.** Delete \$1,198,765, including \$382,863 from the State General Fund, to remove the amount recommended by the Governor for the 2.5 percent base salary adjustment.
 - b. **Classified Employee Pay Plan.** Delete \$605,401, including \$189,127 from the State General Fund, to remove the amount recommended by the Governor for FY 2009 pay increases for basic vocational classes and for those employees identified as having the most disparity relative to market rate.
 - c. **Longevity Pay.** Delete \$653,500, including \$211,500 from the State General Fund, to remove the amount recommended by the Governor for longevity bonus payments.
2. **Increased Tax Fraud Investigations.** Delete \$351,572 from the State General Fund for the salaries and wages for four civil and one criminal fraud investigators. According to the agency, many new tax fraud schemes are increasingly complex. The agency hopes to increase the investigation of fraudulent claims from 500 to 7,000. The Subcommittee recommends that this issue be favorably considered during Omnibus after the consensus revenue estimates for the State General Fund have been revised.
3. **Vehicle Database Integration.** The Subcommittee notes that the Governor recommends \$1,000,000 from the Vehicle Operating Fund to begin the initial phase of the modernization and integration of the Vehicle Information Processing System (VIPS), the Kansas Driver's License System (KDLS), and the Kansas Vehicle Inventory System (KVIS). The software for the three database systems is 20, 17, and 14 years old, respectively. According to the agency, these systems do not provide consistent, real-time updates. Users, such as law enforcement and county treasurer offices, have to manually integrate data from these three databases in order to accomplish their respective work. The agency estimates the total cost to be \$40,155,966 over 5 years. The Subcommittee also notes that HB 2890 (currently in House Committee on Appropriations), as amended, would authorize a \$4 surcharge on most vehicle registrations that would be collected over four calendar years, from January 1, 2009, to January 1, 2013. The Subcommittee recommends that this issue be considered during Omnibus, should HB 2890 pass in some form.

4. **Vehicles.** Delete \$146,000, which includes \$36,500 from the State General Fund and \$109,500 from the Division of Vehicles Operating Fund, for the acquisition of ten vehicles. The Subcommittee recommends this issue be considered further during Omnibus.

5. **Implementation of 2007 SB 9—Real I.D.** The Subcommittee notes the agency is in the process of implementing the provisions of 2007 SB 9, which will improve the security of driver's licenses and identification cards, as required by the federal Real I.D. Act. It is the agency's intention to make the state's driver license and identification cards among the most secure in the nation. The Subcommittee notes that 2008 HB 2770 would increase the photo fee from \$4 to \$12; the additional money would go towards the prevention of fraud. Those measures will include the digital retention of all documents, the photograph of applicants, and data sharing with state and federal agencies.



Kansas Council on Developmental Disabilities

KATHLEEN SEBELIUS, Governor
SCOTT SHEPHERD, Chairperson
JANE RHYS, Ph. D., Executive Director
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"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

SENATE WAYS AND MEANS COMMITTEE

MARCH 7, 2008

Testimony in Regard to Senate Bill 657, an act creating the lifespan respite care program; concerning duties of the department of social and rehabilitation services; making and concerning appropriations for the fiscal years ending June 30, 2009 and June 30, 2010.

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities in support of increased funding for Developmental Disabilities services in support of S.B. 657.

The Kansas Council is federally mandated and funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. We receive no state funds. Members are appointed by the Governor and include primary consumers, immediate family, and representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities to receive adequate supports to make choices about where they live, work, and learn.

We support this bill because we see the need for families to have access to a few hours a week of respite care. We know of families who are the primary care giver for a family member who has special needs. However, they sometimes do not need many hours of services. Some just need one to two hours a week in order to buy groceries, go to the doctor, or do some other activity that many of us take for granted. However, because their need is real, they may apply for and receive Home and Community Based waiver services. The waiver services are in excess of what they need but there are no alternatives. Those who are unable to receive waiver services experience a lot of

Senate Ways and Means
3-7-08
Attachment 4

stress that adversely impacts the family. Ultimately such stress may lead to the family member being placed in residential care that can cost the state from **\$120,000 to \$170,000 per year** (state hospitals for developmental disabilities costs for 2007).

Last fall a friend of mine, a former Nebraska State Senator, contacted me to tell me about lifespan respite care. Senator Dennis Byars introduced the bill on respite care that was passed in Nebraska and also introduced me to Gina Ervay, Chairperson of the Kansas Lifespan Respite Care Coalition. I met with Gina and read her materials. I became convinced that this would help not only family caregivers who had members with developmental disabilities, but also those whose members had other disabilities.

I think that when you hear Gina and the family members who are with her, you too will see the need for this program in Kansas.

As always, we greatly appreciate your time and attention to this and I would be happy to answer any questions you may have.

