Disability Rights Center of Kansas
214 SW 6th Avenue, Suite 100 ♦ Topeka, KS 66603
Phone: 785.273.9661 ♦ Toll Free: 1.877.776.1541
Toll Free TDD: 1.877.335.3725 ♦ Fax: 785-273-9414
www.drckansas.org *info@drckansas.org*

EQUALITY ♦ LAW ♦ JUSTICE

February 12, 2025
House Committee on Judiciary
Opponent Testimony for HB2359
(Note: we would Change to a Strong Proponent if our Amendment were Adopted)

Chair Humphries and members of the committee:

My name is Mike Burgess, Policy Director at the Disability Rights Center of Kansas (DRC). I will significantly summarize my written testimony. DRC is a public interest legal advocacy organization that is part of a national network of federally mandated organizations empowered to advocate for Kansans with disabilities. DRC is officially designated by the State of Kansas as Kansas' protection and advocacy system. DRC is a private, 501(c)(3) nonprofit corporation, organizationally independent of state government and whose focus is the protection and enhancement of the rights of Kansans with disabilities.

DRC, Kansans for Life, the Kansas Catholic Conference, the Kansas Council on Developmental Disabilities and the Big Tent Coalition (which is the longest-standing disability coalition made up of dozens of organizations from across the aging and disability spectrum) are here today to advocate for a life-saving amendment to fix fatal flaws in this bill regarding end-of-life powers of Kansas guardians. The Revisor is drafting this amendment.

To be clear, the **Disability Rights Center of Kansas appreciates and fully supports every other provision of this bill that is not involving end-of-life guardian powers, and if our proposed end-of-life amendment is adopted we would strongly support the amended bill**. Updating Kansas law to be more in line with the Uniform Codes on guardianship/conservatorship in a manner that works for Kansas by balancing the rights of Kansans with disabilities along with the responsibilities of guardians/conservators is much needed. The last time these laws were significantly updated in Kansas was nearly 23 years ago, way back in 2002. **The Judicial Council and its Guardianship/Conservatorship Advisory Committee did an outstanding job of developing effective public policy tailored to the needs of Kansans for every other non-end-of-life policy issue contained in this bill.**

Madam Chair, we were frankly not sure where you should categorize our testimony on your list of conferees, as often conferees are sorted by those who "support," "oppose" or are "neutral" to the bill. Technically, we simply cannot be "neutral." The fatally flawed language prevents us from taking a truly neutral position. As mentioned, we are supportive of every other change proposed in the bill. We think before this committee passes this bill that the fatal flaws in the end-of-life authorities for guardians must be fixed. That is why this testimony lists us as opponents to that flawed language, but that we would fully support this bill with the adoption of the amendment.

DRC Strongly Supports the Work of the Judicial Council on All Policy Changes in this Bill that are Not End-of-Life Issues; DRC also Commends the Judicial Council for not Endorsing the Provisions regarding the End-of-Life Powers of Guardians:
DRC strongly supports every other provision of this bill that does not deal with the end-of-life powers of guardians. **The Guardianship & Conservatorship Advisory Committee of the Judicial Council spent years on this bill, making positive and needed changes, and it shows in their excellent work product. We do have serious concerns about the fatally flawed language regarding the end-of-life powers of guardians.** However, the rest of the work by the Advisory Committee and the full Judicial Council with

this bill is outstanding. They are to be strongly commended. **See the list at the end of our testimony outlining several positive changes in this law.**

We believe one reason why the Judicial Council chose to show total deference to the Legislature and the Chairs of the Judiciary Committees on this issue (by not endorsing provisions regarding guardianship end-of-life decision making), is because of how significant of a problem Kansas law is regarding end-of-life guardianship powers. The fatal flaws expressed in this testimony were also detailed to the Judicial Council, who listened closely, and at some level the Judicial Council also must have had reservations about the end-of-life provisions, because they specifically withheld any recommendation regarding guardianship end-of-life decision-making in the bill, I am sure in part because they understood the significance of this problem. The Chair of the Judicial Council (Judge Eric Rosen) stated during the meeting that these important end-of-life provisions should be decided by the Kansas Legislature, not the Judicial Council. Timing was an issue too. The Judicial Council met in December, and with the Ks Leg session starting the next month, the Council specifically left this to the legislature. We commend the full Judicial Council for understanding the complex nature of this issue and respecting the valid concerns of the pro-life and disability communities.

