Approved: March 8, 2006
Date

MINUTES OF THE HOUSE FEDERAL AND STATE AFFAIRS COMMITTEE

The meeting was called to order by Chairman John Edmonds at 1:30 P.M. on February 13, 2006 in Room 313-S of the Capitol.

All members were present.

Committee staff present:
Athena Andaya, Kansas Legislative Research Department
Dennis Hodgins, Kansas Legislative Research Department
Carol Doel, Committee Secretary

Conferees:
Representative Lance Kinzer
Former Representative Rocky Nichols
Erick Rucker, Office of the Attorney General
Lynn - Victim
Nancy - Victim
John Badger, Chief Legal Cousel, SRS
Jeanne Gawdun, Kansans for Life
Tammy Coleman
David Wilson, AARP
Barb Conant, Department of Aging
Mike Farmer, Kansas Catholic Conference
John Carney, Center for Practical Bioehtics, Kansas LIFE Project
Sandy Kuhlman, Kansas Hospice and Palliative Care Organization

Others attending:
See attached list

Chairman Edmonds opened the floor for bill introductions and recognized Representative Swenson who asked for a resolution requesting the federal government to repeal the Real ID Act portion of HR 418 as part of the Emergency Supplemental Appropriations Act for Defense, the Global War on Terror and Tsunami Relief; 2005, and a bill regarding the teacher-firefighter-police housing development act providing mortgage assistance to public employees who agree to live and work for at least five years in high priority areas, and a bill regarding a health workplace act.

With no objections, those bills were accepted for introduction.

Bill Yanek, a representative of the Kansas Realtors Association, requested legislation that would statutorily authorize real estate sales validation questionnaires.

With no objection, this request for legislation was accepted for introduction.

Representative Pilcher-Cook requested the introduce a bill that would ban chimera research.

With no objections, that was accepted for introduction.

Representative Siegfreid requested the introduction of a bill that designates a portion of Highway 36 as the World War I Veteran's Memorial Highway.

With no objections, that request was accepted for introduction.

With no other person requesting a bill introduction, the Chairman opened the floor for public hearing on **HB 2306** - protection and advocacy for Kansans with disabilities fund.

Former Representative Rocky Nichols, Executive Director of the Disability Rights Center of Kansas was recognized in support of **HB 2306**. Mr. Nichols related that **HB 2306** is legislation that establishes the mechanism by which a unit that a focuses on criminal and civil prosecution of the perpetrators of abuse,

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

neglect or exploitation of the Disabled in Kansas will be established. (Attachment 1)

Mr. Nichols presented case examples that show the opportunity for horrible abuses against Kansans with Disabilities did not end when the Kaufman house was shut down. (Attachment 2)

Also submitted by Mr. Nichols was *Comparison of DRC and APS/SRS Access Authority to Investigate Complaints of Abuse and Neglect.* (Attachment 3)

Two other articles, both written by Randy Scholfield, were submitted for committee review. One was entitled *Kaufman Case Shows Need For Reforms,* (Attachment 4) and the other was an editorial *Abuse Cries Out For Reform.* (Attachment 5)

Lynn, a resident of the Kaufman group homes from 1985 to 1986, presented testimony in support of **HB 2306.** Lynn told of some of the abuse that she suffered while a resident of the Kaufman homes as well as the method in which their medications were dispensed. She also related that her parents paid $1000 a month for her to live there and well as forfeiting her disability check. Dr. Kaufman convinced her parents that she had to remain naked in order to be safe and that he was the therapist and was doing what was best for her. She stated that she came before the committee to make sure they knew the whole truth regarding the Kaufman homes. (Attachment 6)

Nancy, another resident of the Kaufman group homes from March 1986 to March of 1987, addressed the committee supporting **HB 2306**. In her testimony, Nancy also told of her abuse during her residence at the Kaufman homes. She was forced into seclusion, her clothes were taken from her, she had no bed and no blankets. She related that as time went on the abuse grew worse. She requested that the focus not be on what has failed in the past, but focus on fixing the future problems by passing the bill. (Attachment 7)

Kevin Graham, Office of the Attorney General, presented testimony in support of **HB 2306**. Mr. Graham explained that they felt that bill closed the gaps in existing coverage for disabled Kansans, it improved coordination of resources, dedicated resources for protecting vulnerable citizens, and provided justice for victims. He stated that on behalf of the Attorney General Phill Kline, he urged the passage **HB 2306**. (Attachment 8)

John Badger, Chief Counsel for SRS, addressed the committee approving the passage of **HB 2306.** In his testimony, Mr. Badger stated that this bill creates funding for use in advocating and prosecuting criminal and civil actions taken against persons with disabilities. They support the concept proposed in this legislation and view it as an enhancement to the current system to protect vulnerable adults. (Attachment 9)

Kansans for Life was represented by Jeanne Gawdun, their senior lobbyist, who reported they are in support of **HB 2849** - wards and guardians; duties and powers of guardians concerning the withholding of nutrition and hydration. In Ms. Gawdun's testimony she stated that their focus is to correct Kansas law in favor of a presumption for life, when a ward of the state has not executed an informed and express document against certain end-of-life measures. (Attachment 10) Ms. Gawdun also submitted an article *Correcting Fatal Flaws in Guardianship Law for Kansans with Disabilities.* (Attachment 11) Also included for committee review was an article from *Kansans for Life* (Attachment 12), an article entitled *Danger Zone,* (Attachment 13).

Tammy Coleman came before the committee to give her support for **HB 2306** and **2849**. Ms. Coleman told of her injury in an automobile accident when she was 26 years of age. At the time she was a 1st Lieutenant in the Army Reserves preparing to leave for Germany to serve her country in active duty and get a promotion to Captain. She never made that appointment due to her accident. At the time of the accident, her family was told that she would be in a vegetative state if she lived. She is still working on her speech, however she is able to walk with support. She urges the passage of both bills. (Attachment 14)

Mary Kay Culp, addressed the committee to let the them know of the work that Tammy Coleman had done to earn the title of lst Lieutenant and that she was soon to get a promotion of Captain at the time that her serious accident which prevented her from furthering her career. (No Written Testimony)

Barb Conant from the Department On Aging reports that they support **HB 2306** as it would create the protection and advocacy for Kansans with Disabilities Fund. The department supports vigorous prosecution of those found guilty of abuse, neglect or exploitation of seniors. (Attachment 15)

AARP (American Association of Retired Persons) was represented by David Wilson who is a member of the AARP Kansas Executive Council. AARP also supports the passage of **HB 2306** relating that this bill would create protection and the advocacy for Kansans with Disabilities Fund. (Attachment 16)

Written testimony in support of **HB 2306** was submitted by Representative Mike O'Neal and Kerrie Bacon, Legislative Liaison for the Kansas Commission on Disability Concerns (KCDC). (Attachment 17 and 18)

With no opponents to the **HB 2306**, Chairman Edmonds closed the hearing and opened the floor for public hearing on **HB 2849** - wards and guardians relating to the duties and powers of guardians concerning nutrition and hydration.

Representative Lance Kinzer addressed the committee on **HB 2849** - wards and guardians; duties and powers of guardians concerning the withholding of nutrition and hydration. Representative Kinzer proposed deleting the language "is suffering from an illness or other medical condition for which further treatment, other than for relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses." He would suggest replacing it with "comatose and suffering from a severe illness such that life sustaining medical care is objectively futile and would only prolong the dying process." Representative Kinzer's proposal would also require that the court conduct a two part inquiry. The other proposal would establish a separate standard for the withdrawal of nutrition and hydration. (Attachment 19) The Representative also included *Comments of Rud Turnbull Co-founder Beach Center on Disability The University of Kansas* for the committee's review. (Attachment 20)

Kevin Graham of the Attorney General's office came before the committee relate that the Attorney General also supports **HB 2849**. (No Written Testimony)

Mike Farmer, Executive Director of the Kansas Catholic Conference commented on the merits of **HB 2849**. His testimony imparted the opinion that the bill would govern decisions including the provision of nutrition and hydration as part of medical care for persons unable to make these decisions for themselves. Mr. Farmer related that on review of the bill he felt that its intent is certainly in keeping with the principles espoused by the Catholic Church in upholding the dignity of the human person. They do urge that the committee move with caution in determining the best language possible to serve the needs of those who cannot speak for themselves. (Attachment 21) Mr. Farmer also included *The Catholic Declaration On Life & Natural Death* in his testimony. (Attachment 22)

Former Representative Rocky Nichols Executive Director of the Disability Rights Center of Kansas addressed the committee supporting **HB 2849.** Mr. Nichols related that the bill seeks to rebalance the powers of a guardian by: establishing a more clear definition of when medical care can be withheld or withdrawn; establishing clear due process rights that shift the focus of the proceeding to the wishes of the individual, and eliminating the bias in law that says if you have a certain type of disability that your life is not as equal to or valuable as others; as well as giving the court discretion in making its decision on all of the relevant facts. (Attachment 23) Also included in Mr. Nichols testimony were copies of a court case In The Matter Of The Guardianship and Conservatorship and written testimony from H. Rutherford, Turnbull, III of Lawrence who supports the passage of **HB 2849**. (Attachment 24 and Attachment 25)

Speaking neutrally on behalf of the Kansas LIFE Project was John Carney. Mr. Carney is the Vice-President for Aging and End of life at the Center for Practical Bioethics in Kansas City and Co-Chair of the LIFE Project Public Task Force. Mr. Carney spoke on the troubling dilemmas raised in the proposed measures of **HB 2849** with the most troubling being "presumption of life". (Attachment 26)

Sandy Kuhlman, Executive Director Hospice Services, Inc. shared her concerns about how medical decisions are made. They have concerns about the intent and language of **HB 2849**. Ms. Kuhlman encourages the committee to send the issue to the Kansas Judicial Council to allow that group to continue its work on drafting appropriate language to protect our most vulnerable without taking away the individual's and family members' sense of autonomy and individuality, their ability to make decisions in the best interest of the individual. (Attachment 27)

With no other persons wishing to address the bill, Chairman Edmonds closed the hearing on **HB 2849**.

Attention was directed to written information submitted by Senator Journey regarding **HB 2577** which had been previously heard. (Attachment 28)

With no further business before the committee, Chairman Edmonds adjourned the meeting.

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GUEST LIST
Date 2/13/06

Kirk Lowry	DRC
Lynn Kirk	
Nancy [illegible]	
Rocky Nichols	DRC
[illegible] Wilson	AARP
MARK BORANYAK	CAPITOL STRATEGIES
Derek Hein	Hein Law Firm
Jean Krahn	KS G-ship Prog
BILL YANEK	KS Assn. of REALTORS
Sandy [illegible]	KS Hospice & Palliative Care Org
John Carney	LIFE Project
Mike Farmer	KS Catholic Conference
Josie Torrez	SILCK
BILL [illegible]	C.S.
Jeanne Gawd	KFL
Mary [illegible]	KFL
Joyce Grover	KCSDV
Mary Kay Culp	KFL
Cynthia Smith	SCL Health System
Tammy Coleman	
[illegible]	Rep. Brown
[illegible]	INTERHAB
Mary Ellen Conlee	Via Christi
FRED Lucky	KHA
Cindy [illegible]	

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Clayton Sherwell	
Maria Mendlaza	
Ron Roznik	
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EQUALITY ♦ LAW ♦ JUSTICE

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Testimony to the

House Committee on Federal and State Affairs

Testimony in Support of HB 2306 (Abuse, Neglect & Exploitation Unit)

February 13, 2006

Chairman Edmonds and the honorable members of the Committee, my name is Rocky Nichols. I am the Executive Director of the Disability Rights Center of Kansas, formerly Kansas Advocacy and Protective Services (KAPS). The Disability Rights Center of Kansas (DRC) is a public interest legal advocacy agency, part of a national network of federally mandated and funded organizations legally empowered to advocate for Kansans with disabilities. As the state designated protection and advocacy system for Kansans with disabilities our task is to advocate for the legal and civil rights of persons with disabilities as promised by federal, state and local laws, including representing persons with disabilities who experience abuse, neglect or exploitation and are seeking civil remedies as a result.

Attorney General Phill Kline and DRC proposed HB 2306 in the wake of the arrest and indictment of Arlan and Linda Kaufman for horrific abuse, neglect and exploitation of Kansans with mental illness that were in their care. Specifically, Attorney General Kline and DRC proposed HB 2306 to address the lack of a dedicated and focused state effort to bring justice on behalf of not only the Kaufmans' victims, but all other Kansans with disabilities who are abused, neglected or exploited. HB 2306 replicates the victim-focused way in which DRC and the Attorney General got into the Kaufman house and helped obtain the first taste of sweet justice for the victims, builds on that success and institutionalizes that victim-focused model into the way that protective services are provided. Currently the State of Kansas does not focus on nor target resources to hold accountable the perpetrators of abuse, neglect and exploitation of persons with disabilities. HB 2306 would rebalance and refocus the system to obtain justice for victims with disabilities, including seniors with disabilities, through criminal or civil prosecution. HB 2306 is not a line item Appropriations Act. HB 2306 is enabling

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legislation that establishes the mechanism by which a Unit that focuses on criminal and civil prosecution of the perpetrators of abuse, neglect or exploitation will be established. The enabling legislation and mechanism in HB 2306 is identical to the way that the Legislature created the access to justice program, which provides legal services to poor Kansans through Kansas Legal Services, as well as legally based domestic violence advocacy programs through domestic violence shelters, etc. The Unit, like these and other state initiatives, is subject to future appropriations and future Legislator's hands are not tied by HB 2306.

When enacted, HB 2306 will close the glaring gaps in the current protection system for Kansans with disabilities. As was pointed out vividly before this Committee last Wednesday, these gaps helped enable the Kaufmans to get away with their abuse and run house of horrors for over 20 years. Additionally, these gaps are still in existence today and they put the over 300,000 Kansans with disabilities at risk of abuse, neglect and exploitation. These gaps include:

- Inability to Investigate - The inability of state-run protective services to conduct effective investigation when you have hostile or uncooperative guardians, or when the victim is coerced or under the control of their abuser.
- No Effective Coordination - The state does not have an effective coordination mechanism for the different protective systems to obtain justice for the victims of abuse, neglect or exploitation.
- No Dedicated Resources to Obtain Justice - Kansas does not direct any state funding specifically for criminal and civil prosecution of perpetrators of abuse, neglect or exploitation against Kansans with disabilities (other than very minor niche funding in the Attorney General's office). Over half of the States provide resources to their state-designated protection and advocacy systems. Kansas is in the minority and does not.
- Turning the Key the Whole way to Open the Door of Justice for Victims – The Unit will provide turn-key services that refocuses efforts on getting justice for victims with disabilities who are abused, neglected or exploited. The current protective services can only "turn the key" part of the way. The Unit will provide focus on the needs of victims and fill the missing gaps that prevent them from obtaining justice (effective investigations in the hard to get into abusive situations, criminal & civil prosecution, etc.), all without creating a new agency.

Kansas has the same basic protective services model which focuses on bureaucratic responses as when Kansans with disabilities were housed in a handful of large institutions. Kansans with disabilities are now served in group homes and community settings in all 105 Kansas Counties. HB 2306 offers the 2006 Kansas Legislature the

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opportunity to bring its protection system for citizens with disabilities up to date and viable for the 21st century.

Historical Background

Arlan and Linda Kaufman began operating their Kaufman Treatment Center group homes full time in 1985. Mr. Kaufman was a licensed Ph.D. social worker and his wife was a registered nurse. Mr. Kaufman had practiced and taught social work for years in Newton.

According to evidence presented at trial, the Kaufman's began abusing the residents of their group homes from the beginning. As time went on the abuses worsened and became more bizarre. The kinds of abuses presented at trial included sexual abuse, medical neglect, financial exploitation, forced labor, slavery, and a myriad of other federal charges. At the end of a five week trial the jury found Mr. and Mrs. Kaufman guilty of 32 and 31 counts respectively.

Beginning February 2004 a six (6) month process of investigation, fact gathering and collaboration brought down the Kaufman houses and their rein of terror. Frustrated by the 20 year lack of progress of the state's primary protection agencies Attorney General Kline reported the abuses occurring at the Kaufman Treatment Center to DRC. Under its authority in 42 U.S.C. 10805 DRC began its investigation of the activities taking place at the Kaufman's group homes.

By May 2004 DRC had collected the facts necessary to use its federal authority to access the group homes themselves and the residents living there. Barbara T. asked to be represented by DRC and was removed from the home and placed in a safe and less restrictive setting the following day by DRC. Having learned that Barbara's guardian was Mr. Kaufman himself, DRC filed for emergency change in guardianship on that same day.

After taking a new look at the Kaufman case at the urging of Attorney General Kline the U.S. Department of Justice decided to pursue federal charges against the Kaufmans. This decision was made in large part because they now had access to a victim and willing witness. By coordinating their efforts, DRC, the Attorney General's office and the U.S. Attorney were able to construct the case against the Kaufmans. On Oct 26, 2004 the FBI, local law enforcement, Department of Justice officials and the U.S. Attorney's office raided the multiple properties held by the Kaufmans collecting even more evidence of the crimes they had committed against the residents of their homes, and against taxpayers. DRC was on site during the raid to protect the rights of the group home residents and to ensure that they were placed in the appropriate service systems to meet both their needs and their preferences.

As you know Arlan and Linda Kaufman were indicted shortly after the raid and just about a year later convicted. In January 2006, the Kaufman's received their prison sentences. The Kaufman's houses of horror have been closed since Oct 26, 2004.

DRC and the staff of the Kansas Attorney general were integral partners in bringing the Kaufmans to justice. Throughout the investigation and trial, DRC and attorney General Kline's staff worked closely to ensure that justice was brought to the victims. Shortly after the Kaufman houses were closed and the residents taken to safety DRC and the Attorney General began exploring the flaws in the current protection system and to design a new system of protection that protects the interests of the victims of abuse, neglect and exploitation with an eye toward criminal and civil justice. HB 2306 is the result of that work and would replicate systemically the success achieved in the 6 months spent investigating and preparing to prosecute the Kaufmans.

HB 2306 Closes Gaps and Opens Opportunities for Justice

As stated above, HB 2306 is enabling legislation that establishes the mechanism by which a unit that focuses on criminal and civil prosecution of the perpetrators of abuse, neglect or exploitation will be established. This legislation empowers the state to close the gaps in the protection system that have been identified as a result of the Kaufman case. This legislation shifts the focus from the serving the bureaucracy through "complete the checkbox forms" investigations and referrals to a system that seeks swift and real justice for victims of abuse, neglect and exploitation.

