Ohio creates crisis fund to help parents keep custody of severely disabled kids

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Of all the anguish that befell Mark Butler as he fought to obtain care for his severely autistic son, the worst came when he and his wife had to sign over their parental rights.

So Butler couldn’t help but savor the part of Ohio’s new biennial budget that speaks — finally, he and other advocates say — about parents and guardians “at risk of relinquishing custody of the youth” in order to access badly needed services.

“When I saw those words written down, I said, ‘They heard us.’ The dagger that hit us in the heart, this specifically says it wants to pull that out,” Butler said. “No parent should have to go through what we went through.”

For the first time, the state is to create a “crisis stabilization fund” that can be tapped to help so-called multisystem youths — those in danger of entering the child-protective or juvenile-justice systems because of their disabilities, mental illnesses and dangerous behavioral problems.

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Legislators set aside $5 million in federal welfare money each of the next two years to support the fund. County Family and Children First councils will design local plans for administering it.

Although the funding is far short of the $30 million supporters had hoped for, they’re celebrating progress in a tight budget cycle.
Longtime children’s advocate Gayle Channing Tenenbaum thanked legislators “on behalf of the youth and families who have taken out a second mortgage on their home, sold a second car and are working two jobs each to pay for service for their multi-need children.”

Ohio is giving those families hope by saying that custody relinquishment should not be a practice in cases where parents are trying to meet their children’s needs, she said. They now “have a chance to stay together.”

The Dispatch has been reporting on the obstacles and heartbreaking choices families face when Medicaid and private health insurance aren’t sufficient to pay for services and treatment.

The Butlers surrendered custody of their teenage son, who cannot communicate verbally, then saw him placed in a residential treatment center hours away in southern Ohio. The Whitehall family waged a two-year campaign to get local care for Andrew, who is now 19 and back in Franklin County, living in a home staffed with aides to keep him and others safe.

“Everything we went through with Andrew — custody surrendering and relinquishment, all those drives to Ironton and sitting in committee meetings — then if it helps just one dad like me, then my gosh, it was worth it,” Butler said. “Too many of these families suffer in silence.”

The budget provision also calls for a data-collection system to shed light on the number of multisystem youths served and to monitor trends and outcomes. The state hasn’t in the past tracked such cases or counted the number of families who trade or lose custody because of service barriers.

But advocates say that more than half of youths in the custody of Ohio’s child-protection agencies are not there because of abuse or neglect.

“I think a big problem in all this is that we don’t know how many like Andrew there are out there,” Butler said.

In the past year, the Ohio Department of Developmental Disabilities also created a pilot program in central Ohio to aid families whose children have disabilities and volatile behaviors that require expensive treatment. And the Franklin County Board of Developmental Disabilities worked with other local
government agencies and a nonprofit organization to designate a four-bedroom residential center on the East Side to serve youths who can’t safely remain in their family homes.

“The system can change, it really can,” Butler said. “It just takes the hard work and dedication of a lot of people.”

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