Supporters of this Amendment Come from Vastly Different Backgrounds –
It is significant to note that the various organizations supporting the amendment to fix the fatal flaws in the law come from vastly different backgrounds and perspectives. Given that, it is fair to state that our organizations do not always work closely together on public policy. However, when it comes to end-of-life issues and ensuring Kansas public policy does not discriminate against or harm the right to life for Kansans with disabilities, our organizations have a long history of close collaboration. Our organizations are all alarmed that this bill maintains the fatal flaws in Kansas law regarding end-of-life and guardianship issues.

History of this Issue and How Our Organizations Came Together:
Our organizations first came together because we shared significant concerns about the Terri Schiavo case, which made national headlines back in 2005. Likewise, we are also incredibly concerned that Kansas law and this bill do not adequately protect or value the lives of Kansans with disabilities when it comes to guardian's end-of-life powers. This is not just about the Terri Schiavo case, which happened in Florida. In this testimony, we also provide two examples of Kansas cases where current Kansas law failed people with disabilities, one of whom died because of the fatal flaws in the law, and a second person with Down syndrome who almost died. Therefore, when we say the provisions in this bill detailing when a guardian has the power to end the life of a person with a disability are "fatally flawed," this is not spin, hyperbole or merely theoretical. The real-world cases we provide in this testimony, along with the other examples we provide, show that the language of the law is so fatally flawed that far too many Kansans with disabilities can have their lives ended in an incredibly inappropriate and unjust manner.

This issue was proactively considered by the House Judiciary Committee and other stakeholders when it received a hearing in bill form back in 2007. Both House members and many Senators were incredibly concerned about the problems we identified with end-of-life guardianship decisions in the law back then. These same problems are still contained in this bill today. We would also note that back in 2007, the leaders on the House Judiciary Committee assured all of us that the next time the guardianship law was updated, that our concerns would be fully addressed. We didn't think it would take 18 years for that rewrite to happen, but it did. All of the organizations proposing this amendment are just following through to fix these fatal flaws. Additionally, back in 2005, the Kansas House passed a provision by then-Representative Brunk on a strong bipartisan vote to address this significant problem.

One of the most fundamental duties of society is to ensure that the rights and lives of those who need the most protection (such as people with disabilities) are effectively protected. The most fundamental right of all is the right to live. If the state is going to have a process that allows guardians to make end-of-life

decisions that will lead to the death of people with disabilities, because someone must have a disability to be subject to a guardianship. Therefore, the state owes people with disabilities the fullest measure of due process, the best definitions and provisions in law that ensure the protection of life. The changes we will propose in our amendment accomplish those objectives.

Death is Different:
Quite simply, death is different. The state has a legitimate interest in preserving the health, safety, and life of its citizens, including people with disabilities, regardless of their disability and even if they happened to need "artificial means" to live. The changes we are proposing respect the right to refuse medical care while at the same time ensuring the fullest measure of due process before the state essentially sanctions the death of a person with a disability through the powers it grants guardians in end-of-life decisions. Let us be absolutely clear, with our amendment, if a Kansan with a disability has a durable power of attorney for health care decisions (DPOA), a living will or other written advance directives regarding end-of-life decisions, those directives take precedent. The bill and our amendment only apply to people with disabilities who have guardians and does not impact difficult end-of-life decisions that families have to make when there is no court-appointed guardian.

Why Our Amendment is Necessary – Death is Different; Kansas Law Must Err on the Side of Preserving Life:

- Our amendment will fix the significantly fatally flawed language regarding when a guardian can withhold or withdraw food/water or medical care, actions which ultimately result in the death of a Kansan with a disability. Though the due process additions in the bill are appreciated, adding due process to the fatally flawed language will simply require the court to go through the motions and ultimately approve the end-of-life decision. As written, HB 2359 and current law allows a guardian to make these end or life decisions if the person 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 adult other than by artificial means* (emphasis added), *nor would restore the adult to any significant degree of capabilities beyond those the adult currently possesses* (emphasis added)." This is very broad and dangerous language. It allows a guardian to end the life of the person with a disability even if the artificial means would prolong their life, and if that treatment would not "restore the ward to any significant degree of capabilities beyond those the adult currently possesses." The following are simply a few examples of the numerous people with disabilities who either were or would be killed by a guardian exercising their end-of-life powers under this bill. Remember, the full Judicial Council did not endorse this fatally flawed language, I am sure, due in part how problematic the language is, and they left this issue to the legislature to address. That is why the Revisor is drafting our amendment.