Learning from the Kaufman Tragedy - Closing the Gaps:

1. *Inability to Investigate - The inability of state-run protective services to conduct effective investigation when you have hostile or uncooperative guardians, or when the victim is coerced or under the control of their abuser.*

HB 2306 brings the federal investigative powers of the protection and advocacy system (DRC) to bear in investigations that are blocked by guardians or other abusers that lawfully impede the other state protective services, e.g., SRS Adult Protective Services (See chart outlining differences between SRS and DRC investigative powers). The Unit empowered by HB 2306 has the powers and resources to fully investigate and prosecute perpetrators regardless of guardians who do not cooperate and other situations that currently impede investigations.

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2. *No Effective Coordination - The state does not have an effective coordination mechanism for the different protective systems to obtain justice for the victims of abuse, neglect or exploitation.*

HB 2306 provides the mechanism to bring together all state protective services for people with disabilities together in a singular effort to both protect people with disabilities and to prosecute their abusers. As the leader of the Unit and the Chief Law Enforcement Officer, the Attorney General will have the ability to bring together the various protective services (e.g., DRC, SRS, KDOA, and KDHE) as well as the KBI, law enforcement, local prosecutors, etc., to ensure effective investigations, effective referrals to law enforcement, effective criminal prosecution, effective civil prosecution and effective efforts to protect the victims of abuse neglect and exploitation. The Attorney General and DRC have already had successful meetings with the different players in the protective services, and have received commitments that they will all participate in this effort and fully collaborate. By bringing all of the protective systems together, the Attorney general can facilitate access to local law enforcement and prosecutors in order to move more cases toward real justice for victims. The protective system partners will also have a ready civil prosecution team with the highest-level of access authority to conduct effective investigations in DRC that can enhance investigations and represent victims of abuse to pursue civil remedies on behalf of victims. HB 2306 does not create a new state agency. It does create the mechanism and focus to coordinate and collaborate for the state's interest in protecting Kansas' most vulnerable citizens.

3. *No Dedicated Resources to Obtain Justice - Kansas does not direct any state funding specifically for criminal and civil prosecution of perpetrators of abuse, neglect or exploitation against Kansans with disabilities (other than very minor niche funding in the Attorney General's office).*

HB 2306 is enabling legislation that establishes the mechanism by which a Unit that focuses on criminal and civil prosecution of the perpetrators of abuse, neglect or exploitation will be established. Over half of the States provide resources to their state-designated protection and advocacy systems. Kansas is in the minority and does not. Without a legislative commitment that brings focus to the issue of abuse, neglect and exploitation of Kansans with disabilities the current antiquated, patchwork quilt style of protective services system will continue to breed and enable new perpetrators of horrific acts like Arlan and Linda Kaufman. The current only serves to abandon the very citizens the state is supposed to protect.

4. *Turning the Key the Whole way to Open the Door of Justice for Victims – The Unit will provide turn-key services that refocuses efforts on getting justice for victims with disabilities who are abused, neglected or exploited.*

The combination of focus, coordination, and improved investigatory abilities will result in swift and effective justice for victims of abuse, neglect and exploitation. By establishing and empowering the Abuse, Neglect and Exploitation Unit then victims will bring to bear the resources of entire protection system to find them safety and real justice. A focused, coordinated and improved system can assure that no stone is left unturned in seeking justice for the victims. The prior briefing received by the Committee showed how the current system can only "turn the key" part of the way, and it cannot get justice for victims with disabilities (inability to conduct effective investigations, focus, etc.). This new way of doing business ensures that each victim has the ability to turn the key to the door to justice the whole way and opening the doors to freedom, safety and life without the fear and pain of abuse, neglect or exploitation.

Conclusion

As the attached case examples show, the opportunity for horrible abuses against Kansans with disabilities did not end when the Kaufman house was shut down.

HB 2306 legislation brings focus, coordination, resources and the ability for the state to turn the key completely and open the door to justice for those who experience abuse, neglect or exploitation. It is important to note that the above gaps in the system that perpetuated the Kaufman's house of horrors and continue to put Kansans with disabilities at risk were identified over the past year by discussions with the key agencies involved in delivering protective services. HB 2306 replicates the successful model of cooperation and collaboration exhibited in the six (6) months that finally brought the Kaufman house down and provides the enabling legislation and mechanism to help prevent future tragedies.

By passing HB 2306, the Legislature will provide real and effective protections for Kansans with disabilities and ensure more certain and swift justice in the future. Passing HB 2306 cannot take back the 20+ years of problems at the Kaufman house and it cannot give back the victims those lost years or make them whole. However, passing HB 2306 will allow the Kansas Legislature to write the final chapter of this tragedy with a new and promising ending … one that learns from past mistakes, fixes the gaps in the system and refocuses the future protective services efforts to serve the needs of the victims and not just the needs of the bureaucracy.

Case Examples of Abuse, Neglect and Exploitation

At last weeks briefing, members of the House Federal and State Affairs Committee requested information on some other cases involving facilities or homes that have had significant reports of abuse, neglect or exploitation. The protective services agencies receive more than 10,000 reports of abuse, neglect or exploitation annually. Below are several examples of cases DRC has investigated, or is actively investigating. These are just a few of the examples that DRC is familiar with … and this is without an Abuse, Neglect and Exploitation Unit and without HB 2306 being passed into law.

Kansas Nursing Facility – 30 year history of resident preying on and raping others: Please note that this particular facility has had significant deficiencies reported over the years with many, many findings of abuse and neglect. This facility continues to be licensed by the state after years of problems and even after the horrific and atrocious abuse and neglect detailed in this summary. That is because the current system focuses on responses that serve the bureaucracy, like licensure, citations, corrective plans of action, etc. That system does not focus on obtaining justice for the individuals who have been wronged.

A nursing facility failed to protect its residents from being anally raped by another resident even though staff at the facility knew that the male resident who was the perpetrator had a 30+ year history of being a sexual predator against other men who have cognitive impairment. The evidences shows that the perpetrator resident was having forced and unconsensual sodomy of several residents of the facility over a period of time. The facilities own records and files on the perpetrator show a well documented 30 year history of inappropriate sexual behavior and forced anal rape of low functioning male peers. In short, this perpetrator had a 30 year history of preying on low functioning men, of controlling them, and of raping them. The facility knew this, it was clearly spelled out in his records, yet the facility recruited this individual from Larned State Hospital and according to state licensing inspectors, the facility did not take steps to protect the other residents from this known sexual predator.

These are some additional examples of multiple violations listed in multiple survey reports completed by state licensing officials on this same facility. All of these deficiency citations are considered violations of residents' rights to proper care and treatment and to be free from abuse, neglect and exploitation. This is a text book example of how the current system focuses on the bureaucratic response and not the needs of the victims to obtain justice. This facility is still open today. And even if it were closed down, how would that action get justice for the low functioning adults who were not protected from being rapped by a known sexual predator.

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Attachment 2

11/8/04 Survey:

- *Staff did not ensure privacy for opening mail, residents required to open mail in front of staff*
- Privacy Curtains missing
- No private place to make phone calls
- Resident eloped to graveyard, not investigated or reported
- *Incident of one resident hitting another (abuse) not investigated or reported*
- *Resident's personal possessions were taken by staff, the room had no running water and the bathroom and closet were locked*
- RAPS generic and not done by licensed staff
- Residents did not have annually required MDS surveys
- *Resident with MR not given required specialized services, including toileting*

2/13/04 Survey

- *Failure to report and investigate abuse*
- *Room did not have personal belongings, bathroom locked with clothing, etc. inside, and resident was had to urinate in their room*
- Care plan for a resident did not say how often to toilet resident, since bathroom locked
- *Care plan for a resident did not address problems with falls, weakness, balance, even after the person fell or obtained injuries multiple times*
- *Failed to follow doctor order to seek urgent care X-ray for fractured hand*

2/22/05 Survey

- *Resident was diagnosed with colon cancer. Doctor ordered treatment, but facility failed to contact guardian to arrange for treatment. Social worker said guardian was out of the country, however the guardian was not. Records were apparently forged to cover up these mistakes. Life saving treatment was delayed for months.*
- *Resident's bed placed in hallway with no curtain or privacy*
- *Staff, directed by administrator, kept resident out of his room while they cleaned it and threw away his personal property and possessions*
- *Misappropriation of resident's property not investigated or reported*
- *Administrator told resident he would be thrown out because the resident reported a sexual assault. Administrator told the resident that he could call a taxi and go to the rescue mission to live. Resident looked for a phone to call taxi.*
- *Administrator did not want a resident screened into a hospital from the facility, called screener and told screener not to discharge resident, even though this violated the persons legal rights and further violated the requirement of discharge planning.*
- Administrator tried to have resident's home pass revoked to keep him in facility.

Eastern Kansas ICF/MR:
DRC reviews the surveys conducted for every Intermediate Care Facility for persons with Mental Retardation (ICF/MR). The surveys are conducted by the Kansas Department on Aging to determine whether the ICFs/MR are in compliance with the conditions of participation for Medicare and Medicaid. Recently DRC reviewed a survey that reported serious abuse and neglect of at least four individuals in an eight (8) bed ICF/MR. This example represents the results of only one survey. Without violating confidences, here are some examples of wrongs that have been done to these individuals with developmental disabilities.

J.P. is a person with mental retardation. He is also quadriplegic, nonverbal, and uses a feeding tube. J.P. was left uncovered for hours in a very cold room and was infected with pinworms due to maggots in his feeding tube while under the care of the ICF/MR. A.C. is a person with mental retardation and other disabilities that prohibit her from moving herself independently. She was left unattended in the shower for over an hour with the water hitting her in the face. D.H. is another person with mental retardation. D.H. was restrained between his mattress and his fitted sheet by ICF/MR staff (sheet was basically used as a way to "tie" the person to the bed and immobilize the resident). D.P. was put to bed in soiled clothes and dirty shoes. In another incident, the ICF/MR failed to follow up on recommendations by D.P.'s dentist. When the dentist found 10-15 cavities, he recommended a follow-up surgery. The ICF/MR did not return D.P. to the dentist for almost a year. As a result of the failure of the provider to address this dental care need, D.P. refused to eat and drink, leading to dehydration and lithium toxicity.

Suspicious Deaths in Facilities:
Southeast Kansas Nursing Facility - DRC reviews annual survey reports conducted by the state licensure agencies on a variety of Kansas nursing facilities. In a review of a facility located in southeast Kansas, DRC discovered a probable incident of neglect in which the facility had a resident to lay on the floor for three days during the "down" part of her bipolar cycle. The resident was not provided with adequate water, food or health attention and she went to the hospital with kidney failure and sepsis. She died. DRC immediately asked the facility for the identity and contact information for the resident or her guardian, asserting our federal access authority. The facility denied access for several months. DRC was forced to file against the facility in federal court to enforce our federal access authority. DRC was successful in gaining access to the facility, records and staff of the facility in order to conduct its investigation.

Group Home - DP was a man with schizophrenia. He was discharged from a local hospital mental health treatment program in an unstable mental condition. A local mental health center placed him in a group home. DP was having seizures. House log notes showed that staff were supposed to call 911 and obtain medical intervention if he had another seizure. DP had numerous seizures over the course of many days with no medical intervention by staff. On February 9, 2005 DP was found dead in his room.

Western Kansas Nursing Facility – The victims was a long-time resident of a state mental health hospital. DRC was initially contacted by his guardian who requested assistance with adequate discharge planning. Appropriate discharge to an NF was obtained. While at the state hospital, the state hospital staff SRS attorney represented the guardian and filed for authority for a Do Not Resuscitate order (DNR). The district court granted the DNR. This DNR was granted under the current flawed law on withhold/withdraw of medical care (HB 2849 and HB 2884 attempt to fix this flaw). The person transferred to a NF in western Kansas. There were many instances of choking documented in his records. Nonetheless, he was denied medical treatment, choked and died. DRC is investigating this incident and the potential abuse and neglect that occurred, as well as what role the DNR may have played in the persons death.

The above examples are only the tip of a very large iceberg that lies under the surface of the cursory reviews the state currently conducts of places that people with disabilities are served in Kansas. These are not the only examples. They do however clearly illustrate the current bias in the system that focuses on the needs of the bureaucracy (licensure, policy manuals, corrective plans of actions, paper work, etc.) and not the needs of the victims to receive justice. All the above facilities are still open and their licenses have not been pulled.

DISABILITY RIGHTS CENTER OF KANSAS, INC.
Protection & Advocacy for Kansans with Disabilities Fund
Abuse, Neglect and Exploitation Unit
Estimated Budget Summary

BUDGET CATEGORY:		BUDGET AMOUNT
PERSONNEL: (LIST EACH POSITION TO BE FUNDED)		
A.	Victim's Attorneys (5 @ $45,000)	225,000
B.	Vicitm's Investigators / Advocates (8 @ $30,000)	240,000
C.	Fringe Benefits	127,859
	Subtotal	**$592,859**
TRAVEL / TRAINING:		
A.	In-State Travel, Training, and Outreach	46,650
	Subtotal	**$46,650**
CONTRACTUAL SERVICES:		
A.	Audit	3,700
	Subtotal	**$3,700**
OFFICE & OFFICE RELATED EXPENSES:		
A.	Rent - New Wichita Office	49,000
B.	Office Supplies	13,341
C.	Telecommunications Expense	8,700
D.	Postage	1,750
E.	Equipment / Equipment Repair & Maintenance	15,000
	Subtotal	**$87,791**
	TOTAL BUDGET:	**$731,000**

Estimated In-Kind Agency Match Toward DRC's Effort $ 100,000

Total Cases Served by DRC:

FFY 2003	**264**
FFY 2004	**406**
FFY 2005	**885**

Comparison of DRC and APS/SRS Access Authority to Investigate Complaints of Abuse or Neglect

Problem: Hostile, Uncooperative, or Abusive Guardian. Guardian may be the one perpetrating or assisting (ether actively or tacitly) the abuse, neglect or exploitation. For example, at the Kaufman House Mr. Kaufman was the alleged abuser of his ward, and the other guardians uncooperative or were AWOL.

Situation	*Access Sought*	*DRC Authority*	*APS/SRS Authority*
Individual has a guardian, *guardian refuses consent*	**Individual**	Yes. Reasonable Unaccompanied Access, but must terminate interview at individual's request.	No. Can only do so with a court order. Problem: how can SRS convince the court to do this without this information? Protective services includes evaluating need for services, would have to obtain court order to enjoin guardian from interference under 39-1405 (residents) or 39-1437.
	Facility	Yes. Reasonable Unaccompanied Access to public and private places (including private residences)	No. Can only do so with a court order.
	Records	Yes. DRC makes reasonable effort to contact the guardian. If guardian fails to respond or fails to consent or to act on behalf of the individual, DRC still has access authority. 42 U.S.C. §§ 15043(a)(2)(I)(iii), 10805(a)(4)(C).	No. Can only do so with a court order. Problem: how can SRS convince the court to do this without this information? Protective services includes evaluating need for services, may get court order to enjoin guardian from interference under 39-1405 (residents) or 39-1437.
	Conduct ANE Investigation	Yes. Even without a guardians consent, DRC can fully conduct its ANE investigation under federal law.	No. Can only do so with a court order. Problem: how can SRS convince the court to do this without this information?

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Problem: No guardian, person with a disability does not appear to have capacity and person does not provide consent.

Situation (a complaint is received in all)	*Access sought*	*DRC Authority*	*APS/SRS Authority*
Individual does not have a guardian, does not appear to have capacity, and *person does not consent to investigation.*	**Individual**	Yes. Reasonable Unaccompanied Access.	No. Not unless a court order finds that the person does not have capacity and needs a guardian. May petition for appointment of a guardian. § 39-1437(a). May seek court authorization if regarding a resident of a facility 39-1407, May petition for appointment of a guardian if a resident 39-1408.
	Facility	Yes. Reasonable Unaccompanied Access to public and private places (including private residences)	No. Can only do so with a court order.
	Records	Yes. Access to all records 42 U.S.C. §§ 15043(a)(2)(I)(ii), 10805(a)(4)(B).	No. Not unless a court order finds that the person does not have capacity and needs a guardian. May petition for appointment of a guardian. § 39-1437(a). May seek court authorization if regarding a resident of a facility 39-1407, May petition for appointment of a guardian if a resident 39-1408.
	Conduct ANE Investigation	Yes. Even without consent of the individual, DRC can conduct its ANE investigation under federal law (person may or may not talk to DRC, but investigation could be conducted).	No. Not unless a court order finds that the person does not have capacity and needs a guardian. May petition for appointment of a guardian. § 39-1437(a). May seek court authorization if regarding a resident of a facility 39-1407, May petition for appointment of a guardian if a resident 39-1408.

Problem: Person with a disability does not have a guardian, has capacity, but does not consent to the investigation (perhaps because they are being threatened or coerced by the perpetrator).

Situation (a complaint is received in all)	*Access sought*	*DRC Authority*	*APS/SRS Authority*
Individual does not have a guardian, has capacity and ***does not consent to the investigation.***	**Individual**	Yes. Reasonable Unaccompanied Access, but must terminate interview at individual's request	No. 39-1437, 39-1407 (resident).
	Facility	Yes. Reasonable Unaccompanied Access to public and private places (including private residences)	No. Can only do so with a court order.
	Records	No.	No. 39-1437, 39-1407 (resident).
	Conduct ANE Investigation	Yes. Even without consent of the individual, DRC can conduct its ANE investigation under federal law (person may or may not talk to DRC, but investigation could be conducted).	No. If the person clearly has capacity, SRS cannot conduct the abuse and neglect investigation without the persons consent.

Select Citations:

"If the department and such officers determine that no action is necessary to protect the adult but that a criminal prosecution should be considered, the department and such law enforcement officers shall make a report of the case to the appropriate law enforcement agency." § 39-1433(a).

If the complaint is about a resident of an adult care home, medical care facility, or state psychiatric hospital or state institution for the mentally retarded, *"Any . . . agency authorized to carry out the duties enumerated in this act, . . . shall have access to all relevant records." §39-1406*

"The authority of the secretary . . . shall include, but not be limited to, the right to initiate or otherwise take those actions necessary to assure the health, safety or welfare of any resident, subject to any specific requirement for individual consent of the resident." 39-1406 (for IMDs, state ICFMRs, MCFs, & ACHs).

All DRC authority to access facilities and residents comes from: 42 U.S.C. § 15043(a)(2)(H), 45 C.F.R. § 1386.22(f), 42 U.S.C. § 10805(a)(3), and 42 C.F.R. § 51.42(b).