Jane Rhys, Ph.D., Executive Director
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Kansas Lifespan Respite Coalition



Senate Ways and Means Committee
Lifespan Respite Care – SB 657
March 7, 2008

Thank you Chairman Umbarger and members of the committee for today's hearing. I am Gina Ervay, Chair of the Kansas Lifespan Respite Coalition, a network of over 60 respite providers, family caregivers, state and local agencies and organizations across Kansas who support respite (see attachment). **Together we request that the committee support SB 657 to fund a statewide respite study as a first step toward the development of a coordinated lifespan respite program for caregivers.**

Impact

There are 280,000 caregivers across Kansas according to Nov. 2007 data provided by the National Center of Caregiving at Family Caregiver Alliance. These caregivers provide 300 million hours of caregiving each year. Respite care is the number one most requested support service by these caregivers, yet it remains in critically short supply. If caregivers' needs are not addressed, the \$2.8 billion in unpaid supportive services they provide may be jeopardized as they suffer hardship that impedes their ability to give care now and support their own care needs in the future.

In addition to the many people caring for a child or adult with special needs, there are a growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability.

Lifespan Respite, a coordinated system of community-based respite services, helps states use limited resources across age and disability groups more effectively, instead of each separate state agency or community-based organization being forced to constantly reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and the savings used to fund new respite services for families who may not currently qualify for any existing federal or state program.

Respite Benefits Families and is Cost Saving

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability.

The budgetary benefits that accrue because of respite care are just as compelling. Delaying a nursing home placement for just one individual with Alzheimer's or other chronic condition for several months can save Kansas long-term care programs thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities. (Ableson, A.G., 1999).

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999).



In the private sector, a new study by Metropolitan Life Insurance Company and the National Alliance for Caregivers found that Kansas businesses lose from \$157.8 to \$310.2 million per year in lost productivity of family caregivers. Offering respite to working family caregivers could help improve job performance and employers could potentially save billions.

What is the Need for Respite

The 2004 survey of caregivers found that despite the fact that the most frequently reported unmet needs were “finding time for myself,” (35%), “managing emotional and physical stress” (29%), and “balancing work and family responsibilities” (29%), only 5% of family caregivers were receiving respite (NAC and AARP, 2004).

The availability of lifespan respite services in Kansas is limited and access to quality respite care is difficult, especially for individuals with certain disabilities or chronic illness such as behavioral, mental health or severe medical conditions, or in some rural and urban centers where resources are scarce. Shortages of trained providers and quality respite programs, limited family resources to pay for respite care, long waiting lists for HCBS Waivers, restrictive program eligibility criteria based on age, income or disability, and fragmented and duplicative systems, keep many families from accessing the respite they so desperately need.

Lifespan Respite Care Program Will Help

We urge you to include \$65,000 in fiscal year 2008 to fund a lifespan respite care study so Kansas can identify and coordinate existing respite resources, pool and share providers, funds, training resources and administrative capacities, and identify and fill gaps in services. The development of a coordinated statewide lifespan respite care system would provide a way to improve efficiency, save money, and make quality respite available and more accessible to families and caregivers, regardless of their Medicaid status, disability or age.

For Kansas to apply for federal funding under the Lifespan Respite Care Act, we must have a state and local coordinated lifespan respite care system that serves families regardless of age or special need. If funded, the federal Lifespan Respite Care Act, administered by the US Dept. of Health and Human Services, would provide competitive grants to statewide agencies through Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations.

The federal Lifespan Respite Care Act is based on the success of Statewide Lifespan Respite Programs in four US States: Oregon, Nebraska, Oklahoma and Wisconsin. Flexible funding and requirements permit programs to be adapted to meet their individual state needs. The defining characteristic of each is the statewide, coordinated approach to ensure respite services for those in need. Many lifespan respite programs have established community-based networks that rely on local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, state and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities and volunteers.

Services typically offered by Lifespan Respite Programs include public awareness information for communities, building diverse respite partnerships, recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, coordinating respite related

training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services.

SB 657 would enable a study that would be key in determining how to best streamline services and funding sources while building on existing systems. It would help Kansas to compete for federal funding that would expand and enhance our system. The timing to act is now so Kansas can join the leading edge of the national movement toward a coordinated lifespan respite care system. I strongly encourage you to give full consideration to SB 657.

Thank you. I would be happy to answer any questions you may have.

Gina Ervay, Chairperson – Kansas Lifespan Respite Coalition
1603 N. Chapel Hill St., Ste. 300
Wichita, KS 67206
Phone: (316) 687-5700
Email: gervay@rockoinc.org

Emma's story

My name is Jessica Smith, and I am a 30yr old, single mother of two beautiful children. My son, Easton, is 12, and my daughter Emma is nine. We live in the small town of El Dorado Kansas. I work 40 plus hrs a week, as a Hair Stylist, and am also the Fashion/Modeling Director, for "Solo Magazine," in Wichita KS.