Four Examples Showing the Flaws in this Bill

The following four examples of Kansans with disabilities meet that fatally flawed language in the bill and they would die under the current provisions of the bill. Although the proposed bill would require due process, a judge would have no legitimate option but to approve the end-of-life request of the guardian because these Kansans would meet the provisions of the law:

- The first case is a real-life example of someone who died from this fatally flawed language. Our concerns are not theoretical. This person died. It happened shortly prior to the legislature previously debating this issue in 2007. A person with mental illness was living at Larned State Hospital because of a need for acute mental health treatment. He also required kidney dialysis. However, he was fully cognizant, had mobility, and actively participated in his treatment. He was placed under guardianship. His guardian had a petition drafted to allow the guardian to withhold medical care or treatment. The guardian had two doctors certify that the person with mental illness fit the fatally flawed language in the statute, as his treatment prolonged his life but it was through the use of "artificial means" (the kidney dialysis) and

that treatment would not "restore the ward to any significant degree of capabilities beyond those the ward currently possessed." The dialysis was medically necessary, it allowed him to live and ensured he did not get worse, but it would not restore his capabilities. The Court, in accordance to the law, approved the petition. As a result of the Court authorization of the petition, a standing Do Not Resuscitate Order (DNR) was issued. He improved and moved out of Larned into a nursing home. The standing DNR followed him there. He subsequently choked while eating, he was not resuscitated, and he died. This fatally flawed provision of the law was ultimately responsible for his death.

- That was a real example, this is a hypothetical example of the type of person who would have their lives ended due to this flawed language on guardian's end-of-life powers. Under this example, a police officer is shot several times in the line of duty, suffers a spinal cord injury and damage to his lungs and throat to where he eats with a feeding tube and breathes with a respirator (both are artificial means, under the law). The police officer is not on death's door. He is not terminally ill and will not die imminently. Because the things prolonging his life are artificial means, and the treatment simply keeps him alive and stable, and thus it would not "restore" the police officer "to any significant degree of capabilities beyond those he currently possesses," under the fatally flawed language of this bill, the guardian could end this heroic police officer's life. This police officer would die because of the fatally flawed language, and we believe the court would have to approve the end-of-life request, resulting in the officer's death.

- Another example is a K-12 school teacher who has advanced kidney disease, which requires intensive kidney dialysis (which is similar to our real-life first example, above, were the Kansan died). Due to other complications from a car accident, the teacher acquired a brain injury and also needs feeding tubes to eat and drink. The teacher is not terminally ill and will not imminently die. Because the things prolonging the teacher's life are artificial means, and the treatment in question keeps the teacher alive but would not restore the teacher to any significant degree of capabilities beyond those currently possessed, that means that the guardian could withhold or withdraw the medical care, which would result in her death.

- The final example is not hypothetical. This example happened around the time when the legislature last debated this issue. This real-life is a Kansan with Down syndrome who DRC attorneys believed would have died because he met the fatally flawed language of the law. The guardian told others that they wanted to withhold and withdraw medical care because the guardian was "just tired of dealing with him." "Him" being the person with Down syndrome. The only reason why this Kansan with Down syndrome did not die was his friends and advocates made clear to the guardian that DRC was prepared to take legal action to protect the person's life. However, even in this example, DRC attorneys believed that the guardian would ultimately prevail in the withhold/withdrawal case because of the fatally flawed language. Thankfully, the specter of potential litigation caused the guardian to do the right thing and preserve life, despite the guardian being "tired of dealing with" the person with a disability.

- As the fatally flawed language is currently written, the above Kansans, and numerous other examples, could be killed because of their disabilities, and in-fact, one was killed and another would have been killed if not for potential intervention.

How our Amendment Will Fix the Fatal Flaws (the amendment is being written by the Revisor):

- **Fixing the Fatal Flaws –** Our amendment will fix these fatal flaws in Kansas law by ensuring the proper provisions and protections are included in the law. As you can see from the above examples,

the language in the bill and current law is far too broad and allows guardians to inappropriately make end-of-life decisions.

The end-of-life guardianship powers in this bill arbitrarily would take life from people with disabilities who may be no closer to dying than any of us here in the room today. The law regarding end-of-life decisions must take into account where that individual is in the dying process, not whether they simply have a disability.

Our amendment will directly address these significant problems in the law.