DRC access to facilities for an abuse or neglect investigation does include the opportunity: "to interview any facility service recipient, employee, or other person, including the person thought to be the victim of such abuse, who might be reasonably believed by the system to have knowledge of the incident under investigation . . . ." DD Act regulations, 45 C.F.R. 1386.22(f).

Under the PAIMI regs, reasonable unaccompanied access to facilities and residents includes the opportunity "to interview any facility service recipient, employee, or other persons, including the person thought to be the victim of such abuse, who might be reasonably believed by the system to have knowledge of the incident under investigation." 42 C.F.R. § 51.42(b).

The PAIMI provision regarding access to residents states "Residents include adults or minors who have legal guardians or conservators. P&A activities shall be conducted so as to minimize interference with facility programs, respect residents' privacy interests, and honor a resident's request to terminate an interview." 42 C.F.R. § 51.42(c).

Kansas.com

Posted on Wed, Nov. 09, 2005

Failure

Kaufman case shows need for reforms

Justice finally caught up with Arlan and Linda Kaufman -- but justice took far too long. "State policy and state law failed the victims of the Kaufman House," Rocky Nichols, director of the Disability Rights Center of Kansas, told The Eagle editorial board Tuesday.

He's right. And disabled Kansans and their families deserve better.

The Kaufmans were found guilty this week of abusive treatment of patients under their care over two decades. It's good to know that these exploiters now face years behind bars.

But questions linger that state policymakers must address: Why weren't the Newton couple's crimes discovered sooner -- and how can the state ensure that such abuse never happens again?

In fact, the warning signs were everywhere in this case. As far back as 1984, the Kaufmans were the focus of complaints, and for several years afterward the Kansas Department of Social and Rehabilitation Services pressed them to license their facilities.

Instead, the Kaufmans repeatedly ignored the orders and prevented SRS case workers from even having contact with residents. That should have been a huge red flag.

In 1990 the Kaufmans even sued the SRS. Incredibly, SRS settled out of court, awarding the couple $8,250, and then pretty much washed its hands of the Kaufman House.

SRS failed to act -- and no one else did -- after the Kansas Supreme Court ruled in 1991 that the Kaufman homes must be licensed. How could that happen?

SRS officials claimed they didn't have jurisdiction. But all it would have taken, says Nichols, was a simple regulatory change that should have taken weeks. "They've had 15 years to do that," he notes, but never did.

In the last legislative session, Nichols and Attorney General Phill Kline helped enact legislation that closed some of the legal loopholes. Among the changes: Group homes must now be licensed or face prosecution and closure.

But Nichols says two additional reforms are needed to protect disabled Kansans.

One would prevent a nonfamily care provider such as Kaufman from also being a patient's legal guardian. That's a clear conflict of interest and an invitation to abuse and fraud. Another proposal would establish a new state abuse and neglect unit to coordinate protection services for Kansans with disabilities.

At present, such oversight is fragmented among four agencies: the Kansas Department of Health and Environment, SRS, the attorney general's office and the Center for Disability Rights.

"No one is forcing collaboration," says Nichols.

State lawmakers should make these changes a priority in the next session.

For the editorial board, Randy Scholfield

FEDERAL AND STATE AFFAIRS
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Attachment 4

Kansas.com

Posted on Sat, Feb. 11, 2006

Listen

EDITORIAL: ABUSE CRIES OUT FOR REFORM

Nobody listened to them. State officials for two decades largely ignored the pleas of patients and their families to do something about the Kaufman House in Newton.

That's right -- for two decades, Arlan and Linda Kaufman were able to keep their shop of horrors running, despite mounting evidence that they were flouting regulations and routinely abusing mentally ill patients under their care.

"State policy and state law failed the victims of the Kaufman House," Rocky Nichols, director of the Disability Rights Center of Kansas, told The Eagle editorial board in November.

It's time for Kansas legislators and other policymakers to correct those failures.

State officials had plenty of warning signs about the Kaufmans -- including patient complaints as early as 1984 and the Kaufmans' obstinate refusal to license their facilities. But the red flags didn't lead to strong action or follow-up by the state agencies in charge, most notably the Kansas Department of Social and Rehabilitation Services.

Incredibly, even after the Kansas Supreme Court ruled in 1991 that the Kaufman House must be licensed, SRS failed to act.

The Kaufmans are now serving long prison sentences for their crimes. But that's not enough to right this wrong. The case revealed glaring flaws in the state's fragmented protective services system that must be fixed.

To its credit, the Legislature last year closed one loophole by requiring that group homes be licensed or face closure. Two additional measures this session deserve approval by lawmakers:

One would establish an abuse and neglect unit within the attorney general's office to coordinate information and spearhead action on abuse cases. The $1 million annual price tag is worth it to ensure that the protective services network is effective and accountable to its clients.

The other proposal would forbid a nonfamily member from being both legal guardian and therapist. As the Kaufman case showed, that's an invitation to abuse: Arlan Kaufman shifted thousands of dollars from one client into his bank account.

Lawmakers shouldn't let themselves be distracted by a third more controversial proposal involving Terri Schiavo end-of-life euthanasia and consent issues. Pass the first two reforms, which appear to enjoy broad support, and leave this debate out of it.

Lawmakers should ensure that the state never again fails to protect its most vulnerable citizens.

For the editorial board, Randy Scholfield

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Attachment 5

Testimony to the
House Committee on Federal & State Affairs
Testimony in Support of HB 2306 & HB 2849

February 13, 2006

Mr. Chairman and members of the Committee my name is Lynn and I was a resident at one of the Kaufman group homes from 1985 to 1986. I'm here today to tell you my story and ask you to take action because of my experience. But more importantly I'm here today to talk for my friends who were not as lucky as me and can not be here because they were abused by the Kaufmans for more than 20 years.

I spent about half of my time at the Kaufman group home in the locked seclusion room. I was required to stay in seclusion for up to a week at a time. I was naked and forced to sleep on the floor with only a piece of carpet for a blanket. All of the windows in the room were boarded up so I could not see out, and no else could see into the room. I used a wastebasket for a bathroom unless someone heard me pounding on the door and let me into a real bathroom.

The house where I lived was in very bad shape. The Kaufmans didn't want contractors to see what was going on in the House so Mr. Kaufman did all the repair work himself. It was very unsafe. There were loose and exposed wires, the stairs were very unstable and unhealthy. The house was full of roaches and other bugs. It was a disgusting place to live. I lived in fear that the house would catch fire and I would be locked in the seclusion room with no one to let me out.

Mrs. Kaufman was responsible to pass out medications, but the medicine was put in little containers that often spilled. No one really knew which medications they were supposed to take. Sometimes they would spill, get mixed up and we had to just guess which ones were ours. We couldn't tell what was what. She was supposed to be our nurse but instead left us to figure things out for ourselves.

Like the other residents I was under the total control of the Kaufmans. They made me believe that I was a danger to myself and that's why I was required to be naked and stay in the seclusion room. Now I know that he kept me locked in there for other reasons too. He threatened me that if I didn't comply with his demands that he would send me to a state hospital or nursing facility. I was scared of him and I didn't now that I would have been treated better at those places.

My parents paid the Kaufmans $1,000 a month for me to live there. The Kaufmans also took my disability check. Dr. Kaufman convinced my parents that he had to keep me naked in order to keep me safe. He kept telling them that he was the therapist and was doing what was best for me. He justified it by manipulating the truth. Neither my parents no I knew any better. He fooled us all.

I came here today to make sure you knew the whole truth about what happened to me and the others who lived at the Kaufman houses. I can speak for myself but many of the others can't. Their lives have been shattered and they may never recover from what the Kaufmans did to them. Even after all of the years I've been out of that horrible place, I struggle. You are our last hope for justice.

I'm here today to ask you to make sure that neither I, nor anyone else is ever subject to this kind of abuse again. You can change the law to make sure that no more Kaufmans can abuse people for 20 years without being caught.

I'm asking you to take action today to make sure that the people who investigate reports of abuse listen and believe the victims.

I'm asking you to make sure that victims are removed from the people and places that abuse them.

I'm asking you to act today to make sure that people like my friend Barb are not under the control of guardians like Arlan Kaufman.

I'm asking you to pass new laws that guarantee that people like me and others who lived at the Kaufman group homes are fully protected from abuse.

We need you to pass these laws so that people with mental illness and other people with disabilities don't ever have to experience that kind of abuse again.

Testimony to the

House Committee on Federal & State Affairs

Testimony in Support of HB 2306 & HB 2849

February 13, 2006

Mr. Chairman and members of the Committee my name is Nancy and I was a resident at one of the Kaufman group homes from March 1986 to March 1987. Although I left in March 1987 Kaufman continued to pressure me to through my church, my job and my therapists to return to his "treatment facility." I was there when Kaufman started his abuse of the people who were living there. I am one of the lucky ones, I was there at the beginning of the abuse and got out before he got worse and before he started video taping. Because I got out I can be here today to talk for my friends who were not so lucky were abused by him for more than 20 years.

I am a person with mental illness. I was sent to the Kaufman group home by the professionals at Prairie View and my church who trusted Kaufman. They didn't know that he was lying to them and manipulating the truth about what he was really doing.

The time I spent at the group home was the worst days of my life. Kaufman put me into a locked seclusion room for up to three weeks at a time. My clothes were taken from me. There was no bed to sleep in, or blanket to cover up, just me. For me, Kaufman used seclusion as his way to control me, punish me and make me do what he wanted. I was not let out until I agreed to do and say what he directed me to do and say. He made me agree that I could never get married, never have children, never keep lasting friendships, never keep and job and lots of other things. He kept me in the seclusion room until I admitted and believed that I was responsible for my father sexually abusing me. That somehow I purposely seduced my father. He convinced my mother that I played a big part in the abuse. That was SO WRONG.

Other residents were told that they were being put in the seclusion rooms for other reason. For example, they might be told it was for their safety. They were told that they couldn't wear their clothes because the might hurt themselves with them. He convinced them that they were a danger to themselves. None of that was true.

As time went on he got worse. He wouldn't let us talk to anyone without his permission. He began the sexual abuse. He was using money as a disciplinary tool. He made us work for no pay. It was slavery. It was involuntary servitude. He wouldn't let anyone come in to the house and we were too afraid to let people in when he wasn't there. You need to understand that he controlled everything we did and said.

Several of you asked how the Kaufman's got away with their abuses for so long. What you need to understand is that he was a master liar and manipulator. Not only did he lie and manipulate the residents, but he lied and manipulated the resident's families, significant others, the doctors, other therapist and the SRS investigators. He told each of them what he knew they needed to hear to leave him alone and allow him to keep us under his control. He had everyone convinced that he was legit.

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You also asked why no one did anything after they were told about the things happening at the group homes and on the farm. I was the first resident to report what was happening. I told the people at Prairie View, I told people at my church, I told SRS, and I told my therapist and my doctor but no believed me. In fact they made me go back to that terrible place. I did everything I was supposed to do and no believed me, and no one investigated my story. I was one of four reporters that were either residents or a family member. No one listened to me. Everyone failed me. Everyone failed all of us. That must never happen again!

You can not give me back what I lost during the time I was at the Kaufman house, or the 18 years I've suffered since. Now that you have heard my story I want you to take action to make sure that this never happens to anyone again.

You need to take action today make sure that the system that is supposed to protect people with mental illness and other disabilities listens to victims and supports their needs. The people who investigate abuse and neglect must believe the people who are telling their stories regardless of their diagnosis and the stigma attached to mental illness. We needed justice and justice never came.

You need to act today to make sure that guardians like Mr. Kaufman do not have conflicts of interest like he did with Barb. No one believed me about what he was doing to Barb. He was allowed to control her whole life. He abused her, he stole her money, and he stole her life. He should never have been allowed to be her guardian. She needed justice and as her guardian he made sure that justice never came.

You need to make sure that guardians like Arlan Kaufman never have the ability to make end of life decisions without the courts approval. I know that if Barb would needed any kind of medical care to continue living and Kaufman was able to decide her care he would have just let her die. You need to make sure that people like him can not make that kind of decision without real oversight. You need to make sure that people like me, and people like Barb have access to justice.

Arlan and Linda Kaufman have been sentenced to prison but that alone doesn't give me justice. He will spend the rest of his life in seclusion in a jail cell and in a prison that is better than the days I and others spent in his seclusion rooms. So, his being put in jail does not bring me closure, nor does it right the wrongs done to me and the other residents of his group home. I will not know justice, or closure until I know that you have done everything necessary to make sure that this never happens to anyone again.

Please don't focus on what failed in the past, but focus on fixing the future problems by passing these Bills. If we had been children you would have changed the laws immediately. Children are believed when they report abuse. I wasn't believed. We don't deserve anything less than what you would do for child. People with mental illness deserve that same justice. Today is the day for action. Do the right thing.

STATE OF KANSAS
OFFICE OF THE ATTORNEY GENERAL

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February 13, 2006

HOUSE FEDERAL & STATE AFFAIRS COMMITTEE

Testimony in Support of
House Bill No. 2306
Kevin A. Graham
Office of the Attorney General

Dear Chairman Edmonds and Members of the Committee:

Thank you for allowing me to appear before you on behalf of Attorney General Phill Kline and offer testimony in support of HB 2306.

By now virtually everyone has heard some of the details of the tragic case of abuse, neglect and exploitation of those with mental illness in the Kaufman House case. HB 2306 is the product of the collaborative efforts of Attorney General Kline and the Disability Rights Center of Kansas in response to that horrific case. HB 2306 is intended to create a dedicated a mechanism to discover, investigate and prosecute cases of abuse of disabled individuals statewide. While we would all certainly like to find a way to undo what has happened to the Kaufman's victims that is not possible. What is possible is to create a system that will help discover at-risk situations and hopefully prevent other disabled citizens from being victimized in to the future.

Utilizing lessons learned from the Kaufman House case in the area of collaboration and cooperation between existing agencies, HB 2306 seeks to replicate the victim-focused manner through which Attorney General Kline and the DRC first obtained access to the Kaufman victims and obtained justice for those victims through the criminal justice process. As the DRC has high-lighted, currently the State of Kansas does not focus on nor target resources to hold accountable the perpetrators of abuse, neglect and exploitation of persons with disabilities. HB 2306 realigns the system to focus on justice for victims with disabilities, including seniors with disabilities, through criminal or civil prosecution.

HB 2306 may properly be described as enabling legislation for the establishment of a dedicated unit that will focus on criminal and civil prosecution in cases where disabled individuals have been the victims of abuse, neglect or exploitation. This legislation is modeled on the way the legislature created the access to justice program, which provides legal services to disadvantaged Kansans through Kansas Legal Services, as

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well as legally based domestic violence advocacy programs through domestic violence shelters, etc. This new unit, like Kansas Legal Services and others, would be subject to future appropriations each year, and thus would be monitored by the legislature for success or failure through the budget process just like other programs or agencies.

This committee has been briefed on the facts of the Kaufman case and I will not attempt to fully recite those facts herein. One of the lessons learned from the Kaufman case was that there are gaps within the structure of the current protection system for Kansans with disabilities. In his written testimony Rocky Nichols, Executive Director of the DRC, details many of the gaps in coverage/protection that have been identified. In simple terms, HB 2306 is intended help close those gaps and provide an increased level of protection for the over 300,000 Kansans with disabilities.

The Kaufman House has been shut down. Arlan and Linda Kaufman were indicted and convicted in federal court in a case jointly prosecuted by the U.S. Attorney's Office and the Office of the Attorney General. The Kaufman's have been sentenced to prison and ordered to pay restitution and fines in excess of $700,000. While it took far too long to bring the defendants to justice in that case, what is even more important now is to prevent other cases like the Kaufman's in the future. HB 2306 provides tools needed to uncover cases of abuse, neglect or exploitation of disabled individuals and tools necessary to fully prosecute the offenders.

The Attorney General and the DRC were partners in finding justice for the Kaufman n victims. HB 2306 presents the opportunity to further strengthen that partnership and to provide greater resources to the partnership in order to better protect Kansas citizens.

<u>What does HB 2306 do?</u>

- Close gaps in existing coverage for disabled Kansans. HB 2306 allows for the utilization of federal investigative powers afforded to the DRC to investigate cases where guardians or others impede investigations by State agencies.
- Establish a specific unit focused on criminal and civil prosecution of perpetrators of abuse, neglect or exploitation of disabled individuals. Utilizing professional investigators and prosecutors with specialized knowledge and training for handling these types of cases insures a higher quality of investigation and strengthens the ability to prosecute offenders.
- Improved coordination of resources. The new unit will be under the direction of the Attorney General will have the ability to bring together the various protective services (e.g., DRC, SRS, KDOA, and KDHE) as well as the KBI, law enforcement, local prosecutors, etc., to ensure effective investigations, effective referrals to law enforcement, effective criminal prosecution, effective civil prosecution and effective efforts to protect the victims of abuse neglect and exploitation.
- Dedicated resources for protecting vulnerable citizens. Kansas is currently one of a minority of States that does not provide resources to their state-designated protection and advocacy agency. HB 2306 would allow for additional funding of

the DRC thus giving the state additional resources to investigate and uncover acts of abuse, neglect or exploitation of disabled citizens.

- Justice for victims. The creation of the Abuse, Neglect and Exploitation Unit provides a resource that will lead to safety and justice for victims. A dedicated, well-coordinated investigative team with a goal to seek out incidents of abuse, neglect or exploitation and aid the victims demonstrates the State's commitment to protecting those who often can not protect themselves.

On behalf of Attorney General Phill Kline, I encourage the Committee to support HB 2306 and to recommend the bill favorably for passage.

Respectfully,

Kevin A.

Kevin A. Graham
Assistant Attorney General
Director of Legislative Affairs

Kansas Department of

Social and Rehabilitation Services

Gary Daniels, Secretary

For additional information contact:

Federal and State Affairs Committee

February 13, 2006

HB 2306 - Protection and Advocacy Fund

John Badger, Chief Counsel

296-3967

Public and Governmental Services Division
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Kansas Department of Social and Rehabilitation Services
Gary Daniels, Secretary

House Federal and State Affairs Committee
February 13, 2006

HB 2306 - Protection and Advocacy Fund

Chairman Edmonds and members of the committee, thank you for the opportunity to discuss HB 2306. I am John Badger, Chief Legal Counsel for SRS. This bill creates funding for use in advocating and prosecuting criminal and civil actions taken against persons with disabilities The funding would be used to coordinate the efforts of the Attorney General's office and the protection and advocacy system for disabled Kansans, primarily administered through the Disability Rights Center (DRC).

The Department provides adult protective services to help safeguard the well being and general welfare of adults (age 18 and older) in need of protection from abuse, neglect, exploitation or fiduciary abuse. SRS social workers investigate reports and provide protective services to adults, including elderly and disabled adults, who reside in the community and in facilities licensed/certified by SRS.

