

To: Kansas Committee on the Judiciary - Senator Kellie Warren, Chair
Re; HB2359 Position: Opposed as currently written
Date: March 11, 2025

Good morning Madam Chair & members of the committee,

Thank you for the opportunity to provide testimony on behalf of those unable to protect or care for themselves. As co-guardians of a precious, extremely challenging young man affected with profound autism, my husband and I have been advocating for the best interests and civil rights of our grandson, Aidan, now age 34, since he was diagnosed at two years of age.

The National Council on Severe Autism is one of several national organizations advocating for profoundly affected individuals. Although physically adults, our grandson and others like him on the the severe/profound end of the autism spectrum typically function cognitively at the infant/toddler or preschool level. This brief video submitted to the committee is worth a thousand words; it clearly reveals common behaviors that are complex and dangerous amongst our family



members, and the best way to share the realities we face.

We appreciate the hard work of the Kansas Judicial Council drafting HB2359. Their work however, relied heavily upon the Uniform Law Commission, whose professional perspective lacks balance and is void of input from guardians with life-long, personal experience in the care for profoundly affected individuals.

For more than 15 years, the American Bar Association (ABA) and the Uniform Law Commission have ignored various organizations' appeals for a seat at the table. While the ABA showcases a few cases of guardianship abuse, their longstanding pattern of ignoring our requests as well as our realities on the ground, should give everyone pause. Because powerful entities continue to

exclude the actual stakeholders who make life-long sacrificial investments in the care of those most in need of protection, I am compelled to testify today.

The broad effect of this misleading ideology - to discredit and disparage guardianship as a “violation of individual civil rights” creates discrimination against the weakest members of society. We would respectfully ask the Committee-

- Would it be wise to presume capacity of individuals in the 6 minute video?
- Does our society rely on cognition of a three year old child to make decisions affecting their safety and care?
- If not, why would we pretend capacity of adults with the functional cognitive capacity of a 3-5 year old?

The House Judiciary Committee recently stated that there is not enough time to read all bills, and therefore rely on “experts” to draft bills such as HB2359. We have a moral and ethical responsibility to protect our most vulnerable through common sense, integrity and medical reality. HB2359 - if enacted as written, will leave loopholes of ideological interpretation, create undue burden on our families, and further risk our loved ones’ safety in the hands of people with little or no personal experience in providing 24-7 care for profoundly affected persons.

REQUEST: We respectfully request the committee amend the bill and insert protective language (**in bold below**) to support legal representatives who provide oversight and assistance in the lifelong care for individuals with the most significant cognitive deficits:

LANGUAGE: New Sec. 64 - add

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."

Thank you for your consideration of our respectful request and proposed amendment. Additional documentation available upon committee request.

In deep appreciation,

Joan Kelley

Grandmother and Co-Guardian of Aidan, age 34, who functions cognitively as a 3year old
Affiliate Representative, National Council on Severe Autism www.ncsautism.org
President, Kansas Neurological Institute Parent Guardian Group