I suppose my story is like many, these days. I was married at a young age (18) already having our son Easton, a year earlier. My husband Chris, had just graduated college with a degree in Criminal Justice, and went to work for the Butler County Sheriff Department shortly after our wedding, in 1996. I attended Butler County Community College in the fall of 1996, with the hopes of a degree in Nursing, only to be cut short, when pregnant with our daughter, and became very ill during my pregnancy. Other than being young, we were the typical "American Family." Sadly, my husband, and I divorced in January of 2001. The stresses of being such young parents, having a disabled child, amongst other things, had simply taken its toll.

So, I am now a single mom, working as many hours possible to provide for my children. Of course like many others, wishing I would win the lottery so I could give my kids all that they deserve, and more, but being a realist at the same time, knowing that will probably never happen!

My son Easton, is a thriving young boy. He will be turning 13 in May, and is as strong as an ox! He makes good grades, is one of the star players on his baseball team, and has a heart that is as big, as the moon. He's an all around "great kid." Easton is always smiling, and reaching out to help anyone that needs it. When he was younger, he would willingly give away his toys to friends that didn't have as many, or wanted the one that he had. That's just the kind of kid he is... an old soul... an angel.

Almost three years after Easton came into the world, along came my second angel, little Emma. All 6lbs 11oz of her. That is where our story turns from the typical "American Family" story, to one that most people can't even imagine. Emma was born on Dec 16th 1998. After being in labor for almost 8 hrs my doctor decided to come up to the hospital, (it was about 2am at that point) and check on my progress. When he came in, and examined me, he spoke the most frightening words I had ever heard, "This is not a head I feel, it's a butt!" Emma was in the breech position. I was rushed into the OR within minutes of that discovery, and about ten minutes later, we had a beautiful baby.. Emma! She was perfect! Ten fingers, ten toes, and a spitting image of her brother when he was a newborn! The only thing that seemed a little off was the small size of her head. I jokingly said "my husband has a small head, so she must take after her dad!"

We would later find out, that was not the case, and her small head would be a sign of some HUGE challenges that will affect us, especially Emma, for the rest of our lives.

After recovering from my somewhat "rough" delivery, we brought our new bundle of joy home, and settled into our lives, with two children. A few weeks went by, and it was time for Emma's checkup. Looking back, I remember the Doctor commenting again, on the size of her head, but since he didn't seem concerned, neither was I. The annual checkups continued as normal, until her 6th month. That's when we started to notice some abnormalities with Emma. It was the gut instinct that all mothers possess. I knew something, just wasn't right.

She couldn't hold her head up very good, if at all, couldn't roll over, couldn't sit yet, and that little head we all thought was so cute, would bobble almost uncontrollably. We took her to see the Doctor, voiced our concerns, and he agreed, something wasn't right. He chalked it up too, low muscle tone, and said to "give her a few more months. Let's see if she gets stronger."

The months went by, with no improvement. By her tenth month, the Doctor decided it was time to take the next step, and ordered an x-ray of her head. The results came back "abnormal." That was

Senate Ways and Means
3-7-08
Attachment 6

the beginning of our now “abnormal” life. The next step was a C-T scan of her brain, to try and determine what the problem could be. Those results also came back “abnormal.” Finally, the last step was an MRI. Those results would forever change our lives, as we knew it.

The test showed that Emma had “Agenesis of the Corpus Colosseum” that’s the brain, inside your brain. Emma’s brain works from the left, and right side, at the same time. The two sides never communicate with each other. She basically has, no filter. Whatever thought, feeling, word, or emotion that enters her mind, she immediately does. Right, or wrong, she reacts. Sometimes she has bursts of extreme anger, then seconds later, she is giving you a hug, and laughing. She has severe ADHD, learning disabilities (she has the mental capacity of a 4yr old) Autistic tendencies, as well as, hip problems, and balance issues. She usually has bruises from head to toe, from falling, or playing too hard, but because the signals in her brain are not crossing, she has no concept of danger, or pain. Most recently she has become physically violent. Lashing out, hitting, punching, kicking, screaming, and spitting. This is partially due to frustration, and partially due to the fact that she can’t control herself.

My little girl, takes every ounce of energy I have, and requires all of my attention, all day, every day. From the moment we get up, until the time she goes to bed. Even then, she will wake up, and want me to be beside her. Up until a year ago, I simply just had to “deal” with this. I felt like my son was constantly being put on the back burner, because Emma consumed all of me! So, I started searching for someone that could help! That’s when I came across the ROCKO program. I couldn’t believe there was actually a place you can take your disabled child, leave them for several hours, and know that my baby girl, would be well-taken care of. ROCKO has given me a chance to breathe again. I can go to the store alone (without a screaming child, with ADHD) do laundry (without worrying that in the 5 min I’m not next to Emma, she isn’t running outside, or doing something she shouldn’t be) but most important, it has allowed me to have the one on one time with my son, that he very rarely receives, and so much deserves! He, and I can spend quality time together, without Emma throwing one of her infamous fits, or interrupting us, as we talk. I am extremely thankful for this program. Even though it’s only a few hours, every other weekend, it means the world to Easton, and I. If only there was a program that could offer respite on a regular basis, and a little closer to home. (ROCKO is in Wichita except one weekend a month, when they come to El Dorado.)

