

**Chairman** Hackett, Ranking Member Thomas, and Members of the Finance Subcommittee on Health and Medicaid:

My name is Mark Butler. I am a father of three children, two of whom have autism.

I am here today to witness to a truth: forcing parents of children with disabilities and mental illnesses to relinquish custody of their children to get help is wrong!

This should not need to be said, but I have found myself having to say it for the past 5-years. Again and again. Here we are in the year 2019 and, sadly, it still needs to be said. I do not think that anyone disagrees with me. What has been missing has been the willpower to end the evil of forced custody relinquishment in Ohio.

In 2014, my wife and I were forced to relinquish custody of our then 16-year-old son Andrew when his violent outburst and behavioral issues became too extreme to address in our family setting. In addition to autism, Andrew also has a severe intellectual disability and several mental illnesses.

Andrew benefitted from an early diagnosis, just prior to his second birthday, because we were going through that same process with his older sister Katie. As with some children with autism, Andrew experienced developmental regression that affected his ability to communicate. He was able to say simple words like “mama” and “dada” but stopped being able to speak before his diagnosis. He has never spoken since.

Over the course of Andrew’s childhood, we worked hard to meet his needs and to create a loving and nurturing environment for him. We searched for anything that would help him and collaborated with every agency and organization that could help our family.

Eventually Andrew’s behavior reached the point where our family’s safety was at risk. After some especially violent outbursts at home and at school, he was taken to Cincinnati Children’s Hospital. Social workers there told us that it was no longer safe to have him living in our home and that he needed out-of-home residential treatment.

Andrew’s Medicaid Waiver would not assist with this and neither would our family’s private insurance. We were told our only option was to surrender custody to our county children’s services agency.

Making that call to children’s services was the hardest thing I have ever had to do in my life. I promised would do anything I could to prevent this from happening to anyone else.

My family struggled for so long in silence, afraid of what would happen if we ever went down that “rabbit hole”. That fear turned to humiliation, as we had to navigate through the system and have a *guardian ad litem* appointed; a stranger who could allegedly understand the needs of my non-verbal son better than me. That fear turned to sorrow as my wife and I sat in the parking lot of the institution, two-and-a-half hours away where my son was sent, after we were told we were not allowed to see him that first weekend. That fear turned to anger when I sat in my son’s OEDI (Ohio Eligibility Determination Instrument) meeting, a meeting to determine his eligibility

for adult services, and was told I was not allowed to answer any of the questions on the assessment.

My wife and I visited Andrew every weekend for two-years. Over 25,000 miles. That is longer than circumference of the Earth. The only way to have to have a relationship with him is through proximity, so it was something we had to do. Eventually he was able to step down from residential treatment to a supported living environment. After two-years, he was able to return to our community. Now as an adult, we have adult guardianship of him. He is doing well in a supported living environment. He is happy and we have a great relationship with him.

Bruises heal over time. Dry wall can be repaired and replaced. I am still working a second job to help us catch up and recover financially. My oldest daughter still suffers from PTSD, but this year we were even able to celebrate the holidays together as a family. It is tempting to just sit back and try to be happy with where we are now. I cannot do that as long as forced custody relinquishment happens in Ohio.

Ours is just one story from one family in one county. I have heard from parents who have been threatened with charges of child abandonment or threatened that their child could be adopted away from them. I still feel lucky that my son was not sent out of state like other children are. I am still frustrated that no one can look me in the eye and give me a straight answer when I ask "why?" How is this acceptable?

I also ask you as a father who was forced to surrender custody of his son; please work to end forced custody relinquishment in Ohio. Both in your work on this budget and beyond. Help figure out why this is still happening and fight for us wherever you can. Do not let another family, another family already struggling, suffer the way my family did.

Thank you.

Mark Butler