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March 11, 2025
Senate Committee on Judiciary
Testimony in Support of HB2359 (because it includes the House Judiciary Committee Amendment)

Chair Warren and members of the committee:

My name is Rocky Nichols, Executive Director at the Disability Rights Center of Kansas (DRC). I will significantly summarize my written testimony. DRC is part of a national network of federally mandated organizations empowered by federal law to advocate for Kansans with disabilities. DRC is designated by the State of Kansas as the official protection and advocacy system for Kansas. DRC is a private, 501(c)(3) nonprofit corporation, organizationally independent of state government.

DRC strongly supports this bill because of a lifesaving, pro-disability amendment adopted by the House Judiciary Committee. This amendment was jointly proposed and supported by DRC, Kansans for Life, the Kansas Catholic Conference, the Kansas Council on Developmental Disabilities and the Big Tent Coalition of Kansas. It fixed the fatal flaws in the bill regarding end-of-life powers of Kansas guardians.

DRC Kansas strongly supports the bill with the House amendment. Before this amendment was added, we and the other partners opposed the bill. Updating Kansas law to be more in line with the Uniform Codes on guardianship/conservatorship in a manner that works for Kansas is much needed. The last time this law was updated in Kansas was nearly 23 years ago, way back in 2002. The Judicial Council and its Advisory Committee did an outstanding job of developing effective public policy tailored to the needs of Kansans for every non-end-of-life policy issue contained in this bill.

DRC Kansas and the partners (Kansans for Life, Kansas Catholic Charities, Kansas DD Council and the Big Tent Coalition of Kansas) obtained a copy of the Judicial Council's proposed bill in late August of 2024, around the time it was made available to the public. DRC held multiple meetings with stakeholders to analyze the proposed language and gather feedback. After that thorough review, DRC and the partners sent a memo to the Kansas Judicial Council on September 24, 2025, detailing the fatal flaws in the bill regarding end-of-life powers of guardians. In that memo the partners proposed specific amendment language to fix the fatal flaws. The full Judicial Council listened closely to our concerns. The full Judicial Council must have had some reservations about the end-of-life provisions contained in the bill, because at its December 6, 2025, meeting they specifically withheld any recommendation regarding guardianship end-of-life decision-making in the bill. I am sure they did that in part because they understood the significance of this problem. They referred the end-of-life issue to the Kansas Legislature to resolve. The Chair of the Judicial Council (Judge Eric Rosen) stated during the meeting that the concerns regarding end-of-life provisions were important, and they should be decided by the Kansas Legislature, not at the Judicial Council at its December meeting. You see, time constraints were also an issue. The Judicial Council met in December, and with the Kansas Legislature starting the very next month, the Council specifically left this issue to the legislature to address. The House Judiciary Committee responded by adopting the amendment proposed by our organizations (DRC, Kansans for Life, Kansas Catholic Charities, DD Council & the Big Tent Coalition of Kansas). Given the time constraints and the complex nature of the issue, having the full Judicial Council make changes on the fly during its December meeting was probably not advisable. 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.

Organizational Supporters of this Amendment Come from Vastly Different Backgrounds –
It is significant to note that the various organizations that proposed the amendment adopted by the House 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.

Legislative 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 were also incredibly concerned that prior to the amendment that this bill did 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 describe the "fatal flaws" that the House adopted amendment fixed, the term "fatal flaw" is not spin, hyperbole or merely theoretical. The real-world cases we provide in this testimony prove that.

This issue and the specific end-of-life language contained in this bill (which was approved last month by the House committee) was first proactively considered by the House Judiciary Committee (lead by former Chair Rep. Lance Kinzer) when this language in bill form received a hearing back in 2007. Several House members and Senators were incredibly concerned about the problems we identified with end-of-life guardianship decisions in the law back then. We would also note that back in 2007, the leaders on the House Judiciary Committee assured all of our organizations that the next time the guardianship law was re-written, that our concerns would be fully addressed. We frankly didn't think it would take 18 years for that rewrite to happen, but it did. It was clear that these end-of-life issues would be resolved during the next re-write of the law, so we are all just following through to fix the fatal flaws. Additionally, back in 2005, the Kansas House passed an amendment by then-Representative Steve Brunk on a strong bipartisan vote to address this significant problem of end-of-life guardianship powers.

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, 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 amendment adopted by the House Judiciary Committee accomplished 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 amendment adopted by the House 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 the amendment adopted by the House, 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 and control what happens. The bill as amended by the House only applies to people with disabilities who have guardians and does not impact on the difficult end-of-life decisions that families must make for their loved ones when there is no court-appointed guardian.

