

To: Kansas House Judiciary Committee

From: National Council on Severe Autism Affiliate Representative

Re: HB2359 - Position: Neutral

Date: February 12, 2025

Madam Chair and members of the committee,

Thank you for the opportunity to provide testimony today on behalf of our most fragile citizens. My husband and I are co-guardians, with 30 years of firsthand experience in assuring that the 24-7 intensive care supports necessary for Aidan, our 34-year-old severely disabled grandson, are in place.

The National Council on Severe Autism is one of several national organizations representing profoundly affected individuals. I also serve as president of Kansas Neurological Institute (KNI) Parent Guardian Group. We applaud changes to guardianship law that will benefit higher functioning individuals living with cognitive and other developmental disabilities (I/DD). We appreciate the extensive work of the Kansas Judicial Council and the diligence of this esteemed Committee.

We respectfully request however, careful scrutiny by the committee to identify and close any loophole interpretation in proposed changes to present guardianship law that would undermine the role of legal representatives of persons adjudicated incompetent. We request that the panel ensure the appropriate assistance for each person is based on individual need and medical reality.

RATIONALE - Ideological assaults against a subset within the I/DD population, who are affected with extreme, complex conditions.



- The American Bar Association (ABA) portrays guardianship only in the pejorative sense of “removing rights” from affected individuals like our grandson Aidan. It gives no credit to the vast majority of guardians who are parents, close family members or friends who voluntarily and lovingly take on the responsibilities of guardianship to assure that their loved one’s rights are protected.
- Our appeals to the Uniform Law Commission and to the American Bar Association (ABA) over the course of several years, requesting a seat at the table, have been ignored. The commission’s silence leaves us uncertain as to whether it understands the diverse population which may come under guardianship. Both ABA and the commission’s silence compels us to ask you to please view the six minute video link showing the realities our families face.
- Throughout our loved ones’ lifespans, guardians typically engage with a network of informed interdisciplinary team members to assist in making health care and placement decisions for family members living with life-long disabilities. “Presumed Capacity” and “Least Restrictive Environment” have become well-funded catchwords to weaken guardianship and are terms which ignore cognitive deficits amongst our most vulnerable.
- Supported Decision Making (SDM) is an unproven method of providing support. It remains untested across the spectrum of DD individuals with severe, lifelong impairments. Since SDM promotes assistance without the protection of the court, we submit the following amendments for consideration:
 - **Proposed amendment (1)**
New Section 68 APPOINTMENT AND ROLE OF ATTORNEY FOR ADULT. CONFLICT OF INTEREST: The court shall refrain from appointing for the respondent, any attorney who is poised to receive, or whose overarching entity currently receives grants from federal and/or other granting organizations that promote the unproven method across the I/DD spectrum of Supported Decision Making. Goals under such grants may place into harm’s way respondents whose diminished condition is severe or profound, and which may induce attorney conflict of interest in order to comply with “Least Restrictive” grant requirements, promoted under the current definition of Supported Decision Making.
- Provided further, the court shall continue to honor decision making precedence set forth in Federal law, specifically, within the Developmental Disabilities Assistance and Bill of Rights Act of 2000, which recognizes those with intimate knowledge of the respondent:
 PLAW 106-402, Section 101 (c) (3) Policy- *“individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including*

regarding choosing where the individuals live from available options, and play decision-making roles in policies and programs that affect the lives of such individuals and their families....”

- **Proposed amendment (2)**

New Section 82. TERMINATION OR MODIFICATION OF GUARDIANSHIP FOR ADULT - FINDINGS REQUIRED. Before ordering termination of a guardianship of the person, the court must find clear and convincing evidence that:

- (1) that capacity has been restored; or
- (2) the individual remains partially or completely incapacitated.
 - A. Individuals incapacitated by significant neurological or developmental disabilities from birth through life, and whose lack of capacity has remained static or regressive in nature, shall be presumed to remain incapacitated.
 - B. The presumption shall remain dispositive unless and until it is overcome by clear and convincing evidence to the contrary.

REQUEST: We respectfully request the Judiciary Committee address the diverse population which Guardianship serves and insert protective language in support of legal representatives who provide oversight and assistance in the lifelong care for individuals with the most significant cognitive deficits.

Thank you for your consideration of our request and proposed amendments.

Additional documentation is available on request.

Respectfully,

Joan Kelley, Grandmother and Co-Guardian of Aidan, age 34, who functions cognitively as a 3year old

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