Which brings me to the real reason, I am here. The lack of respite care in Kansas, is not only shocking, but sad. Emma has attended every daycare in our town, and within a few weeks of her starting, I get the phone call that I have now come to expect. It’s the daycare provider calling, saying “we apologize, but there just isn’t enough staff, let alone ‘trained staff’ to deal with a child ‘like Emma’,” and I am left without childcare. She is now attending an after school program with the local YMCA, but within the last two weeks they have called several times, asking for someone to come pick her up, due to her behavior, and there lack of staff. Also, due to the young, high school age girls that have absolutely no idea, and no training, on how to take care of a disabled child.

I’m sure you’re thinking “why can’t you have a family member help out?” I have a sad answer to that question. Five years ago, I lost my mother to stomach cancer. She was my rock, my backbone. She adored my children more than any other person in this world. Six months before she passed, I lost my grandmother to a stroke. My only sibling, (an older sister) lives in Kansas City, and my father lives in a town about 45min from us. Emma’s dad currently lives in El Dorado, and is involved in her life, but has had a difficult time dealing with the fact that he has a disabled child, and only spends a few hours out of the week, with her. My son tends to spend much of his time with

his dad, because when he is with Emma and me, as I said earlier, he is somewhat outcast.

I am not telling you my story, for sympathy. I wouldn't change my life for anyone else's, and I am so proud of both children, as different they each may be. I am simply telling my story, to ask the state of Kansas, please realize that there are many families here that need help! In El Dorado, there are no resources for parents that are in need of childcare, for a disabled child. I unfortunately, do not have the option of staying home, and taking care of Emma. She gets \$637.00 a month in disability, which basically covers the cost of her medications, and the after school program with the Y.

So, my question to you is, "what, do I do?" "How does a mother of a disabled child get help, when there is no help out there, to be had?" This is a very serious issue, which I feel has been overlooked, for far too long. I cannot do this alone, especially as Emma gets older. One of my biggest fears, is that someday I will have no choice, but to quit working, and take care of her full time, (How will I do that on \$637.00 a month?) Or, I will have to put her in the care of people I don't trust, and that has no training. All because our state will not help fund respite programs.

As of right now that is the case, those are the only options available for me. These children deserve more than what is available to them.

Sincerely,
Jessica Smith

Austin C. Hanson

Senate Bill 657

March 7, 2008

Mr. Chairperson, and Committee Members,

I stand here before you today in support of Senate Bill 657. I am speaking not only for myself but also for the many Disabled Kansans that do not have a voice.

I have Cerebral Palsy, and I have been totally dependant twenty-four hour a day Attendant Care for thirty-four years.

I would like to help you to understand the need for Respite Care from our point of view. If you would, for a brief moment envision that one of your grown children has returned home. Not for a visit, but forever! They cannot care for their selves and they are now your shadow and responsibility twenty four seven.

For many of us with disabilities and our Families that is our daily and life long reality. We must make it work, but it is not always that simple. Our Attendants weather Family Members or not are forced to spend a great deal of time together, and at times frustrations run very high.

I know that doing Attendant Care is stressful, but so is not being able to take care of your self! It is difficult for Attendants to be on call twenty-four hours a day and have time to take care of their own lives. If Attendants are sick or do not come to work our lives cannot be put on hold.

Many of us weather on HCBS Waivers or not, do not receive enough Attendant Care Hours to support our needs.

I believe that Respite Care is important not only to our Attendants to have some much needed time to recuperate; but we also need a break from our regular Attendants. Believe me it makes you appreciate your regular Attendant's much more.

Respite Care will help to reduces the incidences of abuse that so easily occur from both party's.

I am asking you to listen to everyone here today with an open heart and mind and then help us to improve our lives, because you never know when it may be a part of your life. Please pass Senate Bill 657.

Thank you,

Austin Hanson

Senate Ways and Means
3-7-08
Attachment 7

Mr. Chairperson, committee members, my name is Beth Baldrige and I am here today to support Senate Bill 657, an act creating the lifespan respite care program; concerning duties of the department of social and rehabilitation services; making and concerning appropriations for the fiscal years ending June 30, 2009 and June 30, 2010.