Over 5,000 instances of abuse, neglect, exploitation and fiduciary abuse were investigated in FY 2005. Nearly 1,200 of these cases were confirmed; 75 percent of these were confirmed for self-neglect. Less than 10 percent of investigated cases are referred to law enforcement. An equal proportion of investigations involve individuals over and under the age of 60. The Department works with numerous partners including law enforcement, local attorneys, prosecuting attorneys, Area Agencies on Aging, Community Mental Health Centers, local medical providers, and community organizations and advocates to investigate and offer protective services .

We support the concept proposed in this legislation and view it as an enhancement to the current system to protect vulnerable adults. Development of a system that offers a strong link to civil and criminal prosecution of cases confirmed of abuse, neglect, or exploitation provides an additional resource to staff.

SRS has developed a more collaborative relationship with both the DRC and the Attorney General's office as we work towards the common goal of improving the safety of vulnerable adults in Kansas. If this bill is enacted, a more formalized documentation of the partnership will be needed to further define roles and prevent duplication of effort.

Thank you for the opportunity to support this bill.

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Kansans for Life

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PROPONENT - HB 2306, HB 2849, HB 2884

Feb. 13, 2006
House Committee on Federal-State Affairs
Chairman John Edmonds

Good afternoon, Chairman Edmonds and members of this Committee. I am Jeanne Gawdun, senior lobbyist for Kansans for Life, an affiliate of the National Right to Life Committee. Our concern is protection of innocent human lives, particularly those threatened by abortion, infanticide and euthanasia.

I am here today in support of House bills 2306, 2849 and 2884, proposals to protect Kansans with disabilities. For several years our organization has testified in support of related legislation in the House judiciary committee, most recently, HB 2307. Our focus in this legislation is to correct Kansas law in favor of a presumption <u>for</u> life, when a ward of the state has <u>not</u> executed an informed and express document against certain end-of-life measures.

There is an understandable reluctance to take ordinary matters to court. But we are not dealing with <u>ordinary</u> matters here, and the law would <u>not</u> be imposing new duties to families at the bedside. (See Attachment A.)

Current Kansas law does not afford due process rights for people with disabilities before medical care, including food and water, can be withheld or withdrawn. In fact, current law says that a judge must allow the ward to lose his life without due process and with no discretion to the court.

Unfortunately, a physician's signature can represent a quality of life decision that overshadows a medical analysis. See Attachment B-- a sample of studies in which patients rated their quality of life as high, but their physicians rated the same patients as having a low quality of life. See also Attachment C-- in regards to medical ethics permitting starvation for even non-comatose and non-terminally ill patients.

These three bills are important to pass out of committee. HB 2306 will hold perpetrators of abuse and neglect accountable. HB 2849 will fix our fatally flawed withhold/withdraw law by correcting the vague and broad definition while establishing due process rights for Kansans with disabilities. HB 2884 corrects this same withhold/withdraw law and also prohibits conflicts of interest for non-family guardians. We offer one amendment of a few words length, for clarity – see Attachment D.

In conclusion, it is your grave responsibility to structure the law to protect the lives of Kansans who may not possess a worthy guardian at the time their lives are in jeopardy. Even convicted criminals are afforded due process before the death sentence is carried out -- Kansans with disabilities deserve no less.

Thank you, I stand for questions.

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Kansans for Life Attachment A -- Proponent HB 2306, 2849, 2884 –2/13/06

Correcting fatal flaws in Guardianship law for Kansans with Disabilities - HB 2849 & HB 2884

A ward of the state with disabilities, who is not dying or in a coma, can nonetheless have his/her food & fluids withheld and a DNR (do not resuscitate order) put in place, under current Kansas law. Under current law, the judge must grant the petition filed by the ward's guardian as long as there are 2 physician's signatures verifying the ward's disability and his/her need for assistance (broadly defined). Due process would insure a proper hearing with legal counsel for the ward before granting any death sentence.

Both bills do NOT affect:

- families making end-of-life decisions unless a family member is a ward or guardian

Current Kansas law WRONGLY allows the guardian to withhold food & fluids from

- a disabled individual who is not dying or comatose
- and who needs some assistance (feeding tube, oxygen tank, dialysis, etc.)
- and the judge must permit it

Both bills ONLY affect:

- an individual with a disability
- who has a court-appointed guardian
- and who has NOT executed a living will, advanced directive, or durable power of attorney governing his/her current condition

Corrected Kansas law WILL require:

- that any non-family guardian be free from conflicts of interest
- that the individual who is a ward receives 'due process' before losing his/her life
- that food & fluids not be denied

The third bill, HB 2306, will fund a special unit to investigate & prosecute abuse

HB 2306 would create a special Unit to investigate and prosecute perpetrators of abuse, neglect and exploitation of persons with disabilities. Collaborative investigations would be conducted by the Attorney General's office and the Disability Rights Center. Depending on the facts and resolution needed, criminal or civil actions would be taken to obtain justice.

Convicted murderers get due process before losing their lives; the disabled deserve no less.

Kansans for Life supports HB 2849, HB 2884, and HB 2306.

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How good are physicians at diagnosing DNR patients' quality of life?

Noelle Junod Perron, Alfredo Morabia, Antoine de Totrente -Switzerland

http://www.smw.ch/pdf200x/2002/39/smw-10083.PDF

This 2002 study assessed quality of life evaluation on the implementation of Do-Not-Resuscitate (DNR) orders by physicians and the accuracy of physicians' estimation of DNR patients' quality of life
Methods: A 10-month prospective clinical study in a community hospital including 255 DNR patients and 9 physicians in postgraduate training.

In many fields of medicine quality of life is becoming a common item in the assessment of outcome and health status. Furthermore, it is often used as a criterion for the appropriateness of intervention or treatment in clinical situations. Thus, it is of considerable importance to know to what extent physicians are able to estimate their patients' quality of life. However, **physicians underestimated quality of life components of DNR patients.**

Conclusion: Physicians often (71 %) rely on the assumed quality of life of their patients in their DNR decision but unfortunately tend to underestimate it. Greater involvement of patients in the DNR decision could improve quality of care.

The "misery" perspective: patients more positive than providers

Cheryl Lapp *http://www.uwopartners.org/whatsnews/fall2000/healthview.html*

It has long been noted in professional literature that there is a distinct gap between self-assessed health on the part of older adults and health ratings assigned to them by professional clinicians. Older adults' assessments of their own health are considered to be valid indicators, but interestingly, their health ratings are consistently more positive than the ones presented by professionals.

This 2000 study conducted in the Oshkosh area explored differences in health perceptions, utilizing a sample of 30 **older women, each paired with her own primary health care provider**. The average age of the sample was 83 years, whereas the providers' average age was 48 years, over three decades younger than the subject sample. Most of the women in this semi-rural community had long-standing relationships with their providers, typically ten to fifteen years in duration.

Based on the 60 in-person interviews, paired data were analyzed and compared. In these stable relationships, the health ratings of the patient/provider pairs actually matched 43% of the time. When they **did not match in another 40% of pairs, the older adults' ratings were more positive, a result consistent with the literature.**

Depressed mood in spinal cord injured patients: staff perceptions

Cushman LA, Dijkers MP. University of Rochester School of Medicine and Dentistry, NY.

Arch Phys Med Rehabil. 1990 Mar;71(3):191-6.

This 1990 study examined the correspondence between staff ratings and patient ratings of depressed mood for 102 newly spinal cord injured persons admitted to two regional spinal cord injury rehabilitation centers. Patients rated their mood by using the Depression Adjective Check List (DACL). Treatment staff also rated each patient by completing the DACL as they thought the patient would have on the same day. Ratings were made every three weeks during a patient's stay.

Results: **Staff members typically overestimated levels of patients' depressed moods.** Staff's accuracy in estimating patient mood did not increase with increased exposure to the patient or years of experience in rehabilitation.

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Attachment C --Kansans for Life --Proponent HB 2306, 2849, 2884 --2/13/06

Danger Zone

Even though Haleigh Poutre is conscious, she's not necessarily safe.

By Wesley J. Smith, Feb.1, 2005 *http://www.nationalreview.com/smithw/smith200602010816.asp*

In the court (and courts) of life and death, a little 11-year-old Massachusetts girl named Haleigh Poutre could be the next Terri Schiavo. For those who have not heard the tragic story, Haleigh was beaten nearly to death last September, allegedly by her adoptive mother and stepfather. The beating left her unconscious and barely clinging to life.

Within a week or so of the beating, her **doctors had written her off**. They apparently **told Haleigh's court-appointed guardian,** Harry Spence**, that she was "virtually brain dead."** Even though he had never visited her, Spence quickly went to court seeking permission to remove her respirator and feeding tube. The court agreed, a decision affirmed recently by the supreme court of Massachusetts.

And so, no doubt with the best of intentions, a little girl who had already suffered so much was stripped by the Commonwealth of Massachusetts of even the chance to fight to stay alive. If she didn't stop breathing when the respirator was removed, which doctors expected, she would slowly dehydrate to death.

Close Call

Then came the unexpected: Before "pulling the plug" on Haleigh, Spence finally decided to visit her. He was stunned. Rather than finding a little girl with "not a chance" of recovery, as doctors had described Haleigh's condition to him (as reported by the Boston Globe), Haleigh was conscious. She was able to give Spence a yellow block when asked to by a social worker and respond to other simple requests.

Laudably, Spence immediately called off the dehydration. Haleigh is now off her respirator and breathing on her own. She has been transferred out of the hospital and is currently being treated in a rehabilitation center.

Lest anyone think that Haleigh's apparent consciousness protects her from suffering the fate of Terri Schiavo, who was ordered dehydrated by a Florida court based, in part, on a finding that she was unconscious, think again. In most states, exhibiting consciousness is not a defense against dehydration for profoundly impaired patients. Indeed, cognitively disabled people who are conscious are commonly dehydrated throughout the country. So long as no family member objects, the practice is deemed medically routine.

How can this be? The simple answer is that tube-supplied food and water — often called "**artificial nutrition and hydration" (ANH)** — has been defined in law and in medical ethics as an ordinary medical treatment. This means that it can be refused or withdrawn just like, say, antibiotics, kidney dialysis, chemotherapy, surgery, blood pressure medicine, or any other form of medical care. Indeed, **removing ANH has come to be seen widely in medicine and bioethics as an "ethical" way to end the lives of cognitively disabled "biologically tenacious" patients** (as one prominent bioethicist once described disabled people like Terri Schiavo and Haleigh Poutre), without resorting to active euthanasia.

Defining dehydratable people

It wasn't always so. It used to be thought of as unthinkable to remove a feeding tube. Then, as bioethicists and others among the medical intelligentsia began to worry about the cost of caring for dependent people and the growing number of our elderly — and as personal autonomy increasingly became a driving force in medical ethics — some looked for a way to **shorten the lives of the most marginal people without violating the law** or radically distorting traditional medical values. **Removing tubes providing food and fluids was seen as the answer**. After all, it was argued, use of a feeding tube requires a relatively minor medical procedure. Moreover, the nutrition provided the patient is not steak and potatoes, but a liquid formula prepared under medical auspices so as to ease digestion. There can also be complications such as diarrhea and infection.

Having reached consensus on the matter, the bioethics movement mounted a deliberate and energetic campaign during the 1980s to change the classification of ANH from humane care, which can't be withdrawn, to medical treatment, which can. The first people targeted for potential dehydration were the persistently unconscious or elderly with pronounced morbidity. Thus, bioethics pioneer Daniel Callahan wrote in the October 1983. Hastings Center Report, "**Given the increasingly large pool of superannuated, chronically ill, phys**

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denial of ANH] could well become the non treatment of choice."

In March 1986, the American Medical Association Council on Ethical and Judicial Affairs, responsible for deliberating upon and issuing ethics opinions for the AMA, legitimized dehydration when it issued the following statement: **Although a physician "should never intentionally cause death," it was ethical to terminate life-support treatment, even if:**

...death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient. . . . Life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition and hydration.

There it was: **Food and fluids provided by a feeding tube were officially deemed a medical treatment by the nation's foremost medical association, meaning that withdrawing them was deemed the same as turning off a respirator or stopping kidney dialysis.**

As often happens in bioethics, once the medical intelligentsia reached consensus, their opinion quickly became law. Thus, in 1990, the Supreme Court of the United States issued its decision in Cruzan v. Director, Missouri Department of Health, which upheld Missouri's law allowing for the removal of life-sustaining treatment from a person, provided there was "clear and convincing evidence" that the person would not have wanted to live. Unfortunately, the Court also agreed that tube-supplied food and fluids is a form of medical treatment that can be withdrawn like any other form of treatment. (This is often erroneously called the "right to die.") With the seeming imprimatur of the Supreme Court, all **50 states soon passed statutes permitting the withholding and withdrawal of tube-supplied sustenance — even when the decision was made by a third party.**

With that principle established, what did unconsciousness have to do with it? Not a thing. It didn't take long for the American Medical Association to broaden the categories of dehydratable people. Thus, in 1994, a brief eight years after its first ethics opinion classifying tube feeding as medical treatment that could be withdrawn only when the patient was "beyond doubt" permanently unconscious**, the AMA proclaimed it "not unethical" to withdraw ANH "even if the patient is not terminally ill or permanently unconscious."** And that's where the matter stands today.

But that doesn't make it right. Don't get me wrong: **People can and should be able to refuse unwanted ANH for themselves, either directly or in a written advance medical directive**. But it seems to me that given the certainty of death when denying a patient sustenance — and in light of the profound symbolism of refusing to provide even nourishment — a different standard should apply when third parties seek to refuse tube-supplied food and water on behalf of another.

In such cases, medically inappropriate ANH — such as when the actively dying body can no longer assimilate sustenance — should be able to be refused as other forms of care. **But when the decision is a value judgment that a person's life isn't worth living because of disability or perceived "quality of life," then the decision to dehydrate should be considerably constrained.**

Which brings us back to poor Haleigh Poutre: Until and unless ANH is recognized as a unique category of care to be governed by its own rules for determining when and whether sustenance can be withheld or withdrawn, Haleigh remains very much at risk. After all, her doctors could still conclude that she will not improve. They could still recommend to guardian Harry Spence that he withdraw her food and fluids lest she grow up profoundly disabled. Spence **could still agree that an early death is better than a longer disabled life and ask the courts to sanction her dehydration.** The juvenile court could promptly hold a new hearing in which the judge would undoubtedly be told by a bevy of "expert witness" bioethicists that dehydrating this child to death would be ethical and morally appropriate even though she is conscious. The court could still order her to die slowly, over two weeks, of dehydration despite her being awake and aware. And the supreme court of Massachusetts could still give final approval to the decision. Such is the sad state of medical ethics and the law in the United States of America.

— Wesley J. Smith is a senior fellow at the Discovery Institute and a special consultant to the Center for Bioethics and Culture

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Testimony by Tammy Coleman

February 13, 2006

Federal and State Affairs Committee, Kansas House of Representatives, Topeka, Kansas

In Support for H.B. 2849, 2884, and 2306

Hi, my name is Tammy Coleman & I am a walking, talking miracle of God! I am here in support of House Bills 2849, 2884 and 2306.

I had a bad car wreck when I was twenty-six years old.

I spent about a year & a half in different stages of a coma with a feeding tube. I had to learn how to eat & drink all over again! I had to learn how to walk, talk, write, dress myself, you name it, everything! I remember that I could not even drink water & my mouth would get so dry! I loved sucking on ice chips!

At the time of my car wreck, I was a 1st Lieutenant in the Army Reserves preparing to leave for Germany to serve on active duty & receive my promotion to Captain! I never made it! At the time my plane took off, I was in the Emergency room at Truman West Hospital in Kansas City, Missouri where I was taken to by ambulance, after my car wreck. I remember being told that one night in ICU there was six other men & myself! They all died & I was the only one still living the next morning!

My car wreck happened less than a mile from my home, where I had been living with my boyfriend, Jim Boring for more than six years (I was not wearing my seatbelt at the time of the wreck! The policeman said that if I had been wearing my seatbelt, I would not have been hurt so bad! I learned my lesson, now I wear my seatbelt!) Jim went to court to be appointed as my Legal Guardian.

I was blessed to have a good legal guardian who loved me very much! And thank God I lived in Missouri. If this happened today in Kansas and my guardian was someone assigned to me or someone I knew who was not so loving, a decision by him approved by two doctors to discontinue needed care, and even my feeding tube, would mean that a judge had to do just that!

Jim was my legal guardian for the three years I spent in hospitals & a nursing home. Then I was released from the hospital to live with my Father & Stepmother. I lived with them for about three years.

I had to go to court to be appointed as my own legal guardian again. While I was in Research Hospital, my final stop, I had to be tested all day by the neurophysiologist, Dr. Zehr, to prove to the court that I could handle all my personal affairs again. When I went to court, the Judge even commented on how well I was doing!

Right after the car wreck, doctors told my family that I would be nothing more than a vegetable, if, I lived! God & I proved them wrong!

Thank you for listening to me!

I am still working on improving my speech. My vocal cords were damaged when I had to have a tracheotomy preformed on me in the emergency room to keep me alive!

Tammy Coleman
(816) 356-2768
Kansas City, MO

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Date 2-13-06
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KANSAS

DEPARTMENT ON AGING
KATHY GREENLEE, ACTING SECRETARY

KATHLEEN SEBELIUS, GOVERNOR

House Committee on Federal & State Affairs
Testimony on HB 2306
Feb. 13, 2006

Chairman Edmonds and members of the committee;

Thank you for the opportunity to express the support of the Kansas Department on Aging for HB 2306. HB 2306 would create the Protection and Advocacy for Kansans with Disabilities Fund.

The Licensure, Certification and Evaluation Commission within KDOA is charged with surveying and evaluating the compliance of nursing facilities with state and federal regulations. As such, KDOA operates a complaint hotline for the reporting of abuse, neglect or exploitation occurring in a nursing facility.

KDOA works directly with law enforcement agencies with respect complaints of possible abuse, neglect or exploitation. The department notifies, in writing, local law enforcement agencies of possible criminal acts. KDOA also shares complaint intake forms with Attorney General's Office through its Fraud and Abuse Unit.

KDOA has jurisdiction to pursue certified staff of adult care homes with respect to adding annotations of ANE to entries in the Kansas Nurse Aide Registry. If an act of ANE against a resident of an adult care home appears to have been committed by another person, a referral is made to a local law enforcement agency, another licensing agency/board or SRS Protective Services.

