

Mark Butler
Testimony to the Senate Health Committee on H.B. 110

May 5, 2021

Chairman Huffman, Ranking Member Antonio, and members of the Senate Health Committee, thank you for allowing me to testify on H.B. 110.

My name is Mark Butler. I am the father of three adult 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! I have yet to meet anyone who disagrees with this, but I have found myself coming here say it for the past 7-years. I am pleased and grateful that this was heard and acted upon in the 2020-2021 Biennial Budget.

Some of you may be familiar with my family's story. In 2014, my wife and I were forced to relinquish custody of our then 16-year-old son Andrew when his violent outbursts 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. In other words, Andrew was a multi-system youth.

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 is 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. That is why I keep coming back here.

My family struggled for so long in silence, afraid of what would happen to Andrew once we started down that path. That fear turned to sorrow the first weekend he was away. My wife and I sat in the parking lot of the institution where he was sent, two hours from our home, just to be

close to him. We were told we were not allowed to visit. That sorrow turned to frustration when I sat in meetings and watched multiple agencies act like they were in a game of hot potato with my son's care.

We visited Andrew every weekend for two-years. Over 25,000 miles. That is longer than circumference of the Earth. Andrew is non-verbal. He cannot write an e-mail or use a telephone and he does not understand Zoom. The only way to have to have a relationship with him is through proximity, 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 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, but we will get there eventually. Time and hard work can accomplish a lot for both my family and my state. Thanks to the efforts of a coalition of advocates and legislative champions, Ohio has made strides to end forced custody relinquishment. Over the past two years, our state has kept hundreds of families from enduring what my family had to endure.

This past year has been difficult for every Ohio family. Andrew and Katie have experienced major setbacks. The behavioral issues that families of Multi-System Youth face have only been exasperated by the COVID-19 pandemic. We owe it to those families to continue the progress we made before the pandemic and to make strides toward permanently ending forced custody relinquishment in Ohio

To accomplish this, I ask that you maintain the Multi-System Youth Child Relinquishment Fund as introduced, support funding dedicated for Multi-System Youth across state agencies and support the funding necessary to successfully implement OhioRISE in the Ohio Department of Medicaid budget.

I believe that OhioRISE presents us with an opportunity to make a real difference in the lives of multi-system youth and their families. I know that my family would have benefited from the OhioRISE Intensive Home-Based Treatments before we were in crisis and its Mobile Stabilization Services when we were desperate for help. Its model of Coordinated Care would have helped me navigate the many complex systems my son needed for support. Most importantly, OhioRISE would have helped us access the care he needed without us surrendering custody of our son.

Thank you for your time and for everything you do support Ohio's multi-system youth.

Mark Butler