My name is Beth Baldrige and I am a 55 year old wife, a mother of three adult children, a nana to four grandchildren, a daughter of aging parents, and a friend and caregiver to my 55 year old sister-in-law. Diane has lupus, and is a two-time stroke survivor with limited speech and cognitive abilities. Her first stroke occurred when she was just 43 and she experienced a second stroke at the age of 50. She has poor short term memory and great long term memory. In March '06 we became concerned about Diane's living situation and her well-being because she was often left alone for long periods of time. Three months later, in June of '06 she was living in our home full time, and by Aug. of '06 Diane was abandoned completely by her husband. We began a fast-paced learning curve of the medical and legal system which for the next two years. During this time, we learned that Diane did not have access to community-based services due to her age of 55. Everything became an issue of available funds versus Diane's welfare as bills mounted and her legally responsible party refused involvement. At the conclusion of the legal process (which included her divorce and guardianship), we became aware that at best, Diane's money will last 4 years. In the next few years, Diane and her guardians will be forced to make difficult choices regarding her care. As her caregiver, I would consider funded lifespan respite services a gift to both Diane and myself. She needs a familiar person that will come into the comfort of her safe place, her home, to be to her a friend and confidant beyond a family member. This would provide Diane with some normalcy, dignity, and longed-for friendship. I need a familiar person that will come into the comfort of my safe place to be to Diane a friend and confidant beyond what I can provide. This would allow me, as her caretaker, some normalcy, and freedom to nourish the other relationships left behind when life changed so unexpectedly and suddenly. Therefore, if you choose to fulfill this request for lifespan respite care, my husband, my children, my grandchildren personally thank you. My girlfriends personally thank you and most of all, Diane and I personally thank you. Thank you for your support of Senate Bill 657 and for allowing me to tell our story. I'd be happy to answer any questions you may have.

Name: Beth Baldrige
Address: 1131 Stone Meadows Drive, Lawrence, KS 66049
Phone number: 785-841-2253

Senate Ways and Means
3-7-08
Attachment 8

Mr. Chairperson and committee members,

My name is Duane smith, I am from Wichita and I have been caring for my wife with Alzheimer's for 10 years.

I am a 24/7 caregiver. I am able to put my full strength into the job because I get respite care.

I am here to ask for your support of Senate Bill 657, an act creating the Lifespan respite Care Program. We need it because there are 64,000 Kansans over the age of 65 with Alzheimer's disease. This makes a need for many thousands of caregivers who need the relief of some degree of respite care from their 24/7 job of caring for their loved one. Caregiving is a lonely and highly stressful job.

You have heard statistics- caregivers are practically an endangered species! The odds are heavily stacked against them---because they can't get away from the job day or night. Respite care is their opportunity to "RELOAD" with the hope they don't die before the job is over.

You have the power to change these odds-pass Bill 657. It gives a chance to save Kansas many dollars in Medicaid care home costs. I can't say for sure, but the savings of Medicaid dollars may be more than the cost of funding for 657.

Senate Ways and Means
3-7-08
Attachment 9

Caregivers are able to keep their loved one at home longer, if they have respite. This care helps them stay on the job longer and keeps them from being a burden on the state. This bill goes straight to the needs of thousands of Kansans who are trapped in one of life's most stressful and troubling situations. It meets a lifesaving need for caregivers. You have the opportunity to positively make a difference for many people in your state.

Bill 657 for appropriations for the fiscal years ending June 30, 2009 and June 30, 2010 is critical. It is a direct "helpline" to the "silent ones" out there who are looking to you to bring some HOPE to their lives.

I ask again for your support and passage of bill. Thank you for giving me time to give my views on this important subject. I will be glad to answer any questions you have for me.

March 6, 2008

The Honorable Senator Dwayne Umbarger,
Chair of the Senate Ways and Means Committee
300 SW 10th Street
Topeka, Kansas 66612-1504

Dear Senator Umbarger and Committee Members:

My name is Mary Warren. My family and I live in Wichita, Kansas. I am here today to ask you to support Senate Bill 657 so that one day families like ours may obtain respite relief they need as they care for loved ones who depend on them.

Almost eleven years ago, my husband, Craig, and I lost all hope of having children. We struggled for twelve years to conceive but the doctors told us there was nothing else they could do and encouraged us to consider adopting a child. So after taking a foster/adoptive parent class through Youthville and waiting another year, we were given the opportunity to foster two sibling children, who were then 2 and 8 years old. We fell in love with them almost instantly and about fifteen months later we adopted them. At last we had the family we had dreamed of for so long.

As our youngest child, Jessica, grew, it became more and more obvious that something was not right. When things went her way, everyone was happy because Jessica was happy. But when things did not go her way, our family would endure extended periods of Jessica's violent rages sometimes lasting as long as two hours and occurring as often as 4-5 times each week. About three months after her eleventh birthday, Jessica's behaviors escalated to a new, frightening level when she began running away. During the course of three months she ran away from home eight times. During this most difficult time, Jessica also threatened to kill herself, stab me, and indicated to professionals we sought help from that she did not want to live with us any longer.

At one point, SRS recommended and we reluctantly agreed to put Jessica back into foster care as a way to interrupt her cycle of running away. She was in foster care for about eight months. Though we deeply regret the relational cost of that decision, it made us aware of how exhausted we had become. As we regained our energy level and found balance in our life once again, we rediscovered our tender feelings of love and compassion for our daughter. We also revisited some important family decisions. We decided to eliminate a huge stressor to our family life by downsizing to a smaller, more affordable home so that I would not need to work outside of the home and could care for Jessica's needs and manage the multiple professional and school appointments we had for Jessica each week.

