January 24, 2019 Re: Support of HB 2034 Kansas House Federal and State Affairs Committee

Chairman Barker and members of the Committee:

My name is Nikki Heiman, and I am a mother of three children. I am providing testimony in favor of the supported decision making bill HB 2034. My oldest child is 15 and he has Down Syndrome. He participates with his peers in most of his classes. He gets extra help and receives some modifications so that he can be successful. Sometimes the extra help comes from his regular education teacher, and sometimes it comes from the special education teacher, paraprofessional, or a peer. He plays basketball with his peers, manages the football team, and competes in 4H showmanship activities of his choice.

When he was born, it was our goal as parents to give him the best life we possibly could give him. We feel that a good life involves meaningful friendships, employment that brings you professional happiness and a supportive family. All of those things revolve around the ability and freedom for him to make choices, express his wants and needs and be heard as an individual.

In the school system, various people help him make decisions, not just the specialists. The specialists are available, but they are not usually the first people he goes to. He asks friends for help when he needs it, and he asks us for help when he needs it or wants it. Like a typical teenager, his parents are usually the last ones he asks! Most of the things that he does are just like other teenagers and that shouldn't change when he exits the school system. We didn't support him all through school and teach him about how to have a voice and advocate for himself for him to lose that freedom as an adult.

Supported decision making is an alternative to guardianship that will allow my son and others with similar needs to continue to learn to advocate for themselves as adults. It empowers him to continue to be at the center of his plan for a good life. In school right now, he is a natural part of the school community, receiving help when he needs it and he is allowed to be as independent as often as possible. When he graduates, we plan for him to continue to choose people he trusts to ask for help, just like he does in school. When faced with important decisions, all people consult with other people, whether it's a second professional opinion, a friend or a family member. Supported decision making is a very natural way for people with disabilities to live full, happy lives surrounded and supported by people they love and trust.

Thank you for your support of HB 2034, Kent, Nikki, Trenton, Madelynn and Kaydence Heiman