The department supports vigorous prosecution of those found guilty of abuse, neglect or exploitation of seniors. KDOA supports the enhanced enforcement and increased prosecution tools available in HB 2306 strengthening the ability of law enforcement to keep seniors safe.

KDOA believes HB 2306 provides additional protection for seniors. We appreciate the opportunity to voice the department's support for this bill.

NEW ENGLAND BUILDING, 503 S. KANSAS AVENUE, TOPEK
Voice 785-296-4986
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AARP
Kansas

February 13, 2006
Representative Edmonds, Chair
House Federal and State Affairs Committee
HB 2306

Good Afternoon Chairman Edmonds and Members of the House Federal and State Affairs Committee. My name is David Wilson and I am a member of the AARP Kansas Executive Council. AARP Kansas represents the views of more than 350,000 AARP members in the state of Kansas. Thank you for this opportunity to express our support for HB 2306 which would create the Protection and Advocacy for Kansans with Disabilities Fund.

All Americans have the right to be free from discrimination, crime, physical and emotional abuse, neglect and financial exploitation.

AARP believes that there must be strong legal protections against, and effective protective services addressing, all forms of exploitation and abuse of incapacitated and vulnerable adults. There must also be rigorous enforcement of civil rights and other statutes protecting the rights and safety of individuals.

While increasing awareness among the general public and professionals is the most effective factor in identifying elder abuse, according to experts, additional efforts are often necessary to protect vulnerable older people and provide them with adequate mechanisms to assert their rights.

In recent years Congress has not significantly increased federal resources to help states protect vulnerable adults.

Therefore AARP believes that states should:

- Enact and enforce adult protective services (APS) laws and policies that provide for investigation, access and intervention in emergency and nonemergency situations of abuse, neglect and exploitation of vulnerable individuals in the community and in long-term care facilities.

- Develop public awareness programs and promote interagency coordination to help identify, prevent and treat cases of elder abuse;

- Support the training of professionals from a variety of disciplines— including prosecutors, police officers and sheriffs, and employees of financial institutions and APS agencies—to improve detection and investigation.

Therefore, we respectfully request that you support HB 2306. Thank you.

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Marie Smith, President | William D. Novelli, Executive Director and CEO |

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STATE OF KANSAS
HOUSE OF REPRESENTATIVES

MICHAEL R. (MIKE) O'NEAL
104TH DISTRICT
HUTCHINSON/NORTHEAST RENO COUNTY

LEGISLATIVE HOTLINE
1-800-432-3924

CHAIRMAN:
JUDICIARY COMMITTEE

VICE CHAIRMAN:
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MEMBER:
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AND RETIREMENT BUDGET
RULES AND JOURNAL
UNIFORM LAW COMMISSION
KANSAS JUDICIAL COUNCIL

TESTIMONY ON H.B. 2849
House Federal & State Affairs Committee
Rep. Mike O'Neal
Feb. 13, 2006

CHAIRMAN EDMONDS and members of the Committee, thank you for the opportunity of providing my thoughts and suggestions regarding H.B. 2849. This legislation deals with an issue of great importance and as it affects, literally, life and death decisions, requires a heightened level of legislative scrutiny. At the outset, I wish the Committee to know that I support the core public policy determination being advanced by the proposed legislation. I am a strong supporter of laws protecting the sanctity of life. I am also a strong supporter of the individual freedom we all should have in making end of life decisions unfettered by unnecessary governmental interference. My concern is that the mechanics of this bill in its current form, while advancing the former, fails to achieve the latter.

My concerns and suggestions come from a combination of my 20+ years of legislative experience and probably more so from my experience as an attorney whose emphasis for the past 25 years has been health care law.

Specifically, I support the presumption in New Section 1(a) to provide wards with nutrition and/or hydration to sustain life, subject to specific exceptions. As to the exceptions, I support the role of the ward's treating physician as he/she is in the best position to certify the ward's medical condition and prognosis. From a drafting standpoint, however, Section 1(c)(1) is awkward. I suggest that the language should read: ***"If the ward's treating physician certifies in writing to the guardian that, in the physician's reasonable medical judgment:...".***

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I also have some concerns about use of the phrase "**medically possible**" in Section 1(c)(1)(A). What does that mean and in what circumstances would it not be "possible"? If a patient has either natural or mechanically-assisted respirations it is possible to deliver hydration. In my view, only (B) and (C) are necessary qualifiers.

Next, I have concerns about the use of the phrase "**expressly and with informed consent**" in Section 1(c)(2). The phrase is defined by new language beginning on page 4, line 40 of the bill. This definition is almost completely subjective, as all informed consent issues end up being. That is why written documents, such as advance directives, living wills, durable powers of attorney for health care decisions, DNR documents, and the like, contain express language that addresses and has the signer acknowledge informed consent. What good are the express provisions in a validly executed written document if someone not a party to the document can later challenge the document by merely alleging lack of informed consent? The language of the bill would potentially call into question or at least allow a collateral challenge of every such end-of-life-directive document. At the very least, the express written directives should carry a presumption of validity and the burden should be on one challenging the directive to prove by clear and convincing evidence that the directive should not stand as the express wishes of the ward who executed the document. There is currently no provision that I could see in the bill for adjudicating an issue involving the applicability of Section 1(c)(2) except through an action for injunctive relief. [Note that the procedure outlined in Section 1(d), regarding court intervention, applies only to Section 1(c)(1).]

Another concern involves the protracted court proceeding contemplated by Section 1(d). The procedure would, in my opinion, preclude a non-adversarial resolution of the issue presented. The mere filing by the guardian of a proper certification by the treating physician would automatically trigger the appointment of counsel for the ward and the expense of discovery procedures and outside "experts". The burden would be on the guardian to show that the physician's certification "**is objectively true in all that it attests.**" What does that mean? Keep in mind that what is being evaluated is the treating physician's written certification. Would this protracted litigation be required even if the ward's family, extended family, etc. agreed with the guardian and the treating physician?

Finally, my biggest concern deals with the laundry list of parties who would have standing to file for injunctive relief under the bill. Section 1(e) creates a cause of action for injunctive relief and subsection (f) lists the parties who may bring an action. As worded currently, the bill would allow a "state protection and advocacy agency" to file for injunctive relief even if there were immediate family members, including spouse, parents, children or siblings who were in agreement with the guardian and treating physician. This possible interference by an outside agency or public official flies in the face of personal and family privacy, the personal freedom of families to carry out the known wishes of a loved one or to make compassionate family decisions in keeping with a desire to accomplish death with dignity. The bill, e.g., should provide for involvement of outside parties only in the event there is no family.

In our zeal to protect life, let us not overlook the inevitability of our mortality, the need for peace and dignity and the role treating physicians, guardians and family members play in the cycle of life. Again, I support the spirit and intent of the bill but have concerns that the procedures contemplated by the bill need refined to address the concerns expressed.

Rep. Mike O'Neal

Kansas Commission on Disability Concerns

Testimony to Federal and State Affairs Committee
HB 2306; Protection and advocacy for Kansans with disabilities fund

February 13, 2006

Chairperson Edmonds and members of the committee, I am Kerrie Bacon, Legislative Liaison for the Kansas Commission on Disability Concerns (KCDC). We are charged with providing information to the Governor, the Legislature, and to State agencies about issues of concern to Kansans with disabilities (K.S.A. 74-6706).

The Kansas Commission on Disability Concerns urges you to support HB 2306.

The concern is that the federal funding for the Disability Rights Center (DRC) is very specific in what types of disabilities are served for each of the funding streams. There are some people with disabilities who do not fall in these funding silos, thus limiting who DRC can assist. The funding from Kansas will allow DRC to broaden its support of people with disabilities and ensure that all Kansans with disabilities have an opportunity to be represented by this organization.

The commission is supportive of this bill and encourages you to recommend it favorably for passage to the full House.

Thank you for your time.

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STATE OF KANSAS
HOUSE OF REPRESENTATIVES

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TOPEKA

LANCE KINZER
REPRESENTATIVE, 14TH DISTRICT

TESTIMONY REGARDING HB 2849

"... we must be wary of those who are too willing to end the lives of the elderly and the ill. If we ever decide that a poor quality of life justifies ending that life, we have taken a step down a slippery slope that places all of us in danger. " -- C. Everett Koop, M.D.

Thank you for this opportunity to address HB 2849 regarding end of life decisions under the Guardianship Act. It is important to start by stressing that this legislation applies only to situations where a court appointed guardian is already in place; in other words to cases where a court is already involved in the life of the ward whose medical condition is in question. Under current law guardians are empowered to make a large number of decisions for wards with very little outside interference. However, there are nine categories of decisions over which guardians have limited or no authority to make decisions for their wards (see Section 3 (e)). These include the fact that **under current law a guardian can not** prohibit the wards marriage, consent the termination of the wards parental rights, consent to adoption of the ward without court approval, consent to any organ donation by the ward without court approval, consent to sterilization of the ward without court approval, exercise authority of the wards estate without court approval and a few other items as well. **The point is that the authority of guardians over wards has never been viewed as absolute and is always subject court oversight.**

One further area in which we do not allow guardians' unfettered authority is in the area of end of life decisions. Indeed, **current law begins with the presumption that guardians do not have the authority to consent on behalf of wards, to the withdrawal of life-saving or life sustaining medical care.** There are two basic exceptions to this rule, the first is where the ward has executed an advance directive setting forth his or her wishes in this regard. The second is the situation that is addressed by HB 2849.

In particular, current law says that life sustaining medical care can be withdrawn where the wards doctor, plus one other doctor, confirm that the ward is either in a persistent vegetative state **or** "is suffering from an illness or other medical condition for which further treatment, other than for relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses." I want to stop and consider this language because it one of what I believe to be several problems

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with the existing statute. **The current definition is overly broad in that it could apply to able and highly functioning people who need some artificial means (like a portable respirator) to sustain life.** Many within the disability rights community have expressed real concern that this language opens the door to mischief. Secondly, the use of the term vegetative is offensive to some.

My proposal would involve deleting the language quoted above, replacing it with a requirement that before medical treatment could be removed the ward must be "comatose and suffering from a severe illness such that life sustaining medical care is objectively futile and would only prolong the dying process." The term comatose means a state of profound unconsciousness from which one can not be roused. The remainder of the proposed language is designed to ensure that in the denial of medical care we are giving due attention to the distinction between allowing nature to take its course and actively assisting death.

Under current law once a decision is made by the doctors that the ward meets the statutory definition for withdrawal of medical care the guardian provides their written certification to the court. **The law states that "Such written certification shall be approved by an order issued by the court."** Two points are crucial to consider in this regard, first the existing statute requires judicial involvement in the end of life decision of a guardian for a ward. But second, the current language directing that involvement is confusing. **The use of the term shall in the current law appears to suggest that the Judge has no choice but to sign the withdrawal order.** During the off session the Judicial Council heard testimony on this issue and it was my impression from that testimony that Judges themselves take a range of opinions on the meaning of the current statute. Wherever one stands on this issue I think we can all agree that the nature and extent of the review to be conducted by the court should not depend upon which judicial district you live in. **We need to clarify this portion of the statue and guarantee that wards receive a meaningful due process hearing prior to withdrawal of life sustaining medical care.**

My proposal would require that the court conduct a two part inquiry. First the court would consider evidence as to whether or not the ward is actually in the medical condition specified by the statute. Second, and this is a significant change, the court would consider whether the ward ever expressed consent to the withdrawal of medical care. **My proposal would create a presumption in favor of continued medical care in the absence of evidence of contrary intent by the ward; current law given no consideration to the wards intent under these circumstances.**

Finally, my proposal would establish a separate standard for the withdrawal of nutrition and hydration. **In particular, food and hydration would be viewed as a natural means of preserving life rather than as a medical act. As such they could be withdrawn only if it were not medically possible to provide them without harming the ward, or where the ward has signed a proper advance directive on this issue.** As used in my proposal hydration would be given its common medical definition "the taking in of water." Nutrition is specifically defined in the bill. Where an advance directive is in place no prior court action would be required for withdrawal, but legal standing would be given to interested parties to initiate such action if their was a concern of possible abuse of this process.

This distinction between nutrition and hydration and medical care is based upon the belief that nutrition and hydration are, in principle, *ordinary* and *proportionate*, and as such morally obligatory.

Nutrition and hydration are different from medial care such as respirators for the simple reason that death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission to deny a person food and water. In other words the withdrawal of nutrition and hydration are actions by the very nature of which bring about death.

Furthermore, we must not underestimate the fact that provision of food and water are powerful symbols of care and comfort that acknowledge the inherent value we see in all human begins. **To deny food and water to a fellow human being is to place in question their status of a member of the community for whom we have a duty to act in accordance with the basic demands of human dignity.**

To deny nutrition and hydration as a result of arbitrary considerations regarding an individuals "quality of life", is to risk allowing psychological, social and economic pressures, to take precedence over our obligations to fellow human begins; even fellow human beings who are weak.

No cost benefit analysis can outweigh the fundamental value of human life. To determine that decisions regarding human life can be based upon an external analysis of its quality, introduces a discriminatory and eugenic principle into our social relations.

HB 2849 is ultimately about human dignity and our societal obligations to the weakest among us. Those who are wards are, even under the best of circumstances, persons who lack the capacity to meet their own needs in some respect. Wards in end of life circumstances are particularly vulnerable and deserving of special care. Such persons should be protected by laws that ensure adequate due process and that acknowledge their essential human dignity.

I appreciate the opportunity to address this important issue and look forward to answering any questions you may have.

Comments of Rud Turnbull Co-founder, co-director Beach Center on Disability
The University of Kansas

To Rep Lance Kinzer,

Lance, I am unable to testify at the House Fed and State Affairs Committee re: HB 2849. I have obligations at The University of Kansas that I am unable to postpone, in large part because they involve several of my colleagues and a student who have arranged their schedules to coincide with each other (and mine).

You may read the following statement to the House Committee if you wish:

I believe the bill is a vast improvement over present Kansas law in at least these respects:

1. It creates a presumption in favor of nutrition and hydration
2. It strictly limits the power of a guardian or other person, including a court, to consent to or order the withholding or withdrawal of either or both (substantive standards)
3. It provides for a full due process hearing on the petition to withhold or withdraw (procedural due process)
4. It puts the burden of proof on the petitioner and requires a quantum of proof at clear and convincing
5. It limits the guardian's power where a ward has given valid advance directions
6. It limits the standing to secure a hearing to truly interested parties (no "stranger in the courtroom")
7. It defines consent according to the three traditional elements of that legal construct
8. It defines medical judgment according to an objective standard
9. It requires evidence that is objectively true and thus eliminates the present subjective discretion that a physician is able to bring to bear
10. It implicitly recognizes the possibility of discrimination based on disability

In many respects this bill adheres to the consensus statement of principles of treatment of people at the end of their life developed after the Schiavo proceedings and based in large part on my testimony to the U.S. Senate HELP committee and subscribed to by many individuals and organizations that advocate for the rights of people with disabilities.

In my individual capacity and not in any way as a representative of The University of Kansas or any of its units, I believe the Kansas Legislature will greatly improve present law and take a large step toward protecting wards from discriminatory action if it enacts HB 2849.

Rud Turnbull
Co-founder, co-director
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The University of Kansas
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February 13, 2006
House Federal & State
Affairs Committee

Kansas
Catholic
Conference

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TESTIMONY – H.B. 2849

Chairman Edmonds and members of the committee:

Thank you for the opportunity to give comments on the merits of H.B. 2849. My name is Mike Farmer and I am the Executive Director of the Kansas Catholic Conference the public policy office of the Catholic Church in Kansas.

H.B. 2849 governs decisions including the provision of nutrition and hydration as part of medical care for persons unable to make these decisions for themselves. In my initial review of the bill I find that its intent is certainly in keeping with the principles espoused by the Catholic Church in upholding the dignity of the human person.

Recognizing the difficulties we all face with the decisions inherent in providing medical care with today's technology, the Bishops of Kansas have created for Kansas Catholics the ***Catholic Declaration on Life and Natural Death*** (copy attached). This instrument serves in communicating a person's desires and directions regarding treatment or care in the event of irreversible and terminal illness.

In announcing this new document the bishops reaffirm the Church's teaching on life and death. They say: "While we accept our obligation to care for the gift of life that God has entrusted to us and never to do anything by act or omission to end our life or the life of another, at the same time we look for the resurrection of the dead and the life of the world to come. We need not fear our death, for it is our birth to Eternal Life. We can therefore face death with dignity and grace, ever thankful to the God who gives us life."

The document specifically speaks to the administration of food and hydration as ordinary means of preserving life. As part of the Declaration Item 6 states in part: "...Therefore, I direct my health care provider(s) to provide me with food and fluids orally, intravenously, by tube, or by other means to the full extent necessary both to preserve my life and to assure me the optimal health possible. Furthermore, if at such time I am unable to eat and drink on my own (i.e. in a natural manner) food and fluids must be provided to me in an assisted manner (i.e. by tubes or a similar manner) unless: (a) my death is imminent (i.e. likely to happen without delay); or (b) I am unable to assimilate food or fluids; or (c) food or fluids endanger my condition."

MOST REVEREND RONALD M. GILMORE, S.T.L., D.D.
DIOCESE OF DODGE CITY

MOST REVEREND JOSEPH F. NAUMANN, D.D.
Chairman of Board
ARCHDIOCESE OF KANSAS CITY IN KANSAS

MOST REVEREND PAUL S. COAKLEY, S.T.L., D.D.
DIOCESE OF SALINA

MOST REVEREND MICHAEL O. JACKELS, S.T.D.
DIOCESE OF WICHITA

MICHAEL P. FARMER
Executive Director

MOST REVEREND EUGENE J. GERBER, S.T.L., D.D.
BISHOP EMERITUS - DIOCESE OF WICHITA

MOST REVEREND GEORGE K. FITZSIMONS, D.D.
BISHOP EMERITUS - DIOCESE OF SALINA

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Just as the Catholic Church encourages its members to discuss with family end of life health care decisions, and to make known our individual wishes through this Declaration, and a durable power of attorney for health care decisions; we support efforts by the state to also protect its citizens in these areas.

As I said before, in keeping with the measures already encouraged by our own Catholic Church the Kansas Catholic Conference supports the intent of H.B. 2849. I am not an attorney so I cannot address with skill the legal merits of the bill. In offering suggestions I would urge the committee to pause and consider the concerns of others offered here today as to the bill's clarity, and consistency in processing and applying duties, rights and safeguards.

