

Testimony in Support of HB 2345
House Judiciary Committee
January 17, 2024

Testimony in support of HB 2345: Supported Decision-making Agreements Act

Chairperson Humphries and Committee Members:

Thank you for the opportunity to tell you our supported decision-making story.

My daughter Rachel is 24 years old. She testified in support of the **Kansas ABE Act in 2015**, and in 2017 she was the **first Kansan to open a Kansas ABE Savings Account**. She advocated for the passage of the federal bill for eight years. She also gave powerful testimony for the **Kansas Legislative IDD HCBS Waiver Modernization workgroup** outlining the ways the current BASIS assessment system disrespects her. She also mentioned her need for transportation, currently not provided by the IDD Waiver. Rachel graduated from Olathe South High School in 2018. All four years at Olathe South she was the volleyball manager and on STUCO. Additionally, she was a Thespian, National Honor Society member, and on the Principal's Honor Roll. She has been in 27 plays, served on the board of Inclusion Connections and as an ABE National Resource Center Advisor, and is involved at our church, Blue Valley Baptist. Rachel has voted in local, state, and national elections. She attended the Missouri State University Bear POWER Program for students with intellectual disabilities for three semesters before COVID concerns moved her home.

She works 24 hours a week in patient transport at the University of Kansas Hospital. She dreams of getting married and living in a pink house. Rachel also has Down syndrome and needs supports to be included in classes, to have integrated competitive employment, and to manage many of her decisions. Rachel is quite capable of making most of her own decisions. She also understands the areas where she needs help and seeks help. Faced with important decisions, most of us look to the support and wise counsel of family, friends, ministers, doctors, prayer groups, and others.

As Rachel grew up, we knew that while we had worked tirelessly for her to be included in school, church, and community, we knew that when she turned 18, we would most likely have to get guardianship for her. When she was about 14 years old, the school system and many other agencies began telling us how we would need to pursue this guardianship option. No other options were explained. It seemed to be a given that all individuals with Down syndrome must have guardianship.

It was at about this time I started hearing about "supported decision-making." I went to conferences, started researching, and we decided we wanted to pursue this avenue for Rachel. While Rachel is more vulnerable than many people and needs help with some of her decisions, she is certainly not incapacitated. Both my husband and I were distressed and disgusted at the idea of obtaining guardianship and declaring her "incapacitated." We want to protect Rachel, but we want to treat her with respect so supported decision-making sounded like a perfect option. There was something wrong with this idea that we had told everyone she was capable for 18 years and now we would plead the case that she was not capable?

As Rachel approached 18, I began to inquire about supported decision-making as an option. No one in our school or the many agencies we deal with had ever heard of it. In fact, they all seemed quite baffled and eager to remind me that I would be unable to know about anything to do with Rachel's education, state benefits, or healthcare if we did not have guardianship. I was told all the worst-case scenarios about medical emergencies,

kidnapping, and beyond. However, this information is not accurate. There are some simple forms that can be signed by Rachel allowing us to help her with almost anything.

We found a respected, well-known, and knowledgeable attorney. While he did not know about supported decision-making, and we didn't get a supported decision-making agreement, worked with Rachel and us to develop what was needed. He directed questions to Rachel and then worked with all of us to develop the legal documents necessary that would allow us to assist Rachel. It was and is very important to us that Rachel oversee her own life.

Even with this, the public school system instructed us that we had to have special language in the documents for them to continue to work with us until she graduated in May. This was not true of students without disabilities, however. The default for most agencies seems to be the assumption that all individuals with intellectual disabilities will have a guardian. I will be direct in stating that this is archaic thinking. I assure you that our pursuit of an avenue besides guardianship was not easy. Choosing guardianship would have been much easier. However, we have never looked for the easy path for Rachel. We have looked for the path that allowed her to live the life she wants to live.

Supported Decision-Making Laws have been passed in many states and provide individuals with disabilities and their families with another option. While I know a supported decision-making law cannot address all these issues, it is a necessary step toward truly treating individuals with disabilities as capable individuals. We know that all individuals, including those with disabilities and the elderly, function more effectively when they are allowed to be in control of their lives and choose the individuals who they need to support them. ***This law is needed to provide a framework for empowering individuals with disabilities to live the lives they want to live, with the supports they choose, and to allow them to live with dignity.*** I am asking you to support House Bill 2345 and take this necessary step for all Kansans.

Respectfully submitted,

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