Whitehall couple gives up custody to help autistic child

By Rita Price, The Columbus Dispatch

Posted May 14, 2016 at 12:01 AM
Updated May 15, 2016 at 11:47 AM

IRONTON, Ohio - Six days a week, the parents feel invisible to their son. They cannot call or text or send emails because 17-year-old Andrew Butler cannot converse or read or write. Relief comes on Saturdays. That’s when Mark and Susan Butler make the drive from their home in Whitehall to Andrew’s aide-staffed apartment in the southernmost part of the state, a five-hour round-trip that has put thousands of miles on the couple’s car and immeasurable stress on the family dynamic.

IRONTON, Ohio - Six days a week, the parents feel invisible to their son. They cannot call or text or send emails because 17-year-old Andrew Butler cannot converse or read or write.

Relief comes on Saturdays. That’s when Mark and Susan Butler make the drive from their home in Whitehall to Andrew’s aide-staffed apartment in the southernmost part of the state, a five-hour round-trip that has put thousands of miles on the couple’s car and immeasurable stress on the family dynamic.

“If proximity is the way to have a relationship with him, that’s broken,” Mr. Butler said. “I’ve cried more tears than I thought I had.”

Andrew has severe autism, developmental disabilities and sometimes violent behavioral problems. The only way his parents could get the expensive care needed to manage his worsening condition was to relinquish custody to Franklin
County Children Services, a bitter decision two years ago that led to a residential treatment center and supported-living arrangement far from his mom, dad and two older sisters.

“I'm not aware of any parent who has had to surrender their child because of leukemia,” Mr. Butler said. “If you asked any taxpayer, I think they would say, 'That’s unacceptable.'”

Parents facing such desperate choices are fighting to make their voices heard. A legislative panel is wrapping up public hearings and aims to issue recommendations this summer for addressing the obstacles that Ohio families face as they try to cobble together help and coverage through various systems: mental health, child protective services, developmental disabilities, juvenile courts, Medicaid and private insurance.

Stories of custody relinquishment are among the most heart-wrenching that committee members have heard, said state Sen. Randy Gardner, a Republican from Bowling Green who leads the Joint Legislative Committee on Multi-system Youth.

“Some people said, 'If you can resolve that, the committee’s work will have been worthwhile,'” he said. “Do we want to do more than that? Yes.”

Families “deeply engaged and committed” to meeting their children’s needs shouldn’t wind up in a system designed to serve those who have been abused or neglected, Chip Spinning, executive director of Franklin County Children Services, said in committee testimony.

“There has to be a better way,” he said.

**Bitter choice**

The Butlers see other Columbus-area kids with disabilities and mental-health disorders living in this small Appalachian city, which is close to the Necco Center and its residential and outpatient mental-health services for minors.

“We call them the lost boys,” Mr. Butler said.
When his parents and one of his sisters arrive, Andrew is all movement and touch. He leans close to his dad and inhales his scent. He urges his mom to trace the outline of his hand in chalk.

“You do wonder,” Mrs. Butler said. “Where does he think we’re at when we’re not here?”

The Butlers held on at home as long as they could. But as Andrew grew bigger and stronger - he’s 6 feet tall now and weighs more than 200 pounds - the damage and injuries he inflicted became too much. Nonverbal and occasionally seized by uncontrollable emotion, Andrew could turn into the Incredible Hulk.

“We were getting covered in bruises,” said Mr. Butler, who works at Holy Spirit Catholic Church as director of religious education. “He'd go into these rages, grab us and bite us. He tore my ACL.”< /p>

Mrs. Butler, a teacher in the parish elementary school, has repaired the drywall in their home so often that she’s nearly an expert.

“There’s like a growl that he makes,” she said. “I hate to say it, but when I hear that, I scoot away.”

Andrew was in a behavioral crisis in 2014 when he was admitted to Cincinnati Children’s Hospital Medical Center, where doctors worked to stabilize him and adjust his medications.

“We have some advice for you, and you’re not going to want to hear it,” Mr. Butler says he and his wife were told. “You’re going to have to call Children Services. It’s your only choice.”

Putting Andrew in state custody meant that the child-protection system, the only federal entitlement funding stream that can be used for residential-treatment room and board, would pay for the recommended care. Private insurance is often insufficient; Medicaid covers mental-health treatment but not the residential part.

After the court hearings and the placement decision, Andrew was sent to Necco in southern Ohio’s Lawrence County, one of the relatively few centers that serve teens like him and that had availability.
Over several months he improved and both Necco and Children Services agreed that he could live in a less-restrictive environment such as an apartment with 24-hour staff and nearby services.

“He needs one-on-one,” Mr. Butler said. “In a family, you can’t do that.”

Children Services, which doesn’t typically fund supported-living arrangements, returned custody to the Butlers. The Franklin County Board of Developmental Disabilities also serves Andrew, but that agency is geared toward providing supported-living arrangements for adults, not minors.

Mr. Butler said he felt like they were engaged in a game of hot potato.

“To have two county agencies arguing over who had responsibility for my son was just awful,” he said. “Neither really wants it.”

‘Ironton might as well be the moon’

Eventually, meetings and discussions led to an arrangement last year in which the county disabilities agency approved funding for Necco to provide residential staffing for Andrew to live in a home in Ironton. He shares it with another Franklin County teen who has similar disabilities.

“I lucked out and got custody of my son back in a year, but he's still living down there,” Mr. Butler said. “Ironton might as well be the moon.”

Jed Morison, superintendent of the Franklin County Board of Developmental Disabilities, said there wasn’t a comparable living arrangement readily available for Andrew in the Columbus area. The Butlers say they weren’t offered any help finding one.

“Why would they pay for him to have supported living in Ironton but not Franklin County?” Mr. Butler said. The distance makes it difficult for case managers to monitor the situation, the family says, and they have dealt with landlord problems, poor-quality care and theft.

Morison said the county strives to provide support to keep children in their own homes and succeeds in the overwhelming majority of cases. Through an agreement with Children Services, the disabilities board also provides about
$450,000 a year to help cover costs for kids who qualify for disabilities services and are under the care of Children Services.

Still, Morison agreed with other officials that children shouldn't have to become wards of the state to get appropriate care.

"It is frustrating, and I can only imagine how difficult it must be for families," he said. "Frankly, we would welcome a legislative initiative that would develop some kind of treatment options for these challenging cases."

Although the state doesn't track the number of families that relinquish custody solely to gain behavioral-health services, the Public Children Services Association of Ohio says more than half of all kids in the custody of county agencies in 2013 came into care for reasons other than abuse or neglect.

Child-welfare advocates also say the supply of residential-treatment beds for minors is insufficient, even in high-population areas, leading to long waiting lists and placements far from home.

For the Butlers, who stress that they remain grateful for the services they have had and will receive in the future, the long drives to see Andrew finally are coming to a close. He turns 18 later this month and soon will move back to the Whitehall area, very close to his parents, to a home with care providers funded through the disabilities board. The family had faced a waiting list for an apartment and was overjoyed when a member of their church purchased a house just for Andrew and a roommate to rent.

"I'm Catholic, so I'm good with miracles," Mr. Butler said, smiling.

Andrew likely doesn't understand any of the reasons behind his two-year journey.

"But he knows where he belongs," his father said. "He smiles when he's happy. And he can't pretend if he's not."

rprice@dispatch.com

@RitaPrice