The bill should promote communication among patient, family and physician. In legislative guidelines given by our Church through the Secretariat for Pro-Life Activities of the National Conference of Catholic Bishops in creating laws in this area they say, "As a general rule, documents and legal proceedings are no substitute for a physician's personal consultation with the patient and/or family at the time a decision must be made on a particular course of treatment." H.B. 2849 as it is currently written may create obstacles in accomplishing this goal.

Additionally, the same guidelines mentioned above state in the Introduction: "Our [Catholic] tradition not only condemns direct attacks on innocent life, but also promotes a general view of life as a sacred trust over which we claim stewardship but not absolute dominion. As conscientious stewards we see a duty to preserve life while recognizing certain limits to that duty." These are grave matters that require serious consideration.

We urge the committee to move with caution in determining the best language possible to serve the needs of those who cannot speak for themselves.

Thank you,

Michael P. Farmer

Michael P. Farmer
Executive Director

Catholic Declaration on Life & Natural Death

Prologue. To my family, friends, physician, lawyer & pastor:

I believe:

...that each individual human person is created by God our Father in love, and that God maintains a loving relationship with each person throughout human life and eternity;

...that each human person's worth and dignity derives from the relationship of love in Christ that God has for each individual person, not from one's usefulness or effectiveness in society;

...that God our Father has entrusted to me, a human person, a shared dominion with Him over my earthly existence so that I am bound to use ordinary means to preserve my life but I am free to refuse extraordinary means to preserve my life;

...that Jesus Christ lived, suffered, and died for me and that His suffering, death, and resurrection prefigure and make possible my own resurrection from the dead, for which I hope;

...that through death, life is not ended, but merely changed, and though I may experience fear, suffering and sorrow, by the grace of the Holy Spirit, I want my acceptance of my death to be a free human act, seeing it as my surrender of this earthly life and my union with God for eternity.

Therefore, I request that my family, the Catholic community, and all my friends join me in prayer and sacrifice as I prepare for death. I further request that, after my death, others continue to pray for me that, with God's grace, I will enjoy eternal life.

Declaration

1. **Purpose.** This Catholic Declaration on Life and Natural Death, made while I am of sound mind, is provided as a means of making known my desires and directions regarding treatment or care for me in the event I become irreversibly and terminally ill. In the absence of my ability to give directions regarding any of the above, I intend that this Declaration shall be honored by my family and physician(s) as the final expression of my legal right to make decisions regarding medical or surgical treatment and accept the consequences for such decisions.

2. **Full Disclosure of Facts.** I admonish and direct my family, physicians, lawyer, pastor, and friends that, because of my Catholic belief in the dignity of the human person and my eternal destiny in God, if I become irreversibly, incurably, and terminally ill, I be informed fully of the facts so that spiritually I can prepare myself to die.

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3. General Presumption for Life. This Declaration is to be interpreted in favor of continued life. I direct that health care decisions be made which are consistent with my general desire for the use of medical treatment that would preserve my life, as well as for the use of medical treatment that can cure, improve, or reduce or prevent the deterioration in, any physical or mental condition. I request and direct that medical treatment and care be provided to me to preserve my life without discrimination based on my age or physical or mental ability. I reject any action or omission that is intended to cause or hasten my death. If the instructions contained herein do not adequately address an issue concerning my medical treatment and care, those making decisions on my behalf should be guided generally by the pro-life teachings of the Catholic Church.

4. Natural Death Instructions. I have the right to make my own decisions concerning treatment that might inordinately prolong the dying process beyond the limits dictated by reason and good judgment. If I should have an incurable injury, disease or illness, certified to be a terminal condition by two physicians who have examined me (one of whom shall be my attending physician), and the physicians have determined, to the best of their professional ability, that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process; and if I am unable to make my own decisions and have no reasonable expectations of recovery, then I request and direct that no life-sustaining procedures be used to preserve my life. No means should be used with the intention of shortening my life. I intend for the term "life-sustaining procedure" to mean: any medical procedure or intervention which would only serve to prolong the dying process and where, in the judgment of the attending physician, natural death will occur whether or not such procedure or intervention is utilized.

5. Comfort Care. I direct that if I have a terminal condition as described above, I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care and relief of pain, even if such may have the known, but unintended side-effect of hastening my death.

6. Nutrition and Hydration. I believe that food (nutrition) and fluids (hydration) are not medical treatments, nor medical procedures, but ordinary means of preserving life. Therefore, I direct my health care provider(s) to provide me with food and fluids orally, intravenously, by tube, or by other means to the full extent necessary both to preserve my life and to assure me the optimal health possible. Furthermore, if at such time I am unable to eat and drink on my own (i.e. in a natural manner) food and fluids must be provided to me in an assisted manner (i.e. by tubes or a similar manner) unless: (a) my death is imminent (i.e. likely to happen without delay); or (b) I am unable to assimilate food or fluids; or (c) food or fluids endanger my condition.

I understand the full import of this Declaration and I am emotionally and mentally competent to make this Declaration.

Signed this ____ day of __________________, 200__.

____

Printed Name: ____________________

____

Address

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NOTE: THIS DOCUMENT MUST BE WITNESSED BY EITHER 2 WITNESSES OR 1 NOTARY PUBLIC.

The Declarant has been personally known to me and I believe the Declarant to be of sound mind. I did not sign the Declarant's signature above for or at the direction of the Declarant. I am not related to the Declarant by blood or marriage, entitled to any portion of the estate of the Declarant according to the laws of intestate succession or under any will of Declarant or codicil thereto, or directly financially responsible for Declarant's medical care.

Witness	Address
Witness	Address

-OR-

STATE OF KANSAS, COUNTY OF ________________, ss:

This instrument was acknowledged before me on the _____ day of ___________, 200__, by ______________________.

Notary Public

My commission expires:

Copy to: Family, Physician, Lawyer, Pastor

22-3

DISABILITY RIGHTS CENTER of KANSAS
EQUALITY ♦ LAW ♦ JUSTICE

Disability Rights Center of Kansas
Rocky Nichols, Executive Director
635 SW Harrison, Ste 100 ♦ Topeka, KS 66603
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877.335.3725 (TDD) ♦ 785.273.9414 FAX
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Testimony to the
House Committee on Federal and State Affairs
Testimony in Support of HB 2849 (Withhold/Withdraw)

February 13, 2006

Chairman Edmonds and the honorable members of the committee, my name is Rocky Nichols. I am the Executive Director of the Disability Rights Center of Kansas, formerly Kansas Advocacy and Protective Services (KAPS). The Disability Rights Center of Kansas (DRC) is a public interest legal advocacy agency, part of a national network of federally mandated and funded organizations legally empowered to advocate for Kansans with disabilities. As the state designated protection and advocacy system for Kansans with disabilities our task is to advocate for the legal and civil rights of persons with disabilities as promised by federal, state and local laws.

The way that Guardians make life and death decisions on behalf of their ward is an uncomfortable and sometimes controversial discussion. However, DRC and Kansas Attorney General Phill Kline proposed HB 2307 in 2005 because of the fatal flaws inherent in the current Kansas guardianship statute that must be addressed. Since that time new language was authored by Representative Kinzer which we are supporting.

Any time that the process found in K.S.A. 59-3075 (e)(7)(C) is used it will likely result in the death of the person with the disability. Guardians that are appointed by the court to protect and defend the rights of their ward have many powers that are granted and exercised with very little court oversight. However, the ability of a guardian to withhold or withdraw medical care (including food or water) currently requires the issue to go before a court, however **current law is fatally flawed in three ways … 1) broad definition, 2) no due process rights, 3) no discretion by the court (the current law says that the court shall approve the guardian's request to withhold/withdraw).**

Death Is Different

The U.S. Supreme Court has handed down many decisions involving the due process rights of convicted murderers who have been given the death penalty. In numerous

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cases they have reinforced that any person who is subject to a death sentence must be afforded full and complete due process. For example, in *Ford v. Wainwright*, 477 U.S. 399, 411 (1986) the court states, "In capital proceedings generally, <u>this Court has demanded that fact finding procedures aspire to a heightened standard of reliability</u>. This especial concern is a natural consequence of the knowledge that execution is the most irremediable and unfathomable of penalties; <u>that death is different</u>." (*citation omitted*)

In situations where death is the result, persons with disabilities in need of a guardian deserve no less due process protections than the person convicted of a capital crime.

Let me be absolutely clear, in situations where the person with the disability has executed a durable power of attorney for health care decisions (DPOA), a living will or other form of written advance directives regarding end of life decisions, the requirements of K.S.A. 59-3075 (e)(7)(C) <u>do not apply</u>. The flaws in K.S.A. 59-3075 (e)(7)(C) **<u>only apply</u>** in situations when there is a court appointed guardian.

Historical Background

Guardianship law in Kansas was substantially unchanged from 1965 until 2002. In 1997, the Kansas Judicial Council advisory committee on guardianship and conservatorship started to review and draft an entire new code. The advisory committee's proposal was adopted by the Judicial Council and introduced in 2001 in the House Judiciary Committee as HB 2469. The bill was over 110 pages long. There were many opponents to the bill, including the Disability Rights Center of Kansas, then known as Kansas Advocacy & Protective Services. The bill was referred for an interim study. No changes were proposed by the interim committee. The Judicial Council proposed some changes. The withhold / withdraw provisions in HB 2469 went through multiple variations during the process. For example, at times HB 2469 included due process rights and of course in the final version those rights were withdrawn. Once again, even though everyone agreed that overall the changes were positive, many opponents testified. After much debate, all the parties agreed that it was better to have the bill pass in that session and for advocates and other interested parties to come back with changes individually in succeeding years.

Fatal Flaws in Definition, Due Process and Discretion:

The issue addressed in HB 2849 eliminates the three fatal flaws in current state law: 1) The DEFINITION of who can have medical care withheld or withdrawn; 2) The lack of DUE PROCESS RIGHTS of the individual with a disability affected by the guardians petition and court action; 3) The lack of DISCRETION by the current as directed in the current statute. HB 2849 addresses those three flaws, Definition, Due Process and Discretion.

DEFINITION FLAW: K.S.A. 59-3075 (e)(7)(C) puts at risk all wards who have disabilities who are "in a persistent vegetative state or is suffering from an illness or other medical condition for which further treatment, other than for the relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses." This very broad definition can include any person with a disability who relies on any type of "artificial means" for day to day living.

For example, an individual who experiences a cervical spine injury in vertebras 1, 2 or three may require artificial respiration to breathe. Or, a person with advanced kidney disease might require kidney dialysis. Many Kansans with significant disabilities utilize feeding tubes for nutrition. None of these conditions by themselves are not an indication that the person is on terminally ill, or waiting on deaths door. However, as it is currently enacted K.S.A. 59-3075 (e)(7)(C) applies to those individuals. DRC does not believe that the legislature intended that consequence when they revised the guardianship statute in 2002, but it is the current reality.

DRC fully supports the new definition proposed in HB 2849 that reads, ". . . the ward is comatose and suffering from a severe illness such that life sustaining medical care is objectively futile and would only prolong the dying process, and which opinion is concurred in by either a second physician or by any medical ethics or similar committee to which the health care provider has access established for the purposes of reviewing such circumstances and the appropriateness of any type of physician's order which would have the effect of withholding or withdrawing life-saving or life sustaining medical care."

DUE PROCESS FLAW: Although K.S.A. 59-3075 (e)(7)(C) currently requires that a guardian who desires to withhold or withdraw medical from their ward go to the Court for authorization it does not guarantee due process rights to the ward who has the disability. Due process is a right that all Americans are granted under the 14th Amendment of the Constitution of the United States regardless of disability, and regardless of whether or not they have a disability. DRC has great concern that K.S.A. 59-3075 (e)(7)(C) in its current form violates those rights.

One striking example of how K.S.A. 59-3075 (e)(7)(C) differs from other statutes affecting persons with disabilities in needs of a guardian is K.S.A2004 Supp. 59-3075 (e)(5) that addresses the ability of a guardian to forcibly sterilize their ward. "A guardian shall not have the power to consent, on behalf of the ward, to the sterilization of the ward, unless approved by the court following a due process hearing held for the purposes of determining whether to approve such, and during which hearing the ward is represented by an attorney appointed by the court." In this provision due process rights are assured, in (e)(7)(c) due process rights are absent.

HB 2849 addresses the lack of due process by ensuring that the court ". . . afford the ward full and complete due process including, but not limited to, the right to court appointed counsel, notice, hearing, subpoena power, discovery and payment of costs for experts if the ward is deemed indigent." (Page 8, line 29 and following) DRC believes that this provision corrects the current flaw in K.S.A. 59-3075 (e)(7)(C).

DISCRETION FLAW: K.S.A. 59-3075 (e)(7)(C) does not provide discretion to the Court when deciding whether or not to allow a guardian to withhold or withdraw medical care from a ward. K.S.A. 59-3075 (e)(7)(C) currently requires that the guardian file a petition with the court requesting authorization to withhold or withdraw medical care from their ward accompanied by the "certification" of two doctors that the ward meets the definition (as described above). It further requires that "Such written certification shall be approved by an order issued by the court." (page 8, line 28)

HB 2849 grants the Court discretion in making a determination, by "clear and convincing evidence" based on the facts presented by the Wards doctor, the guardian, the Wards court appointed attorney and when possible, the ward him, or her self. The decision by the Court is made based on the objective facts presented with an eye toward what the individual with a disability specifically expressed as their intentions for withholding or withdrawing of medical care, or what they likely would have wanted based on the facts presented.

It is important to remember two facts regarding these provisions: 1) If the individual has already provided any kind of written advance directives, e.g., DPOA or living will, then the Court never hears the case; 2) If number 1 is not met, then under current law the guardian is required to petition the Court for approval to withhold or withdraw medical care.

Two Case Examples: As the protection and advocacy system for Kansas DRC has received several reports where a guardian has either petitioned the Court to withhold or withdraw medical, or has attempted to do it apart from the required Court involvement. Two examples follow.

Example #1 - A man with mental illness was living at Larned State Hospital as a result of his need for acute mental health treatment. In addition to his mental illness he also required kidney dialysis due to kidney disease. However, he was fully cognizant, walking, talking and actively participating in his treatment. He was placed under guardianship. The ward continued his mental health treatment and steadily improved. His guardian had a petition drafted to allow him to withhold medical care. The guardian had two doctors certify that he was a person with multiple disabilities described in the statute (K.S.A. 59-3075 (e)(7)(C)). The Court, in accordance to the statute approved the certification petition. As a result of the Court authorization of the petition a standing Do Not Resuscitate Order (DNR) was issued at Larned.

The gentleman's health improved to where he could move out of Larned State Hospital and into a nursing home for further treatment. The standing DNR followed him to his new residence. Consequently he choked while eating, was not resuscitated and died. Although DRC staff have not concluded their investigation into this mans death, there is cause to believe that the DNR had to play a role in this wards premature death.

Example #2 – DRC received a call from a developmental disability service provider in Kansas City, Kansas who reported that a man who has cerebral palsy was about to have medical withdrawn. The person with the disability had a bowel obstruction and needed acute medical care. The direct care staff that worked with this gentleman were gravely concerned that his guardian was making a decision that was not in the best interest of the man with cerebral palsy. The caller reported that the guardian was "just tired of dealing with him." After an initial investigation DRC prepared to intervene on the wards behalf. Fortunately, the court had determined that the guardian's petition was both premature and not in the wards best interest.

Conclusion

In its report on HB 2307 (DRC's original proposal) the Judicial Council found that there are numerous withhold / withdraw cases in Kansas each year. The council also found that judges are confused about the various provisions of the law including the DEFINITION, DUE PROCESS and DISCRETION provided. The council recognized the need for clarification.

HB 2849 seeks to rebalance the powers of a guardian by: establishing a more clear definition of when medical care can be withheld or withdrawn; establishing clear due process rights that shift the focus of the proceeding on the wishes of the individual, and eliminating the bias in law that says if you have a certain type of disability that your life is not as equal to, or valuable as others; and giving the court discretion in making its decision on all of the relevant facts.

Current law left unchanged will continue the bias against disability and bias that perpetuates bigoted sentiments like "why would anyone want to live like that." You must confront the history of discrimination of people with disabilities. You must confront head-on the utterly wrong notion that it is better to be dead than disabled. Every study about people with disabilities shows that in the first year after substantial disability, many people are depressed and may consider suicide. But after that first year, people come to accept their disability and consider their own life very worth living.

Quite simply, death is different. The state has a legitimate interest in preserving the health, welfare, safety and life of its citizens. This state interest must include all people with disabilities, regardless of their label or "condition" that needs "artificial means." The proposed amendment includes a burden of proof on the person who wants to withhold medical care, notice, hearing, jury trial, unanimous verdict, appointment of counsel, and a presumption in favor of continued treatment. The bill attempts to respect the constitutional right to refuse medical care while at the same time ensuring the fullest measure of due process before the state sanctions the death of a person with a disability.

One of the most fundamental duties of society is to ensure that the rights of people with disabilities are protected. The most fundamental right of all is the right to life. If the state is going to sanction the death of a person with a disability, it owes people with disabilities the fullest measure of due process. This bill does that, and nothing more.

NOTE: attached is a one page summary that details a few changes to HB 2849 that DRC is seeking. These changes clarify some language and offer a couple more protections to people with disabilities.

DRC's suggested improvement to Rep. Kinzer's HB 2849 Withold/Withdraw Guardianship Bill on W/W issues.

Page 2, lines 19-21, change wording to:
(4) the state protection and advocacy system designated pursuant to 42 USD 15043, 42 USC 10805, 29 USC 794e.
(reason: the protection and advocacy system is a creature of federal law, and these are the exact federal cites)

Page 5, lines 5-6, definitions, change nutrition definition to
(t) "Nutrition" means sustenance administered in any manner.
(reason: we are concerned with limiting the protections for sustenance to that which is ingested "by way of the gastrointestinal tract" may be too narrow).

Page 5, after line 6, definitions, Add a definition for hydration
New (v) "Hydration" means providing water or fluids in any manner.
(reason: we don't see a definition for hydration in HB 2849.)

Page 5, lins 7-14, definitions, change the "or" to an "and" between (A) and (B) and change (A) the "Has been declared legally incompetent …" definition to

(A) Has been expressly declared through a guardianship to be unable to make any decisions affecting medical treatment or care; *AND*
(B) {Keep current wording in W/W bill … }

(reason: The KSA does not use the term legally incompetent anymore. Also, when a guardianship is imposed, the order is supposed to clearly spell out what decisions the guardian can and cannot make for the ward. Defining it this way offers more protection for the life of the person with a disability. More importantly, the "or" is a HUGE loophole that would allow food and water to be withheld. The "or" should be changed to an "and" … or sub (B) should be deleted. Whether the person can make this health care decision is specifically decided by the court in issuing a guardianship over the person. Only a court can strip this right away from people. Death is different.

