

Testimony in Support of HB 2122
House Committee on Federal and State Affairs
March 8, 2021

Chairman Patton and Committee Members:

Today, I am testifying in support of **House Bill 2122 – Enacting the supported decision-making agreements act to provide a statutory framework for adults who want decision-making assistance.**

My daughter Rachel is 21 years old. She testified in support of the **Kansas ABL Act in 2015**, and in 2017, she was the **first Kansan to open a Kansas ABL Savings Account**. She advocated for the passage of the federal bill for six -years. 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 23 plays, served on the board of Inclusion Connections and as an ABL National Resource Center Advisor, and is involved at our church, Blue Valley Baptist. Rachel has voted in in local, state, and national election. She attended the Missouri State University Bear POWER Program for students with intellectual disabilities for three semesters before COVID concerns moved her home. In addition to working part-time as a hostess at the Olive Garden, she is participating in an internship-based job program called Project SEARCH. She dreams of a full-time fulfilling job, 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.

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 15 or 16 years old, the school system and many other agencies began telling us how we would need to pursue this 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 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 option. No one in our school or these many agencies 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 or state benefits (Medicaid Waiver, etc.) if we did not have guardianship. I was told all the worst-case scenarios about medical emergencies, kidnapping, and beyond.

I called several attorneys to speak about this and none had heard of it. I wanted to know if they could assist in drafting power of attorney documents that might assist Rachel with her decision-making as needed. Rachel is fiercely independent and wants to be treated like her friends. Still, she will readily tell you she needs and wants help specifically when it comes to money management. My inquiry baffled the law offices. One office even told me they didn’t think they would consider doing a “power of attorney for a person with Down syndrome,” and

another told me they believed all individuals with Down syndrome had to have a guardian. I spent hours over the course of several months trying to figure out a path.

Finally, I found an attorney who seemed knowledgeable and willing to consider our wishes. The appointment was scheduled shortly after Rachel's 18th birthday though. Therefore, I used some examples from the internet to draft power of attorney agreements for Rachel and hoped that nothing happened before we could get something official and that they would hold up in a court of law.

The attorney was extremely helpful. While he did not know about supported decision-making, and we didn't get a supported decision-making agreement, he agreed that Rachel did not need guardianship. He directed questions to her and then worked with all of us to develop the legal documents necessary that would allow us to assist Rachel. It was 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 Social Security Administration was totally baffled. Their default, as well as most agencies, is the assumption that all individuals with intellectual disabilities will have a guardian. I assure you that our pursuit of an avenue or avenues 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.

While I know a supported decision-making law cannot address all these bureaucratic issues, it is a necessary first 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 2122 and take this necessary step for all Kansans.

Respectfully submitted,

Jawanda Barnett Mast
Parent and Disability Rights Advocate
1389 E. 154th Terrace
Olathe, KS 66062
913.940.4199 (cell)
jmast3@earthlink.net
Founder #321Advocate



Rachel on her 21st Birthday