Why the House Adopted Amendment is Necessary – Err on the Side of Preserving Life:

- The House Judiciary Committee amendment fixed the problematic language regarding when a guardian can make end-of-life decisions. To understand the House amendment, you have to understand how the prior language in the bill endangered the lives of Kansans with disabilities. As written prior to the House amendment, the bill would have allowed a guardian to make these end-of-life decisions if the person was simply "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 bill prior to the House amendment contained very broad and dangerous language. The version before the House amendment would have allowed a guardian to end the life of a person with a disability if they use artificial means (such as kidney dialysis or using a feeding tube), if the treatment would not restore the adult's capabilities beyond what they currently possess. Under that problematic language, even people who could continue to live for many more years could be put to death. Remember, the full Judicial Council did not endorse the flawed language in the underlying bill concerning end-of-life powers of guardians, I am sure due in part to how problematic the language is, and they left this issue to the legislature to address – which the House acted and adopt the amendment.

Four Examples Showing the Fatal Flaws in this Bill Prior to the House Amendment:
The following are simply a few examples of Kansans with disabilities who would die if the House amendment regarding end-of-life guardianship powers is removed:

- The first case is a real-life example of someone who died from this fatally flawed language. Again, 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 dialysis treatment would not "restore the ward to any significant degree of capabilities beyond those the ward currently possessed." The dialysis allowed him to live and ensured he did not get worse, but it would not restore his capabilities. The Court, in accordance with 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 provision of the law was ultimately responsible for his death. Thankfully, that fatal flaw was fixed by the House.

- That first one was a real example. This next one 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 was 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 flawed language of the bill prior to the House amendment, the guardian could end this heroic police officer's life. This police officer would die because of the 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 schoolteacher 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 example 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 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 the House Judiciary Committee Amendment Contained in this Bill Fixed the Fatal Flaws:

- **Without the House Amendment, Guardians Can Inappropriately Take the Life of a Kansan with a Disability –** Prior to the adoption of the House amendment, the end-of-life guardianship powers would take life from people with disabilities who are 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 the person with a disability is in the dying process, not whether they simply have a disability, use "artificial means," or the treatment will not "restore" them to "any significant degree of capabilities beyond those the ward currently possesses." . Someone who requires kidney dialysis or who uses a feeding tube often live long, happy lives for many years. Under the original language a doctor is certifying they meet the definitions, not that they are imminently dying. The House amendment fixed this.

- **Distinct Provision for Withholding/Withdrawing Food and Water –** The House amendment was absolutely necessary to ensure that the proper framework exists for end-of-life decisions involving Kansans with disabilities who have a guardian. For example, as amended, the language now takes pains to have distinct provisions for the withholding or withdrawing of food/water. Many people with disabilities get their food/water through artificial means such as a feeding tube (like the example of the heroic police officer). Death by withholding/withdrawing food or water is often a horrific, long and painful way to die. The House amendment provided sufficient protections for people with disabilities, while also recognizing the delicate nature of end-of-life decisions involving guardians. Thanks to the House amendment, the language makes clear that regarding withholding/withdrawing food and water: 1) if the person with a disability had a written directive, then that directive controls what happens, and 2) allows a guardian to withhold/withdraw food and water if providing it would hasten the person's death or the adult is incapable of digesting or absorbing the food or water, thus the food/water does not contribute to sustaining the person's life.

- **Withhold / Withdraw of Medical Treatment –** The House Judiciary Committee amendment inserted effective language regarding withhold/withdraw of medical treatment. Before the amendment, a guardian had broad powers to end the life of people who are no closer to dying than any of us in this room. The prior language allowed guardians to end the lives of people with disabilities if they were "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)." The prior examples I gave prove how deadly that language was to people with disabilities. Now, thanks to the amendment passed in by the House Judiciary Committee, the language makes clear that regarding withholding or withdrawing of medical care/treatment: 1) if the person with a disability had a written directive, then

that directive controls what happens, and 2) these end-of-life decisions are limited to when "the adult is suffering from a severe illness and that life sustaining medical care is objectively futile and would only prolong the dying process."

- **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.

- **Injunctive Relief –** Having the option for certain categories of people to obtain injunctive relief in these cases is crucial. Again, death is different. If Kansas policy is to err, it must err on the side of preserving life for Kansans with disabilities. Kansas law must allow for this injunctive relief to ensure the decision to terminate a life is correct, appropriate, and based on all of the appropriate facts. Having parties be able to obtain injunctive relief can ensure all the facts are presented, which better enables the court to make the right decision with all the evidence, which again, is a decision of life and death.

DRC Strongly Supports the Pro-Disability and Person-Centered Aspects 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) are written more clearly than the existing Kansas law. This improved clarity and organizational changes will also assist persons under guardianship or conservatorship and their agency/natural supports better understand their rights.

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 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 it 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 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 full guardianship for an adult must state the basis for granting 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 of 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 share our strong support for this bill and to explain the amendment the House adopted, which as you can see was much needed.

I will answer questions at the appropriate time.