TO: State of Kansas Senate Judiciary Committee FROM: Joan Kelley, Concerned Family Alliance RE: HB 2034 - Supported Decision-making DATE: March 12, 2019

Chairman Wilborn and Members of the Committee,

On behalf of families charged with the care and protection of the highest risk individuals, thank you for the opportunity to provide testimony today. Families representing a broad spectrum of disabilities have serious concerns relating to HB2034 regarding capacity, guardianship and supported decision-making. Our families were not notified in a timely or adequate manner to express opposition of this bill. As a result, we were unable to provide testimony prior to vote and passage of this bill in the House.

As an advocate working with families in crisis, I can tell you first hand that individuals on the severe/profound end of the spectrum are also also the most under-represented, marginalized individuals in current ideological policy-making, including but not limited to Supported Decision making initiatives. This bill unnecessarily and dangerously encroaches upon long-standing, judicially designated responsibilities of the guardian established in Kansas Guardianship Laws.

- Our families were not notified in a timely or adequate manner to express opposition to HB2034 before the hearing and subsequent passage in the House.
- HB2034 Lacks sufficient oversight mechanisms that would protect vulnerable individuals across the broad I/DD spectrum of disability.
- HB2034 erodes and encroaches upon the protections established in Kansas guardianship laws through the use of highly subjective language.

Background

Supported Decision-Making (SDM) is a movement based on an ideology that promotes the idea that all people with I/DD have capacity to make their own decisions with support from an informal network of "supporters". Supporters are not court-appointed, nor do they bear any accountability for ensuring successful outcomes. Proponents of SDM view the "right to fail" as an important freedom regardless of the individual's ability, vulnerability, or how dangerous the failure.

Arbitrary interpretation of highly subjective language

1. An individual ruled incompetent by a probate court has a guardian appointed to assume decision-making responsibilities. The Revisor of Statutes states that an individual (known as the principal) who may or may not be under guardianship can enter into a Supported Decision Making agreement. We are also told that SDM does not encroach upon guardianship, yet under the agreement, the principal can make legally binding decisions without assistance. What could be a larger encroachment than to allow a ward to make a legally binding decision without the assistance or knowledge of the guardian?

2. Further, Bill language: "An adult shall not enter into a supported decision-making agreement if the agreement encroaches on the authority of a guardian..... unless the guardian or conservator approves in writing the adult entering into the supported decision-making agreement." Therefore, guardianship approval in writing to the establishment of an SDM agreement can be interpreted as relinquishing the guardian's responsibilities, which are firmly established in Kansas Law. How can a guardian relinquish his responsibilities without the involvement or knowledge

of the probate court?

3. HB 2034 gives legal guardians no authority to terminate or monitor ongoing decisions made under an agreement, and clarifies that the "principal" alone can terminate an agreement. How can a principal who is also under guardianship (therefore determined to be incompetent by a probate court) understand when a SDM agreement should be terminated?

4. While the Revisor of Statute states that a supporter cannot encroach on the authority of the guardian, HB 2034 allows a supporter to assist an individual in understanding and communicating any decisions including health care, living and financial arrangements, etc - all which are direct responsibilities of the legal guardian.

What part of this bill does not encroach upon guardianship and ultimately the Kansas probate courts since guardians serve as agents of the probate court?

For the families here today that are proponents of this bill, I ask you, is it appropriate for your loved one in all cases to make legally binding decisions without assistance, because this bill will allow just that.

I respectfully ask this committee to obtain answers from proponents as to why there is no oversight mechanism to monitor the SDM arrangement, to ensure adherence to Kansas statutes stated in HB 2034 regarding mistreatment of a "dependent adult.". What

safeguards in HB2034 ensure the statutes/requirements of this bill are followed? I ask because in reading this bill I was unable to find any oversight mechanisms.

How does "presumed capacity" for principals to make decisions in HB2034 align with Kansas statutes and their definition of a "dependent adult"?

Recognizing Scope and Depth of the Disability spectrum

Fully grown I/DD individuals functioning cognitively at the infant/toddler level, including those with severe behavior problems, who often pose public safety risks, or those with complex medical conditions are all a part of the DD population who require the highest levels of care. Time prevents discussion of the distinct individual, medical, and cognitive complexity of I/DD individuals. I know personally that when it comes to profound autism, the challenges are mightier than most people can imagine.

Alternatives to guardianship already exist

Long-established means, including but not limited to Durable Power of Attorney, conservators, trustees, social workers, autism/ behavioral specialists, etc. and natural supports such as family members already provide alternatives to guardianship. These means do not encroach upon the authority of the guardian, nor do they broad-brush capacity of individuals.

Our love for our family members is what motivates our decision-making.

They depend on our compassion and insights to make sound decisions in their best interests. Presumptions that people can make decisions when there is clear evidence that they cannot exposes them to unacceptable risks.

I challenge the members of this committee to tell me how undue influence, coercion and duress by supporters will be defined and monitored in the thousands of individual supported decision making arrangements that will take place throughout Kansas? Everyone is this room knows that it would be impossible to do so.

Regardless of what committee members have been told by bill proponents, there is no tangible oversight of SDM supporters, who in essence are held harmless under highly subjective terms within HB 2034.

Conclusion

There are good intentions on both sides of this issue. What we all need to do, however, is not let the good intentions lead to unintended consequences. We need to ensure this bill does not override guardianship and that proper protections are put into place for those

who wish to be served by Supported Decision Making. I do not believe proper scrutiny has taken place to guarantee both of these objectives.

I ask each of you to read the bill and ask yourself what court or body or other mechanism is in place to ensure the Statue requirements established for supporters are followed. Under the HB2034, the Kansas Judicial Council is assigned with developing the SDM Agreement Form. There are (at least) two members who serve on the Judicial Council's Guardianship Advisory Committee who have a history of undermining guardianship rights. Could this represent a possible conflict of interest?

In closing, let us ask ourselves: Does HB2034 reflect sound policy?

I would be happy to honor Committee members requests to offer suggested language changes to this bill, but it will take significant time to do so responsibly, and would go beyond the current timeframes allotted.

I urge this committee to postpone passage of this bill until adequate changes are made to ensure the protection of the vulnerable people who will be directly impacted by HB 2034.

Respectfully,

Joan Kelley, Legal Guardian for Aidan Kelley Affiliate Representative, National Council on Severe Autism <u>www.ncsautism.org</u> Kansas State Coordinator, VOR <u>www.vor.net</u> Gardner, Kansas 66030 E-mail: concernedfamilyalliance@gmail.com