Page 8, after line 39, add a new definition "legally capable"
New (w) "Legally Capable" means that every person with a disability is presumed to have capacity and be legally capable of making any decision, including but not limited to health care and medical care, unless they have been expressly declared to be incapable to make that decision through a specific portion of the guardianship order.
(reason: like with the language above on "legally incapable," a guardianship order is supposed to specifically take away the decision making ability of the person with that type of decision. That is current policy and law. Also, nowhere in the definitions is "legally capable" defined. Because "legally capable" is a linchpin word used in 7 C on page 11, it needs to be defined and defined in this way. Not doing this creates a loophole that will unnecessarily take the lives of people with disabilities).

Page 8, line 20, add "likely to be permanently" before the word "comatose"
(reason: someone can be in a coma for a few days or weeks. Just saying "comatose" does not offer enough protection).

DISTRICT COURT
PAWNEE COUNTY
04 JUL 27 PM 4:32

BRENDA WEST HAGERMAN, #10459
Legal Counsel
Larned State Hospital
Rural Route #3, Box 89
Larned, Kansas 67550
Telephone: 620/285-4595

IN THE DISTRICT COURT OF PAWNEE COUNTY, KANSAS

In The Matter Of The Guardianship)
and Conservatorship of)
) Case No. [redacted]
[redacted])
)

PETITION TO APPROVE WRITTEN CERTIFICATION OF TREATING PHYSICIAN AND FOR APPOINTMENT OF A GUARDIAN AD LITEM

COMES NOW [redacted], Petitioner, and alleges:

1. I reside at, and my present address is, [redacted]

2. I am the Guardian of the Ward herein, [redacted] by virtue of Letters of Guardianship and Conservatorship issued by Ellis County District Court on April 13, 1999.

3. Renato Sandoval, M.D., [redacted] ating physician, has certified that:

☐ The ward is in a persistent vegetative state; or

☒ The ward is suffering from an illness or other medical condition for which further treatment, other than for relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would such treatment be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses.

FEDERAL AND STATE AFFAIRS
Date 2-13-06
Attachment 24

The written certification with concurring signatures is attached hereto as Exhibit A.

4. Petitioner also seeks from this Court appointing [redacted], to represent [redacted] connection with this Petition and requests that notice of this Petition be given by serving with a copy of this Petition to Approve Written Certification of Treating Physician and for Appointment of Guardian Ad Litem, the Order for Hearing and the Order Appointing Guardian ad Litem by first class postage prepaid mail.

WHEREFORE, Petitioner requests that the Court enter an Order pursuant to the authority of K.S.A. 59-3075(e)(7)(C) as amended, to allow the Guardian authority to withhold or withdraw lifesaving or life sustaining medical care, treatment, services or medical procedures.

[redacted]

STATE OF Oklahoma
ss:
COUNTY OF Ottawa

[redacted] lawful age, being first duly sworn on oath states: That he is the Petitioner above named, that he has read the above and foregoing Petition To Approve Written Certification of Treating Physician and For Appointment of Guardian Ad Litem; is familiar with the contents thereof, and knows of his own personal knowledge that all statements therein contained are true.

99011052
EXP. 7/30/07

[redacted]

SUBSCRIBED AND SWORN TO before me this 24th day of July, 2004.

Notary Public

My Appointment Expires: 7/30/07 99011052

SUBMITTED BY:

BRENDA WEST HAGERMAN, #10459
Legal Counsel
Larned State Hospital
Rural Route #3, Box 89
Larned, Kansas 67550
Telephone: 620/285-4595

KANSAS

Janet Schalansky, Secretary

Social and Rehabilitation Services
Larned State Hospital
Dr. Mark E. Schutter, Superintendent

Kathleen Sebelius, Governor

CERTIFICATE OF TREATING PHYSICIAN

Pursuant to K.S.A. 59-3075(e)(7)(C)

RE: [redacted] (Name of Patient) 1/10/1952 (DOB) 52 (Age)

ATC-South (Unit or Ward) [redacted] (ID#) 4/15/2004 (DOA)

TO: [redacted] (Name of Legal Guardian)

[redacted] (Address)

I hereby certify under penalty of perjury that I am the above named patient's treating physician, that I have examined the patient, and based upon such examination and after review of the patient's medical records, that (check as appropriate):

☐ The patient is in a persistent vegetative state;

OR

☑ The patient is suffering from an illness or other medical condition for which further treatment, other than for the relief of pain, would not likely prolong the life of the patient other than by artificial means, nor would such treatment be likely to restore teo the patient any significant degree of capabilities beyond those the patient currently possesses.

7/20/04
(Date)

(Signature of Physician)

Renato Sandoval, M.D.
(Physician's Name Printed)

24-4

KANSAS

Janet Schalansky, Secretary

Social and Rehabilitation Services
Larned State Hospital
Dr. Mark E. Schutter, Superintendent

Kathleen Sebelius, Governor

July 16, 2004

To Whom It May Concern:

This letter is in regards to [redacted] who is a patient here in Larned State Hospital and has been under my care medically for 2 years. [redacted] has multiple medical problems including severe cerebral damage presumably due to hypoxic injury, seizure disorder, brittle Type 1 Diabetes Mellitus, diabetic neuropathy, peripheral vascular disease, secondary parkinsonism, history of 2 hip fractures. He has severe mental disorder due to his cerebral damage and very dependent on others for his routine daily activities. His physical condition has been slowly deteriorating over the years because of the progression and chronicity of his medical conditions. Because of the above reasons and poor prognosis and quality of life with total dependence from others, if in the event that [redacted] goes into cardiac or respiratory arrest, I recommend he not be resuscitated and therefore have a Do Not Resuscitate status. I think this is the humane thing to do and let [redacted] [redacted] rest when that time comes. Thank you very much.

Sincerely,

Renato Sandoval, M.D.
Diplomate, American Board of Internal Medicine

24-5

KANSAS

Janet Schalansky, Secretary

Social and Rehabilitation Services
Larned State Hospital
Dr. Mark E. Schutter, Superintendent

Kathleen Sebelius, Governor

July 19, 2004

RE: [redacted]

To Whom It May Concern:

I am Huynh, Kim-Giam, Senior Supervising Physician for the Medical Services of Larned State Hospital. I have known and taken care of [redacted] off and on since 1979. [redacted]as suffered from irreversible brain damage (consequences of chemical abuse in college and neglect of proper care for Type 1 diabetes mellitus) since 1972, which have left him severely dysfunctional psychiatrically and unable to care for himself.

[redacted]as required total hospital care since then and a recent attempt to release him to a nursing home has failed. He is one of the rare, genuine cases of the so-called brittle diabetes and has had repeated incidents of hypoglycemia even while under the constant care provided by our hospital endocrinology specialist. He has also suffered from epilepsy since 1972. The treatment of the epilepsy is difficult and is causing complicated adverse effects which, by themselves, further impair [redacted]lready limited quality of life.

Since his recent readmission to Larned State Hospital, [redacted]physical health has deteriorated and he has required transfers to a general hospital for stabilization. We hope that the present situation is temporary, but we have to be prepared for the dire eventuality of a downward and terminal course. [redacted]relatives expressed wishes to have a DNR order in place, and I agree that it would be unethical to try to keep [redacted] [redacted] alive once it's clear that his body and spirit give out.

Sincerely,

Huynh, Kim-Giam, M.D.

KANSAS

Janet Schalansky, Secretary

Social and Rehabilitation Services
Larned State Hospital
Dr. Mark E. Schutter, Superintendent

Kathleen Sebelius, Governor

CONCURRENCE OF SECOND PHYSICIAN

Pursuant to K.S.A. 59-3075(e)(7)(C)

RE: [redacted] (Name of Patient) 1/10/1952 (DOB) 52 (Age)

ATC-South (Unit or Ward) [redacted] (ID#) 4/15/2004 (DOA)

TO: [redacted] (Name of Legal Guardian)

[redacted] (Address)

I hereby certify under penalty of perjury that I have independently examined the above name patient, and based upon such examination and after review of the patient's medical records, I concur in the findings stated in the certificate of

Renato Sandoval, M.D.
(Name of Treating Physician)

7/20/ 2004
(Date)

(Signature of Physician)

HUYNH, KIM - GIAM, M.D
(Physician's Name Printed)

DISTRICT COURT
PAWNEE COUNTY
04 AUG -3 AM 11:10

IN THE DISTRICT COURT OF PAWNEE COUNTY, KANSAS

In The Matter Of The Guardianship of)
[redacted])
Case No. [redacted]

ORDER APPROVING WRITTEN CERTIFICATION OF TREATING PHYSICIAN

NOW ON THIS 3 day of August, 2004, this matter comes before the Court upon the guardian's presentation of a physician's certificate in accordance with K.S.A. 59-3075(e)(7)(C). The guardian appears by counsel, [redacted], and BRENDA WEST HAGERMAN, Legal Counsel, Larned State Hospital.

Upon review of the presented certification, the Court finds that:

1. Notice of this hearing has been given as required by law and the order of the Court, and proof has been duly filed herein and is hereby approved.

2. The allegations of the Petition are true.

3. The physician's certification is in proper form and in compliance with the provisions of K.S.A. 59-3075(e)(7)(C).

4. The certification demonstrates a finding by the ward's treating physician that:

☐ The ward is in a persistent vegetative state; or

☒ The ward is suffering from an illness or other medical condition for which further treatment, other than for relief of pain, would not likely prolong the life of the ward other than by artificial means, nor would such treatment be likely to restore to the ward any significant degree of capabilities beyond those the ward currently possesses.

5. The findings stated within the certification are concurred in by a second physician or a medical ethics or similar committee.

COPY

24-8

It appearing to the Court that the procedures set out in the above statute have been met, the Court hereby orders that the certificate of the ward's treating physician is hereby approved.

IT IS SO ORDERED.

JUDGE OF THE DISTRICT COURT

SUBMITTED BY:

BRENDA WEST HAGERMAN, #10459
LARNED STATE HOSPITAL
LEGAL COUNSEL
Route 3, Box 89
Larned, Kansas 67550
Telephone: (620) 285-4595

APPROVED BY:

[redacted]
[redacted]
P. O. Box 75
Larned, Kansas 67550
Court-Appointed Attorney for
[redacted]

Testimony to the

House Committee on Federal and State Affairs

Testimony regarding HB 2849 / 2884

H. Rutherford Turnbull, III
Lawrence, Kansas

February 13, 2006

Chairman Edmonds and members of the Committee, I am not able to be present at today's hearing due to prior commitments but offer the comments below in support of the provisions proposed in HB 2849 and 2884. You may read the following statement to the House Committee if you wish:

I believe the bill is a vast improvement over present Kansas law in at least these respects:

1. It creates a presumption in favor of nutrition and hydration
2. It strictly limits the power of a guardian or other person, including a court, to consent to or order the withholding or withdrawal of either or both (substantive standards)
3. It provides for a full due process hearing on the petition to withhold or withdraw procedural due process)
4. It puts the burden of proof on the petitioner and requires a quantum of proof at clear and convincing
5. It limits the guardian's power where a ward has given valid advance directions
6. It limits the standing to secure a hearing to truly interested parties (no "stranger in the courtroom")
7. It defines consent according to the three traditional elements of that legal construct
8. It defines medical judgment according to an objective standard
9. It requires evidence that is objectively true and thus eliminates the present subjective discretion that a physician is able to bring to bear
10. It implicitly recognizes the possibility of discrimination based on disability

In many respects this bill adheres to the consensus statement of principles of treatment of people at the end of their life developed after the Schiavo proceedings and based in large part on my testimony to the U.S. Senate HELP committee (attached) and subscribed to by many individuals and organizations that advocate for the rights of people with disabilities.

In my individual capacity and not in any way as a representative of The University of Kansas or any of its units, I believe the Kansas Legislature will greatly improve present law and take a large step toward protecting wards from discriminatory action if it enacts HB 2849.

Rud Turnbull

Rud Turnbull
Co-founder, co-director
Beach Center on Disability
The University of Kansas
3111 Haworth Hall, 1200 Sunnyside Drive
Lawrence, Kansas, 66045-7534
tel: 785-864-7610, -7611, -7600
fax: 785-864-5825
www.beachcenter.org

FEDERAL AND STATE AFFAIRS
Date 2-13-06
Attachment 25

Health Care Provided to Non-ambulatory Persons

Bill Number:

Hearing Date: April 6, 2005, 9:30 am

Location: SD562

Witness:
Mr. Rud Turnbull
University of Kansas Beach Center on Disability, Lawrence, KS
Co-Director

Testimony

Senator Enzi, Senator Kennedy, Senator Roberts, Senator Harkin, and Members of the Committee.

I am Rud Turnbull, the father of Jay Turnbull, a 37-year old man with significant mental retardation (measured IQ of approximately 40, mental age of approximately 6), rapid cycling bi-polar illness, autism, an irregular heat beat, and frequently challenging behaviors.

At the University of Kansas, I am a professor of special education, former chairman of the department of special education, co-founder and co-director of the Beach Center on Disability (a research center focused on the effects of policy on families who have children with disabilities), and former courtesy full professor of law. Before coming to the University of Kansas in late-1980, I was professor of public law and government at the University of North Carolina at Chapel Hill, beginning in 1969.

Here and today, I speak for no organizations. Instead, I have been asked and am pleased to share my perspectives as a father and friend of many people with intellectual and associated disabilities and their families, and to provide a précis of what I have learned about policy from their perspectives.

There are literally millions of people with intellectual and associated disabilities. So whatever you do on this topic we discuss today will change their lives dramatically. But you will also affect those who will acquire a disability as they age. That population includes nearly every one of us, should we live long enough.

After Jay was born and his disability confirmed, I responded by shaping my life to his and his peers and their families. I have learned a great deal about their lives by being an active participant in developing services locally; advocating at the local, state, and federal governmental levels for my son and his peers and their families; researching and writing about them in over 250 publications; and carrying out research, training, and technical assistance on their behalf, in nearly every state, for nearly 35 years.

Although I do not personally know these millions of people whom you can affect, I know how they have experienced discrimination and sometimes been surprisingly successful in overcoming it, and I have a solid sense about their aspirations for how they want to live.

Many of them are in the same position as my son: graduates of special education under the Individuals with Disabilities Education Act; beneficiaries of the Home and Community Based Services Waiver under Medicaid; and recipients of SSDI or SSI; supported employment services under the Rehabilitation Act; and rent subsidies under Section 8 of the Housing Act. Some of them live according to their choices; my son does, because of these programs.

Many, however, live according to how policies and service systems find it convenient for them to live. Unlike Jay, they are not supported to be self-determined.

Allow me to talk about self-determination, for it is at the heart of debates about health-care decision making. And allow me to give you the example I know best, my son.

If you were to ask Jay where he wants to live and work, who his friends are, and how he wants to be a fully participating member of his community, he would tell you, by words, behavior, or both, and you would have no doubt about the authenticity of his answer.

If you ask him where his deceased grandparents are, he would tell you, "In Heaven with Baby Jesus." Here, too, you would know his answer to be utterly genuine and complete.

I tell you this because I want you to understand that Jay, like many people with mental retardation or associated intellectual disabilities, is "situationally competent." Whether he has sufficient ability to be self-determined depends wholly on the situation he faces and on who asks him, how much he trusts that person, and how familiar he is with the questions. That can be true of his peers, too.

Jay knows about his life as he leads it, day by day. He has, however, little knowledge about the various medical procedures that he must have, especially those involving surgery. And he has no concept about death.

For Jay, death is the permanent absence of a loved one from him and the permanent presence of that person with God.

This snapshot of Jay is important to you because you need to understand the world that Jay and his peers live in. You need to understand that people with intellectual and associated disabilities have always been subjected to discrimination. Often, they have been put to death or allowed to die when they might have been kept alive. The discrimination that they have experienced in education, employment, and housing are matters that you have addressed by various laws. More to the point today is the discrimination in health care that they have experienced.

The roots of that discrimination are ancient. They originate in the debates of the Greek philosophers, Hippocrates, Socrates, Plato, and Aristotle.

Hippocrates posed the question, "Which children should be raised?"

Plato answered by writing that a state's "medical and judicial provision" will "leave the unhealthy to die, and those whose psychological constitution is incurably corrupt, it will put to death." He added, "… we must look at our offspring from every angle to make sure we are not taken in by a lifeless phantom not worth the rearing."

Aristotle agreed: "With regard to the choice between abandoning or rearing an infant, let there be a law that no crippled child be raised."

And the pre-Christian Romans' Twelve Tables, their equivalent of our federal constitution, admonished the head of the family to "kill quickly…a dreadfully deformed child."

One would have thought our more enlightened age would have settled the question about which individuals should be treated so that they will live.

Yet, even nowadays the debate rages: what are the indispensable elements of being, the sine qua non of human-ness. Those debates frighten me, and they should alarm you, too. The slippery slope is slick and awaits us all.

In our own country, Justice Thurgood Marshall, in his opinion in City of Cleburne v. Cleburne Living Center (473 U.S. 432 (1985)), which struck down exclusionary zoning that targeted only people with mental retardation, characterized this country's discrimination against people with mental retardation as "grotesque."

That case and others from the Supreme Court, as well as our own laws, affirm that the stigma attached to disability of all kinds is simply abhorrent and has no role in public policy.

To remedy the discrimination as a matter of federal law, Congress enacted the Americans with Disabilities Act, 15 years ago. That bi-partisan law, bravely sponsored by Senators Harkin, Hatch, Kennedy, and my own former Senator, Bob Dole, and powerfully supported by President Bush and many senior-level members of his Administration, declared that --

- disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society, and

- the nation's policy for people with disabilities is to assure their equal protection under the law, advance their self-determination, and promote their independent living.

The implicit message of ADA's "natural experience" language is that each of us at some time may have a disability, especially as we age, but that we should not therefore lose our rights, including our rights to choose what happens to us, whether in health-care decision making or other aspects of life.

Among the many questions before you nowadays is this simple one: What role, if any, does Congress have in responding to –

- theories that people with disabilities are not human enough to have rights, and, if they pass some test of being human, still have no rights, much less the right to live,

- a sense among the some Americans that "I would not want to live like THAT!", that a person with a disability "suffers" from the disability when, often, it is not the disability that causes the suffering but our social and legal refusal to support the person,

- a sense among some in the public and media that living as a person with a disability is such an undesirable condition that death itself is preferable to life,

- public perceptions that people with disabilities are useless consumers of public and private resources,

- cost-containment pressures and rationing criteria within the health-care and insurance industries, and

- public opinion that too often is not ashamed to say that, when it comes to protecting and allotting health-care resources to people with disabilities, they should, in the words of former Governor Lamm of Colorado, "Just roll over and die."