Today we remain committed to being a "forever family," but every day is a challenge. So far, our efforts to stabilize Jessica's behaviors and address her mental health needs, has had limited impact. It is clear, however, that the early trauma Jessica endured at the hands of her birthparents forever altered Jessica's brain, neurology, and biochemistry. Her current diagnoses include Reactive Attachment Disorder, Attention Deficit/Hyperactivity Disorder, Oppositional Defiant Disorder, Depression, and Bipolar Disorder.

As hard as we try to care for our own health and wellbeing while caring for Jessica, too, we don't always succeed at maintaining balance. More than once my husband has expressed gratitude for having a job he can go to for escape from the intensity at home. Because of Jessica's special needs, we no longer have any friends we can count on to help care for her because her behavior is too scary and threatening to risk letting their children interact with her. And, as supportive as our extended family has been of our decision to adopt our children, our children's behaviors have been too scary for our family to help us much either.

Senate Ways and Means
3-7-08
Attachment 10

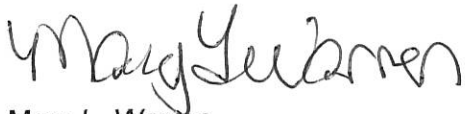
As far as professional support, we have been given lots of help, especially during the last two years; we thank God every day for their part in our lives. But every time things get really intense with Jessica and she has to go back to the hospital, the clearest advice we get is a recommendation to put our daughter into long term residential treatment. But what would be the cost of doing that? Besides the emotional and relational destruction a decision like that would have for our family, it would also add to the financial burden we and the state of Kansas would have to bear. One day we asked one provider, "What do other parents do who have kids like our children?" We were told, "There are no other parents like you. Most other parents give up and release their children back into the foster care system."

Instead of abandoning our daughter, time and again, we have pleaded with our providers. Surely there is somewhere we could turn to get even a night away to recharge our batteries so we can start fresh the next day. After all, when our daughter was in foster care, her foster parents only needed to make a phone call and within two days notice could get respite care for an entire weekend. But instead of getting us help, we have been told, "Your problem is you live in Kansas. Other states might have that kind of assistance for families, but Kansas does not."

Please, for families like mine and the other families represented here today, we urge you to support Senate Bill 657 so that someday we will have the respite relief we need so we can keep our daughter at home where she belongs.

Thank you for listening and thank you for the awesome and important work you do for Kansans.

Yours truly,



Mary L. Warren
234 North Ridgewood
Wichita, Kansas 67208
316-650-9724
mary.warren@cox.net



Families Together, Inc.

Parent Training & Information Centers for Kansas

Home Page:
<http://www.families-togetherinc.org>

Wichita Parent &
Administrative Center
3033 W. 2nd, Suite 106
Wichita, KS 67203
Voice/TDD (316) 945-7747
1-888-815-6364
Fax (316) 945-7795
wichita@families-togetherinc.org

Topeka Parent Center
501 Jackson, Suite 400
Topeka, KS 66603
Voice/TDD (785) 233-4777
1-800-264-6343
Fax (785) 233-4787
topeka@families-togetherinc.org

Garden City Parent Center
1518 Taylor Plaza
Garden City, KS 67846
Voice/TDD (620) 276-6364
1-888-820-6364
Español (620) 276-2380
Fax (620) 276-3488
gardencity@families-togetherinc.org

Kansas City Parent Center
1333 Meadowlark Ln., Suite 103
Kansas City, KS 66102
Voice/TDD (913) 287-1970
1-877-499-5369
Fax (913) 287-1972
kansascity@families-togetherinc.org

Statewide Spanish Parent Line
1-800-499-9443

March 7, 2008

Senate Ways and Means Committee
Senator Dwayne Umbarger, chairperson

Committee members:

Families Together, Inc. is pleased to support Senate Bill 657 to provide \$65,000 for a study to identify the need for respite care for families, of persons with disability and/or aging related care needs. Families Together, Inc. is the Parent Training and Information Center for Kansas families who have children or youth, birth – age 26, with any disability. Our organization provides training for families and individual assistance to help families find appropriate services for their sons and daughters in schools and in the community.

In our work with families, and in the experience of many of our staff, the need for “a break” from care-giving is vital to the physical and mental health of caregivers. This study is one way to quantify the amount of respite needed, the funding needed to provide that respite, training needs of respite providers, and ways to pay for the services identified.

Families Together, Inc. has been a member of Respite Coalition of Kansas since its inception. This group is comprised of organizations and individuals who serve the constituent populations in our state. It is clear from our work with this group that families love their members who have disability and / or aging related care needs, but have other responsibilities and commitments which may interfere with their ability to provide this care. Without a means of obtaining respite, these family members will lose their own health, injure themselves in the care giving task, or become overwhelmed with the caregiver role.