- **Distinct Provisions for Withholding/Withdrawing Food and Water and Medical Care –** Our amendment is absolutely necessary to ensure that the proper framework exists for end-of-life decisions involving Kansans with disabilities who have a guardian. For example, our language (when it is completed by the Revisor and provided to this Committee) will take great pains to have distinct protections for the withholding or withdrawing of food/water versus medical care. Many people with disabilities get their food/water through artificial means such as a feeding tube, and the delicate differences between withholding food/water versus medical care necessitate specific public provisions for each. Death by withholding/withdrawing food or water is often a horrific, long and painful way to die. Both provisions in our amendment will offer sufficient protections for people with disabilities, while also recognizing the delicate nature of end-of-life decisions involving guardians.

- **Definitions -** Having clear definitions to accompany the right due process and procedures are also crucial to having an effective policy on end-of-life guardianship decisions. There must be no ambiguity regarding the public policy for end-of-life decisions and guardianship. The definitions we propose help ensure that.

DRC Strongly Supports Every Other Part of HB 2359 – The Following are some Examples of the Much Needed and Effective Policies Contained in HB 2359:

First, we would note that the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA) much more clearly written than the existing Kansas law. This change alone will greatly assist guardians, conservators and others better understand roles and responsibilities under the law. This improved clarity and organizational changes will also assist persons under guardianship or conservatorship and their agency/natural supports better understand their rights.

HB 2359 also contains some critically important aspects that will improve Kansas guardianship and conservatorship law.

1. Person-Centered Philosophy

HB 2359 requires an individualized plan for each person subject to guardianship or conservatorship. It also includes requirements that persons subject to guardianship or conservatorship be given meaningful notice of their rights and an opportunity to be involved in decision-making. The act uses person-centered terminology such as “individual subject to guardianship” rather than “ward” or “incapacitated person.” The act clarifies how appointees are to make decisions, including decisions about particularly fraught issues such as residential placement. These clarifications are consistent with the person-centered approach embraced by the act in that appointees are given specific guidance on involving the individual in decisions.

2. Standard of Decision Making

HB 2359 moves away from a best interest standard and toward a substituted decision-making standard, where a guardian or conservator must consider the preferences of the individual as expressed either in the past or the present. This is a very positive change, reinforcing the person-centered philosophy of the bill.

3. Alternatives to Guardianship and Conservatorship
This bill encourages the use of less restrictive alternatives such as limited guardianship and conservatorship, supported decision-making or single-issue court orders ("other protective arrangements") as an alternative to full guardianship or conservatorship. For example, this might mean authorizing a single transaction such as admission to a nursing home or sale of a house in situations where a full guardianship or conservatorship is not needed.

The bill also expands the procedural rights for respondents to ensure that respondents' rights are fully respected and that guardianships and conservatorships are only imposed when less restrictive alternatives are not feasible.

4. Resident Agent
Guardians or conservators that reside outside the state of Kansas shall appoint a resident agent, which is a positive change. The resident agent shall (1) maintain contact with the guardian or conservator, including current address and phone number; (2) accept service of process and other communication directed to the guardian or conservator; and (3) forward to the guardian or conservator documents sent by the court, the secretary of state or any other state agency.

There are times that persons under guardianship or conservatorship have no contact information for an out of state guardian or conservator. This will ensure that a person living in Kansas is responsible for making sure the guardian or conservatorship can be contacted and receive vital information from the person under guardianship or conservatorship, the court or other agencies.

5. Successor Guardian or Conservator.
HB 2359 also expands the circumstance that the court may appoint a successor guardian or successor conservator to serve immediately or when a designated event occurs, including the absence, impairment, resignation, or death of the guardian or conservator.

6. Notice of a petition for a guardian or conservator to resign must be given to the person subject to guardianship or conservatorship and any other person the court determines.

7. Guardian Ad Litem
Under the bill, the court at any time may appoint a guardian ad litem for an individual if the court determines the individual's interest otherwise would not be adequately represented. If no conflict of interest exists, a guardian ad litem may be appointed to represent multiple individuals or interests. This makes it clear that the guardian ad litem may not be the same individual as the attorney representing the respondent.

8. Service Providers
Rather than authorizing a guardian or conservator to delegate powers, it authorizes a guardian or conservator to retain a service provider. The section would require a guardian or conservator to exercise reasonable care, skill and caution in selecting such a service provider, establishing the scope and terms of work, and monitoring the service provider's performance.

9. Temporary Substitute Guardian or Conservator
There is a six month limit in this provision. If the person subject to guardianship or conservatorship is represented by an attorney, the court shall appoint an attorney.