So, as the first order of business, in any bill it enacts Congress should –

- affirm and recommit itself to the ADA principles of self-determination (in constitutional terms, liberty and autonomy), independent living, and equal protection, and

- proclaim in no uncertain terms that these policies are still the nation's law for people with disabilities and that they apply to health-care and end of life decision making.

Second, in that same bill, Congress should recognize that –

- people with significant intellectual and other associated disabilities are situationally competent,

- their abilities vary according to type and severity, and in contexts and over time,

- they need and under the ADA have rights to be supported to be as self-determined as they can be at the times when they and their designated representatives must make choices, and

- the families of newborns, infants, children, and adults with disabilities are the core social units for them and for society itself, and that it is proper for the nation to commit its resources to supporting those families.

Third, Congress should recognize that there already are principles guiding health-care decision making and that these principles have garnered widespread consensus from health-care providers and organizations representing people with disabilities and their professional care-givers.

Those principles are the foundations for the regulations implementing the Child Abuse Prevention and Treatment Act (42 U.S.C. Sec. 5101; 45 C.F.R. Part 84, Section 84.55). As one who helped draft the Principles some 20 years ago, I know them well, and I urge you to consider reviewing them and weighing their appropriateness for any policy you decide to enact.

The Principles and regulations, taken as a whole, state that –

- discrimination against any person with a disability, regardless of the nature or severity of the disability, is morally and legally indefensible,

- the rights of people with disabilities must be recognized at birth (and, I believe, at the other edge of their lives),

- when medical care is clearly beneficial, it must be provided,

- it is impermissible to take into account any anticipated or actual limited potential of a person or lack of resources,

- there is a presumption in favor of treatment at the edges of life,

- the presumption is rebuttable and it is permissible in law and ethics to withhold or withdraw medical or surgical procedures that are clearly futile and will only prolong the act of dying and when the person is in an irreversible coma or the treatment would be so painful as to render it unconscionable, and

- the person's disability itself must never be the basis for a decision to withhold treatment.

Fourth, Congress should recognize that its actions will affect millions of people, not just those with disabilities but also children, the aged, and their families.

Fifth, Congress should recognize that the primary responsibility for legislating health care and protecting against abuse and neglect in health care traditionally has resided in state legislature and state courts. However, given the significant federal civil rights issues involved, it is appropriate for Congress to consider the extent of any federal role. Later in my testimony I suggest principles for Congressional action.

Sixth, Congress should recognize that end of life decision making, however much it may be guided by various legal instruments or other reliable expressions of self-determination, is a dynamic process, and that people's conditions change with prompt, state-of-the-art treatment, and so do their and their families', other designated representatives', and health/medical care-givers' judgments about how much to honor the previously executed instruments or expressions of autonomy.

Seventh, Congress should acknowledge that any government that compels a life to be lived is ethically obliged to provide the person with a right to individually chosen and appropriate supports necessary to implement the ADA "natural experience" declaration and the ADA national policy aspirations. Civil rights are the necessary precursors to rights and entitlements within service-delivery systems.

Eighth, Congress should not retreat from the laws that already commit our nation to enhancing the quality of life of people with disabilities and their families. More than that, Congress should enhance existing rights and benefits and create new ones.

- Preserving Medicaid as an entitlement is absolutely necessary for people with disabilities. It is desirable for the federal government to give states greater flexibility in structuring their Medicaid programs, including by adding more self-determination and self-direction to the service system. But it would be devastating to present and future Medicaid beneficiaries for the federal government to tighten the present eligibility criteria and reduce the present benefits.

- Preserving the eligibility and funding for the programs that my son and millions of other people with disabilities rely on to live as full citizens, consistent with ADA, is also absolutely essential. These include Section 8 rental assistance, supported employment programs, SSDI and SSI,

25-6

Medicare, the Developmental Disabilities Act and its family support provisions, the federal respite-care assistance program, and the Protection and Advocacy Systems.

- Enacting the Family Opportunities Act and MICASA in order to strengthen families and assure greater self-determination for them and for people with disabilities is way overdue.

Ninth, knowledge is a precursor to good decision-making, so Congress should authorize and enable a wide range of parent and family training and information centers, in both the disability and non-disability arenas, to offer objective and current information about the legal instruments that individuals may execute and about the treatment options that the health-care and hospice systems can offer at the end of life.

Lastly, there are various issues that Congress might well consider if it debates whether it is desirable to enact a law that allows for federal intervention in end of life decision making.

Among those issues are the cases in which federal intervention is warranted. In my judgment, the cases would be ones in which –

- the person is not near death but most certainly will die if the treatment, hydration, or nutrition is withheld, or

- there are no clear advance directives from the person or other reliable, at the clear and convincing level, expressions of the person's autonomy, or

- there is irreconcilable disagreement among family members concerning the decision to be made.

If Congress does indeed debate a federal role, it may well also consider such issues as –

- expedited hearings and appeals,

- standing to sue,

- burden of proof,

- standard of proof,

- criteria for third-party decisions,

- utilization of independent medical judgments, and

- grounds for overturning a state court decision.

For just a moment and in conclusion, please allow me to return to the beginning of my testimony, to my son Jay. He has two parents who agree among themselves about his care; two sisters and a brother in law who know him extremely well, love him devotedly, and have thought carefully about their and his lives and the decisions they will make for themselves and for him; and friends who also know him well and honor his self-determination. In Jay's case, the issue is not one of rights, but of going beyond rights.

Rights and their associated principles and regulations direct us, but they cannot fully answer our questions about what to do for Jay and people with intellectual and other disabilities. So family, friends, and Jay himself invariably turn to those two elements that have added quality to his life – to trust, hard-earned over time, and compassion, generously shared and untainted by disability discrimination.

As I lay dying, I will have confidence that Jay's family and friends will do for him what he most would want done for himself, if he could decide. His life – not his disability – gives them a warrant for action. And the "them" who will carry out that warrant are those whom he has trusted and who have made his life an intrinsic part of their own. Jay's most enduring social security is his circle of family and friends.

But he and millions of others also look to you to preserve his civil rights under the Constitution, the ADA, and other laws; maintain existing rights and entitlements and expand, not shrink, them; rely on principles for decision making that have wide support and that have protected many newborns and infants with disabilities; and assure an appropriate federal role in reviewing state-based decisions.

Thank you for the opportunity to testify and for your careful and deliberate consideration about how to proceed on behalf of all of the present and future "Jays" of our country.

H. Rutherford Turnbull, III
Lawrence, Kansas

FEDERAL AND STATE AFFAIRS COMMITTEE OF THE KANSAS HOUSE OF REPRESENTATIVES
PUBLIC TESTIMONY ON House Bills 2849 and 2884
Monday, February 13, 2006
State Capitol, Room S-313
John G. Carney

Chairman Edmonds and members of the Committee; thank you for the opportunity to present testimony regarding HB 2849 and 2884 on behalf of the Kansas LIFE Project. My name is John Carney and I am vice president for Aging and End of Life at the Center for Practical Bioethics in Kansas City and co-chair of the LIFE Project Public Task Force as well as a founding member of the organization. I also served as a member of the HB 2307 Committee assigned in 2005 by the Kansas Judicial Council to review proposed revisions to the Kansas Guardianship Statute related to hydration and nutrition for wards of the court.

My remarks today will be limited primarily to the provisions in the House Bills under consideration dealing with the administration of nutrition and hydration for wards of the court, and the attendant responsibilities of guardians in medical end of life decisions for their wards.

For most of my professional career I have worked in the realm of hospice and palliative care – at the local level in south central Kansas, at the state level, within the region and nationally, having served on the boards of directors of state and national hospice and palliative care organizations including a brief stint as the latter's chief operating officer. That professional experience notwithstanding, what I believe provides me far more meaningful perspective on this issue is the 26 years I assisted my mother in caring for my recently deceased father, who for more than a quarter of a century was disabled by stroke, facing the slow and often undetectable diminishment of his ability to care for himself. I stand before you, not so much as a career professional, but more as a son and family caregiver who knows the meaning of providing and deciding with and for a disabled person.

Secondly, in the broader context of my professional work it has been my experience that Kansas healthcare professionals are guided in their end of life care practice by the following convictions:

1. Respect for the principle of personal autonomy is pervasive, protected not only for those who can speak for themselves but equally for those who rely on others to speak for them. This conviction ensures access to safe, appropriate medical care regardless of (dis)ability. For the most part it also includes a respect to honor the wishes of patients when those desires are known regardless of whether they are expressed in writing or through a silent nod or a squeeze of the hand.
2. We respect the accrediting, credentialing and licensing processes that govern our healthcare care system to ensure competent medical practitioners. We rely in the obligations dictated by license and professional standard for those professionals to act in our best interest.
3. Healthcare decisions are first and foremost private matters between patients and their professional caregivers, naturally inclusive of those who by patient choice or legal appointment become involved.
4. Dying has changed. From this point forward, death for most of us will no longer result from a single acute event, but rather from a series of slow and often imperceptible changes – disabling over time; the result of multiple chronic diseases that ebb and flow. This process of subtle decline will be affected by new medicines and new procedures, but only rarely by new discoveries. For the majority of us the most common disability we face is dementia, the ability to make reliable decisions.
5. We cannot know, direct or predict with specific certainty today what future treatment decisions we will be asked to make for ourselves or for those we love. While we may describe our values, express our desires and discuss our intentions in healthcare directives based on today's understanding of our health status and current medical interventions, we must trust and rely on those expressions to guide our proxies and agents in the future.

FEDERAL AND STATE AFFAIRS
Date 2-13-06
Attachment 26

6. All medical procedures, especially those requiring surgery and the administration of anesthetics just as all medications, carry risks, burdens, side effects and benefits which must be measured, weighed and evaluated by patient, family and medical professional.
7. Dying is part of life. Death will come to all of us. Though unwelcome it does not have to be inhumane, nor must it at every turn be the enemy to be avoided at all costs.
8. Within the last 10 years, Americans have discovered that modern medicine is capable of creating "mechanical paths to death" whose impact can be more devastating and burdensome than the natural progression of some mortal diseases.

How do we balance the need to protect those who are vulnerable, whose wishes may be unknown or unknowable with the private healthcare decisions of patients and families who decline or refuse treatment?

First and foremost, overwhelming evidence suggests that relying on existing written advance directive will not achieve that end. A number of recent studies including one sponsored by the Pew Charitable Trust released in early 2006, point to the woeful progress in the Advance Care Planning arena. This is not a subject Americans approach comfortably or handle well even in conversation let alone in writing. Many may speak with family members but do not, as a rule, write their wishes down or discuss them in detail with their physicians. Physicians also express reluctance in discussing the issues with patients. Consider the following facts:

1) Only a minority of Americans even have advance healthcare directives in place. Unfortunately in many instances they are unavailable at the time they are needed for healthcare providers and evidence points to their not being honored due to standard protocols that favor treatment.
2) Most advance healthcare care directives are not explicit, often describing values, treatment **preferences** and general conditions. Topics such as hydration and nutrition, while referenced may offer no instruction or guidance on, as proposed language requires, "current circumstances."

The reliance of House Bills 2849 and 2884 on previous explicit written instructions, when no such support or structure within the healthcare system exists is unrealistic and problematic.

Before proceeding with further analysis of the measures under consideration, it is important to point out that the particular provision related to the withholding and withdrawal of nutrition and hydration for wards of the court was referred to the Kansas Judicial Council during the interim session last summer and fall. The work group assigned to study the provision was named the **HB2307 Advisory Committee**. I, along with representatives from the legislative and judicial systems; healthcare ethics, legal, nursing and medical professions; long term care, hospice and disability fields met for five months to address the language. Our recommendations were forwarded to and approved by the Judicial Council in December 2005. The language recommended by Council is not part of either of these two bills.

Furthermore, the provision [59-3075 (e)(7)(C)] is still part of HB2307 in the House Judiciary Committee and Senate Bill 92. Given the uncertainty of where the Judicial Council's report will be reviewed, it seems premature to act on yet another version of the language before full consideration is given to the Judicial Council's recommendation.

As an example, new language appearing in both 2849 and 2884 references the term ***objectively futile*** as if it had some basis in ethical or medical literature. To our knowledge there is no accepted term in either field, and in fact AMA ethics representatives indicate that disagreement exists on the use of the term **futile** itself, some arguing that it has negative values associated with it, is ultimately subjective in nature and can effectively be applied only retrospectively. In this application, the reference to ***objectively futile*** may serve neither ward nor guardian.

The Center for Practical Bioethics is currently involved in an almost year long process with member Kansas City area hospitals in developing a policy guidance document on the use of the term futility. Focus group feedback from disability and minority stakeholder groups reflect ***no consensus on the use***

of the term futility. Requiring this level of evidence may not prove helpful to either the affected parties or the court. At the outset the use of the term appears problematic.

In addition, how is it that the court system is better equipped to handle these delicate, gut wrenching, emotionally charged issues than are healthcare professionals, carefully selected and legally bound guardians, and family members? Thousands of these kinds of decisions get made daily in the privacy of homes, hospitals and nursing homes in the best interest of disabled patients without incident.

No evidence of the system failing Kansans was presented during the five month review conducted by the HB2307 Committee for the Judicial Council. Despite the lack of evidence, the committee nonetheless made a number of recommendations to accommodate perceived risks. Those recommended changes deserve serious consideration.

To assume that surgical procedures performed on disabled persons would not be considered medical care if the purpose is to provide artificial hydration and nutrition appears to be contradictory. Would surgeons and physicians be exempt from liability should the procedures fail? Why do the provisions not include efforts to assist with artificial or mechanical assistance for breathing or elimination – two other equally important physical requirements for sustaining life?

The assumption that these two procedures (hydration and nutrition) are fundamentally different than others, outside the parameters of medical care, and carry no **relative** risks oversimplifies the complexity of caring for disabled persons usually affected by a multi-organ and multiple system issues.

Reducing or limiting the physician's reasonable medical judgment in addressing burden and benefits of interventions or risks (side effects) to "hastening death", "medical impossibility" or incapacity again appears to oversimplify the physician's responsibility to manage the patient's care.

Finally, the most troubling dilemma raised in these proposed measures is the provision for "presumption of life", only because the definition of what it means to sustain or preserve life is never addressed. Nearly every religious and philosophical traditions, from east to west, accepts the purpose of life as being more than the physical function of bodily organs. Humans are social animals, functioning within family systems and social units. Meaning in life, for most of us comes not only from within but from outside of us as well – through a higher power or social construct. There is a give and take with the world.

If the presumption of life argument is followed to its natural conclusion, without definition as to what preserving and sustaining life means, then the bodily function of organs, mechanically assisted or artificially supported, most likely wins out. But can we stop at hydration and nutrition? If preserving and sustaining life finds its meaning in organ function, assisted or not, then we need to return to the question of what society in general has already resolved - the meaning of brain death; what it means to be an organ/tissue donor and how can anyone can determine when my time has come.

John G. Carney
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Public Testimony
Federal and State Affairs Committee
Kansas House of Representatives
House Bill 2849
2-13-06

Chairman Edmonds and Members of the Federal and State Affairs Committee:

Thank you for the opportunity to share my concerns about how medical decisions are made. I am a hospice nurse with more than twenty-five years of experience in end-of-life care. In the vision of the National Hospice and Palliative Care Organization, hospice promotes a world where individuals and families facing serious illness, death and grief will experience the very best that humankind can offer.

Decisions about withholding or withdrawing artificial nutrition and hydration (ANH) should be made in the same way as decisions about other medical treatments, by considering the patient's preferences and the relevant risks and potential benefits. The provision of artificial nutrition and hydration are medical treatments. Decisions about ANH can be complicated and are always based on factors relevant to the individual. While ANH may be medically possible, there are a number of factors to be weighed – in each individual case—to determine the appropriateness of the treatment. The decision is a personal/family decision that is to be made in consultation with the medical providers.

Physicians and nurses must complete required education, pass state boards, and seek continued education for license renewal. The focus for physicians and nurses is to provide the very best care for each individual. Professional Codes of Conduct for practitioners exist to protect patients. Medical care providers work in concert with the person and the family to consider the benefits and burdens of medical treatment.

These decisions should ideally be made by a person with decision-making capacity. If the person lacks decision-making capacity, choices should be made by a surrogate decision-maker with knowledge of the person's preferences. Current Kansas law creates processes for decision making that are meant to protect each person.

I have concern about the intent and the language of these bills. I encourage you to send this issue to the Kansas Judicial Council to allow that group to continue its work on drafting appropriate language to protect our most vulnerable without taking away the individual's and family members' sense of autonomy and individuality, their ability to make decisions in the best interest of the individual. During this past year, the Kansas Judicial Council has been working on language to address these concerns. This process includes a broad-based representative group and I believe the language created by that group creates much better public policy than the language in this bill. Please give careful consideration to the work that has been done by that group and avoid moving forward with this bill which, I believe, does not create good public policy.

Thank you.

Sandy Kuhlman
Executive Director
Hospice Services, Inc.
Phillipsburg, KS
Chair, Public Policy Task Group
Kansas Hospice and Palliative Care Organization
Board Member, National Hospice and Palliative Care Organization

FEDERAL AND STATE AFFAIRS
Date 2-13-06
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SUMMARY OF "DUTY TO RETREAT" LAW IN ALL 50 STATES

PREPARED JULY 2005 – NRA/ILA OFFICE OF LEGISLATIVE COUNSEL

Number of states that impose a legal duty to retreat if outside the home: 25
Number of states that allow necessary self-defense in or out of the home without retreat: 25

These states may require a duty to retreat <u>if outside the home</u> (legislation or case law after the date of this review may affect these lists, or in some situations, conflicting case law may exist):

- Alabama
- Alaska
- Arkansas
- Colorado
- Connecticut
- Delaware
- Hawaii
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Missouri
- Nebraska
- New Hampshire
- New Jersey
- New York
- North Carolina
- Ohio
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Texas
- Wyoming

Washington D.C. is a "retreat to the wall" jurisdiction.

These states may not legally require a defender to retreat when he reasonably believes it is necessary to defend himself.

- Arizona
- California
- Florida
- Georgia
- Idaho
- Illinois
- Indiana
- Iowa
- Kentucky
- Kansas
- Louisiana
- Mississippi
- Montana
- Nevada
- New Mexico
- North Dakota
- Oklahoma
- Oregon
- Tennessee
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin

FEDERAL AND STATE AFFAIRS
Date 2-13-06
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