Please provide this small appropriation to help quantify the need of Kansas families in their attempt to support their family member at home.

Sincerely,

Connie Zienkewicz, Executive Director
Families Together, Inc.

Assisting Parents and Their Sons and Daughters with Disabilities

*Senate Ways and Means
3-7-08
Attachment 11*



March 7, 2008

Senate Ways and Means Committee
Senator Dwayne Umbarger, chairperson

Committee members:

Independent Living Resource Center, Inc. (ILRC) is pleased to support Senate Bill 657 to provide \$65,000 for a study to identify the need for respite care for families, of persons with disability and/or aging related care needs. The mission of ILRC is to empower people with disabilities to lead independent lives by providing advocacy, community education and direct services. We serve as a resources and support connection for individuals and there families to find resources and services to enhance their lives.

Many individuals have family support who assist the person with a disability continue to remain in a home setting in the community. This support can be very draining and taxing for the family members and puts a strain on their ability to maintain family unit and employment. It is important to take the time to identify what support is needed, the funding that would be support the efforts, training needs for respite providers and ways to pay for the services needed.

Independent Living Resource Center, Inc. has been a member of Respite Coalition of Kansas since its inception. This group is comprised of organizations and individuals who serve the constituent populations in our state. It is clear from our work with this group that families love their members who have disability and/or aging related care needs, but have other responsibilities and commitments which may interfere with their ability to provide this care. Without a means of obtaining respite, these family members will loose their own health, injure themselves in the care giving task, or become overwhelmed with the caregiver role.

It is important that you provide this appropriations to help identify the needs of Kansans who are attempting to support their family member at home.

Sincerely,

Judy Weigel
Executive Director

Senate Ways and Means
3-7-08
Attachment 12
Attachment 13



Sedgwick County
Developmental Disability Organization

Chad VonAhnen -- Director

615 N. Main Wichita, Kansas 67203 T 316-660-7630 F 316-4911 TTY 316-660-4893

March 7, 2008

TO: Senator Dwayne Umbarger, Chair and Members of the Senate Ways and Means Committee

FR: Chad VonAhnen, Director
Sedgwick County Developmental Disability Organization

RE: SB657

**Testimony on SB657 Creating the Lifespan Respite Care Program
Friday March 7, 2008**

Thank you, members of the committee, for the opportunity to provide this testimony. The Sedgwick County Developmental Disability Organization (SCDDO) would like to express support of Senate Bill 657 to provide \$65,000 for a study to identify the need for respite care for families of those with disabilities and/or aging related care needs.

At the SCDDO we hear the stories of families who are in need of respite care for a child, a sibling, or someone they care for. This bill will help us start to determine the need in Kansas and to begin to determine the best way to provide assistance to these families.

In 2005, the SCDDO initiated a community-wide strategic planning process with persons served; parents, family members, and guardians; and community partners. The number one area of focus was and continues to be "Expanding Social Support Resources." The need for respite care strategies was one of the goals identified in this area.

This study would help us identify not only the need for lifespan respite statewide but would also help to determine what this means in terms of funding. This data would also be helpful in determining the best ways to coordinate current services and the most appropriate model to serve our families.

Again, the SCDDO supports this appropriation to examine the need of our Kansas families as they are supporting their loved ones at home.

Sedgwick County...working for you

*Senate Ways and Means
3-7-08
Attachment 14*



March 7, 2008

Senate Ways and Means Committee
Honorable Senator Umbarger, Chairperson
State Capitol
300 SW 10th Avenue
Topeka, KS 66612-1504

Dear Committee Members,

I am writing in support of Senate Bill 657, which establishes the foundation of a statewide respite care program for individuals of all ages with disabilities. Trinity In-Home Care, Inc. is pleased to support this legislation for families, caregivers, and individuals with disabilities in the state of Kansas. As a non-profit home-health agency, Trinity's purposes are to 1) provide in-home care to individuals of all ages with disabilities, and 2) to support their caregivers by providing occasional relief ("respite").

The need for caregiver support and respite is tremendous, and will continue to grow exponentially. It is imperative that Kansas works now to establish a mechanism of supporting caregivers to support the current need for respite care and to prepare for growing need which will be evident in the next few years.

Respite care is a preventative measure, necessary to maintain healthy community-based environments for individuals in need of care. While the needs and ages of individuals for whom caregivers support may vary, the need for caregiver respite and support are common among all caregivers. According to the National Resource Center on Community-Based Child Abuse Prevention, "respite services directly promote the preservation and strengthening of marriages in families caring for a dependent family member." Research continues to show that respite care plays a critical role in supporting family stability and prevention of abuse and neglect.

As a member of the Kansas Lifespan Respite Coalition, Trinity hopes to see passage of Senate Bill 657 so that Kansas can join other states such as Oklahoma and Nebraska, in providing a statewide network of respite care. Development of such respite infrastructure will also allow Kansas to compete for federal funds related to Lifespan Respite Care.