10. Grievance Against Guardian or Conservator

An individual who is subject to guardianship or conservatorship, or person interested in the welfare of an individual subject to guardianship or conservatorship, that reasonably believes the guardian or conservator is breaching the guardian's or conservator's fiduciary duty or otherwise acting in a manner inconsistent with this act may file a grievance in a record with the court.

11. Right to attorney for a minor 12 years of age or older and the court has authority to appoint an attorney for parents of the minor.

12. Guardianship Plans

For minors, the court may require a guardianship plan. For adults, the court shall require a guardianship plan. The plan must be a person-centered plan, based on the adult's needs and best interests, as well as the adult's preferences, values, and prior directions, to the extent known to or reasonably ascertainable by the guardian. In crafting a plan, guardians should strive to produce a plan that is not only person- centered and reflects a robust understanding of the resources potentially available to the adult, but also one that is clear, organized, and detailed.

13. Petition for Guardianship for an Adult

This change emphasizes that guardianship is a last resort and that less restrictive alternatives are to be preferred. The petitioner is required to identify all less restrictive alternatives for meeting that respondent's alleged needs that have been considered or implemented, to justify any failure to pursue less restrictive alternatives, and to explain why less restrictive alternatives would not meet the respondent's alleged needs. These requirements serve to provide the court with important information relevant to whether guardianship is appropriate. These also prompt would-be petitioners to explore less restrictive alternatives.

This also encourages the petitioner to consider limited guardianship. The petition must state whether the petitioner seeks a limited or full guardianship, or a protective arrangement instead of guardianship. When requesting a full guardianship, the petition must state why a limited guardianship or protective arrangement instead of guardianship would not meet the respondent's needs.

A court order establishing a full guardianship for an adult must state the basis for granting a full guardianship and include specific findings that support the conclusion that a limited guardianship would not meet the functional needs of the adult subject to guardianship.

14. Appointment of an Advocate

The court may appoint an advocate when a petition for guardianship of an adult is filed. An advocate may include, among others, physicians, psychologists, social workers, nurses, etc.. Regardless of the visitor's profession, the visitor shall have training and experience in the type of abilities, limitations, and needs alleged in the petition.

The advocate is tasked with interviewing the respondent in person and explaining to the respondent the nature and potential consequences of the petition and the respondent's rights. The visitor must determine the respondent's views about the appointment or order sought. This includes the respondent's views about any proposed guardian.

15. Appointment of an Attorney for an Adult

The court shall appoint an attorney for the adult when a petition for guardianship of an adult is filed, or at other times when the adult requests the appointment of an attorney. The attorney must make reasonable efforts to ascertain what the respondent wishes and must advocate for those wishes. This has the effect of directing the attorney to maintain a normal attorney-client relationship with the respondent.

16. Attendance and Rights at Hearing

A petition for guardianship of an adult may generally not proceed unless the respondent attends the hearing. However, a hearing may proceed without the respondent if the court finds by clear and convincing evidence that the respondent is choosing not to attend or there is no practicable way for the respondent to attend and participate in the hearing even with appropriate supportive services and technological assistance.

This will ensure that the court makes a finding before a hearing without the respondent proceeds and not a cursory statement by an attorney or evaluator.

17. Powers of a Guardian for an Adult
This section sets out the powers a guardian for an adult and what the guardian must take into consideration. This is a more understandable and comprehensive list of powers and supports the importance of person-centered decisions and including of the adult into those decisions.

18. Limitations on guardian's powers are listed specifically in anew section, and it is more person-centered. As noted in this testimony, DRC Kansas, Kansans for Life, the Kansas Catholic Conference, Kansas Council on Developmental Disabilities and the Big Tent Coalition of Kansas are proposing an amendment to the end-of-life powers of guardians.

19. Termination of Guardianship
The burden for terminating a guardianship ensures that it never shifts to the adult subject to guardianship to prove that a guardianship is no longer necessary.

20. Alternative to Guardianship – other protective arrangements
HB 2359 creates an alternative to guardianship and conservatorship for individuals whose needs can be met without the imposition of such a restrictive arrangement. Specifically, these sections allow the court to enter an order that is precisely tailored to the individual's circumstances and needs, and that is limited in scope and, potentially, duration.

Thank you for the opportunity to explain the need for one important amendment to fix the fatally flawed language regarding guardian's end-of-life powers as well as sharing some of the incredibly positive changes proposed in the bill. Again, while we are an opponent for one very significant reason, we would very much become a strong supporter of the bill if the proposed amendment is adopted.

I would be happy to answer questions at the appropriate time.