SB 35 Proponent Testimony
Joy Shusner
Ohio Senate Judiciary Committee
Chair Nathan Manning
March 5, 2025

Chairman Manning, Vice Chair Reynolds, Ranking Member Hicks-Hudson, and members of the Senate Judiciary Committee, my name is Joy Shusner. I practiced as a family law attorney in Cincinnati for twenty years. In the twenty years since I left the practice of law, I have served as a mediator and advocate for Ohioans living with intellectual and developmental disabilities and their families. More importantly, I was deeply honored to be the mother of a wonderful young woman, Rosie Lawrence-Slater. I am here today submitting this testimony as a proponent of SB 35.

Rosie was born with Kabuki Syndrome and lived with multiple serious health conditions and a mild intellectual disability. Rosie would have been so excited to be here today to tell you her story and to persuade you to join her in the growing movement to bring supported decision-making to Ohio. Unfortunately, we lost her three months ago to the rare lung disease that she lived with her whole life. She was 35; we buried her on the Monday before Thanksgiving.

Supported decision-making is not a new idea. Few of us cut our own hair, change our own oil or write our own prescriptions. If we're lucky, we all have people in our lives know more about various life domains than we do. We consult those people for advice and support in making our own decisions.

For those living with intellectual and developmental disabilities, there is both solid evidence-based scholarship and ample anecdotal experience that show that using supported decision-making as opposed to legal guardianship, leads those with IDD to healthier, wealthier, safer and more self-directed lives in their chosen communities. I encourage you to go to the National Resource Center for Supported Decision-Making, which is part of the Administration for Community Living at the federal Department of Health and Human Services to read more about why supported decision-making is better. https://supporteddecisionmaking.org/

In closing, I want to tell you a little more about Rosie. Just after her 18th birthday, Rosie's dad and I were going through a divorce. Through a combination of circumstances, she was put under legal guardianship by a non-family guardian. She had almost no say over her own life. She was forced to live in a series of group homes and apartments with roommates that she didn't know and with whom she had nothing in common. She worked as a bagger at Kroger; her guardian would not allow her to take the training needed to work in the Kroger bakery where she desperately wanted to work. Her guardian decided when she could see her family and what medical care she would receive. Rosie quickly became compliant and "institutionalized". She wanted whatever her guardian and staff said she wanted. She gave up her own wishes and dreams because she knew that her life was completely controlled by others.

Six years ago this past September, after eleven years under guardianship and a tremendous amount of her own hard work demonstrating her ability to manage her own life, Rosie was set free by the Hamilton County Probate Court. It was like watching a bird who had lived her whole life in a cage, be set free. She started expressing her opinions and preferences, often very strongly. She met new people and made many friends. She got promoted to the Kroger bakery. She also became a paid self-

determination trainer through Project S.T.I.R. and she worked as a paid grant consultant for the Nisonger Center at Ohio State University. She mentored others helping several of her friends to end their own guardianships. She traveled and attended conferences and met important people. She had a boyfriend and she lived in her own apartment in a neighborhood that she chose with her service dog, Moose. And she signed the lease on that apartment. She even wrote and won a $5000 grant to help pay for Moose's training.

As her mom, I had spent a lifetime worrying about her and looking out for Rosie. It wasn't always easy for me to keep my mouth shut and let her lead but over time, I saw that Rosie was fully capable of making her own decisions. She knew what she didn't know and what she needed help with and she wasn't afraid to ask for help. Sometimes she asked me. Very often, she asked others who knew more than I did.

I'll close with a story. Four years ago last October, Rosie was admitted to the ICU with pneumonia. After a terrible first night, her pulmonologist came into her room. By then, Rosie's blood oxygen was in the 80s and she was working hard to breathe even with high flow oxygen. He sat down and told her directly that she was in danger of dying and needed to be intubated to give her lungs time to rest. He knew Rosie and he knew she would be making the decision so he didn't even look at me. Rosie asked several good questions finishing with asking what the doctor would recommend if she was his family member. Only then did she look at me and ask for my opinion. I told her that she had asked all of the questions that I would ask and that I trusted her ability to make a solid decision. And she did. She signed the consent and then crawled into bed, allowing the doctors to paralyze her and then she spent the next 17 days on a ventilator and after that, another 20 days in the ICU.

Most of life's decisions aren't as dramatic as being intubated but Rosie was fully capable of making that big decision because she had successfully made thousands of smaller decisions. Rosie wanted to live and she made the decision to undergo painful, invasive treatment so that she would have a better chance of living.

Chair Manning and members of the committee, I appreciate your attention and thank you for the opportunity to submit this testimony as a proponent on SB 35.