Thank you for your time and interest in Senate Bill 657. Please feel free to contact me with any questions.

Sincerely,

Kelly Evans, LBSW
Executive Director
Trinity In-Home Care, Inc.

Senate Ways and Means

Dear Senator Umbarger and members:

After the traumatic birth of our daughter Mia, my husband and I were left to care for a newborn with special needs. Monitors, medicine and equipment became part of Mia's entourage as opposed to a diaper bag and carrier. As you can imagine for a young couple the idea that Mia will never walk, talk, run, skip or play is very disheartening. Now, eight years later but still immobile, nonverbal and blind, we face the inevitable everyday of grooming, bathing, tube feedings and suctioning—and this is on a healthy and cooperative day along with transportation, education and social commitments. My husband and I have never given up on Mia and promise to give her the best care possible the rest of our lives. That is a commitment that every parent makes despite ability. Parents and caregivers of persons with disabilities have a much more demanding role. Day in and day out without reward or regard to their own well-being—physically or mentally—caregivers sacrifice careers, relationships, development and finances to care for their loved ones.

Luxuries such as weekend getaways, conferences out of town for work, getting a hair cut and simple chores such as grocery shopping or mowing the lawn become obstacles for families with a special needs child. I recall a time that I was required to attend a conference in St. Louis that my sister and Mia were forced to come with me because we could not find adequate respite care to fit our needs. I am constantly the subject of mayhem when I have to take Mia and our son Dylan grocery shopping. Imagine pushing a wheelchair and pulling a cart on a busy Saturday morning. While typical families can relate to these stresses, special needs family have a bit more to worry about. For instance, typical kids might play outside while their mom grocery shops and dad mows the lawn. Grandparents can give quick breaks to parents by taking the kids to the zoo or to the park. Mia's grandparents, not even sixty years old, cannot physically pick her up to change her diaper and lack the training to feed her via her g-tube.

I am blessed in so many ways. Mia is a very happy young girl with a tremendous spirit, my husband is an amazing sense of support for me and Mia, we were able to adopt our son Dylan at an age that he already knew how to walk so we didn't have to carry him and push Mia. We also have wonderful family close geographically that help out as much as possible. After six years of waiting, we finally began to receive services for respite care. I was able to go back to work full-time and Mia became more independent. Jeremy and I were finally able to take a much needed vacation and our relationship and dedication to Mia was reenergized.

The need for respite care is overwhelming at so many different levels. Although we still receive services, emergencies and life in general arises. Most twelve to eighteen year olds would be able to stay at home while their mother grocery shops or gets her hair cut, or simply to come home after school thus relieving everyday stress on the parent of daycare and homework. Unfortunately, special needs families will never get to that point. Respite care is their only ally in maintaining a healthy and happy state of mind for the caregiver and person served.

Respectfully submitted,

Rachel Mendoza Banning
3235 North Lake Ridge Court
Wichita, Kansas 67205
316.683.1816

Senate Ways and Means
3-7-08
Attachment 16



700 SW Jackson, Suite 803, Topeka, KS 66603-3737 phone 785/235-5103 fax 785/235-0020 interhab@interhab.org www.interhab.org

March 7th, 2008

TO: Members of the Senate Ways and Means Committee
FR: Matt Fletcher, Associate Director, InterHab
RE: SB 657

Chairman Umbarger and members of the committee, thank you for the opportunity to share information with you regarding Senate Bill 657 on behalf of the members of InterHab.

For parents who care for Kansans with developmental disabilities, the ability to reach out and receive respite care is literally a service that keeps families together and keeps family members from sliding over the cliff of personal exhaustion and despair.

Respite services are in-home 'relief valves' for those family members who also find themselves as caregivers – a 24-hour-a-day daunting task.

Fortunately, for many families of persons with developmental disabilities, respite services are available, accessible and affordable. However, there are segments of the disability population which, due to current funding mechanisms, do not qualify for existing services. Many more families who live in rural areas may have a great deal of difficulty accessing respite care even if their funding allows for it.

As a result, some families fall through the cracks of the current system. Many more break apart under the enormous stress of caring for a child or young adult who may have significant cognitive challenges, be physically aggressive or need constant physical redirection.

Additionally, these families are aging along with the disabled family member they care for, and more and more care givers will be faced with caring for multiple members of the family. The result will be a crisis of care for many Kansas families who had been successfully coping with care giving for one member of their family.

SB 657 marks a beginning for coordinated efforts to help the state and community plan for quality respite services exist for Kansas families who need them. The bill will provide \$65,000 for a study that will identify existing respite resources as well as needed areas for growth within the respite care system. This study will serve as an excellent first step to ensure that family caregivers of increasing aging and disabled populations within our state will have the resources they need.

Thank you for your consideration of SB 657. We urge your support of the measure.

Senate Ways and Means
3-7-08
Attachment 17