

Parents struggle to find care for autistic child

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When Kathleen Fenlon drove by a McDonald's and her 14-year-old son, Colin, wanted to eat there, there would be little choice for her but to acquiesce.

If she didn't, Colin likely would undo his seat belt and try to wrestle the steering wheel from her to steer the car into the parking lot.

Inside, if there were someone sitting where Colin always sat, Kathleen would have to try to explain the situation to the complete strangers and hope they would move. If they didn't, Colin would go into a grunting, falling-down tantrum.

During one of what she calls Colin's public "meltdowns," people were so shocked by his behavior, they called police. They don't understand, she said.

Colin is lucky he hasn't been hit by a car. Because of his impulsiveness, he's been known to run out into traffic in the Oak Forest neighborhood of single-family homes where the family lives. And if a classmate had something he wanted, Colin would climb over furniture, throw things out of his way, push, punch and do just about anything he could to get it.

Colin can't help these aberrant behaviors, though.

He was diagnosed with a particularly severe form of autism exacerbated by obsessive compulsive disorder.

He simply doesn't know how to act appropriately when he doesn't get his way.

Colin's doctors, therapists and, reluctantly, his family all agreed the best option for his continued treatment and education would be to have him placed in a residential facility.

With the state being in such an economic crisis, the family figured finding a facility would be easier than getting state aid to help pay for Colin's treatment.

They found the exact opposite to be true: The state would pay for the residential part of Colin's care; the local school district would be responsible for paying for his educational services.

Finding a place that would take Colin, it turns out, was the real challenge.

The difficulty

Besides his disability, Colin has physical challenges that made his placement more difficult. He's highly allergic to a rather long list of foods: wheat, soy, corn, tomatoes, egg whites and oranges. If he eats any of them by mistake, they can cause painful lesions in his esophagus. The most serious of his allergies is to peanuts, which will send him into anaphylactic shock.

To compound matters, Colin's behavior became more violent and potentially harmful to himself and others. He took to head-banging when he didn't get what he wanted. And he's put his head through a window and damaged walls during outbursts.

Colin's mother, Kathleen, and father, Mark Panozzo, believe the rush of hormones brought on by puberty made his behavior more erratic and violent. To get Colin under control in those instances, the family would have to get him admitted to Streamwood Hospital, a special psychiatric hospital where he would be heavily sedated and could receive 1-on-1 care. He was hospitalized nine times in three years, with his last hospitalization lasting 120 days.

Caring for Colin became a full-time job for Kathleen and Mark; so much so that Kathleen lost her job in retail and Mark lost his job as an insurance salesman because of the extraordinary time they spent caring for Colin.

"There is nothing I would want more than to have my son at home," Kathleen said as she wiped away tears. "But he has progressively gotten more difficult to manage. We just can't do it anymore."

The first problem encountered by Colin's family in placing him in a residential facility: There weren't many to choose from, especially for children. Of the facilities that could accommodate Colin, none was run by the state. All are managed by private companies.

Colin's applications were rejected because of his allergies and the potential liability they could expose a private company to, his mother said.

The family hired professional advocate Matthew Wanzenberg to help with Colin's placement.

Wanzenberg is a former teacher and school administrator who helps parents navigate state and federal laws pertaining to children with

disabilities to get the services they need.

"For the lion's share of kids (with disabilities), 98 or 99 percent have their needs met within the public school system. Of that 1 or 2 percent of those who aren't having their needs met, there are very few with the severity of Colin's disabilities," Wanzenberg said.

He said Colin needs a round-the-clock educational program. When he lacks structure at home or when school isn't in session, that's when he's prone to aggressive behavior. But because of Colin's allergies, which complicate his care, private facilities get nervous, Wanzenberg said.

"Their defenses go up. There are a lot of knee-jerk reactions. People are scared of liability. And these private companies can make their own rules and regulations, and that can be frustrating to families," Wanzenberg said.

Besides hiring Wanzenberg, Colin's family went through numerous state agencies looking for help and usually came up empty. They even tried to enlist the help of Illinois Attorney General Lisa Madigan and U.S. Sen. Dick Durbin. Both told the family it was not within their purview to help, Kathleen said.

They even considered out-of-state facilities.

Kathleen and Mark were able to connect with some sympathetic staff members at the Illinois Department of Human Services, who helped pursue placement for Colin. Ultimately, the Camelot facility in Des Plaines took a second look at Colin's application. After 1 1 / 2 of Kathleen and Mark searching and making more phone calls than either can count, Camelot accepted Colin's application, and he was placed at the facility in July. He will receive the kind of therapy he needs as well as continue his education, all in a residential setting.

The Department of Human Services' division of developmental disabilities is paying for the residential part of his care. The educational services he receives are to be funded by Bremen High School District 228, according to the family, because Colin would have been a high school freshman in the district this year.

Time to revise the system

Despite relief at finding a place for their son, the whole experience has left Kathleen and Mark with an unpleasant opinion of mental health care systems, both public and private. Colin's parents said it shouldn't have taken so long to find a place for their son.

"Illinois has to be one of the worst states for helping the disabled," Mark said. "It seems as though you really have to know someone if you want to get anything done."

Dr. Peter Nichols, who treated Colin at Streamwood Hospital, said he wasn't surprised by the difficulty the family had in finding placement for him.

"Colin is definitely one of the most severe cases of Autism Spectrum Disorder I've ever had. And there are a limited number of beds in Illinois for treating the disorder on a long-term basis," he said. "Allergies played a role (in placement). These facilities don't want to make a mistake and don't want the child to have a bad reaction."

Nichols said a hospital setting such as Streamwood isn't as worried about liability because it provides medication and 1-to-1 staff-to-patient ratios to curb destructive behavior. A residential facility might be wary of a case such as Colin's because it is likely to have fewer staff members and cannot keep as close an eye on its residents, he said.

Lilia Teninty, director of the development disabilities division for the Department of Human Services, said placing a child in a residential facility can be a long process. There are more people who need services than there is funding available.

The agency doesn't provide services directly. It acts more as a facilitator between those who need services and the private agencies that provide them. The state encourages home-based services if at all possible, Teninty said. But in extreme cases when there is no other option but a residential placement, the department will assist families in finding the right setting.

Ultimately, placement is left up to the individual facility. Teninty said if that facility doesn't feel it can provide the right services, it has the right to turn away the applicant.

Calls to Camelot for comment on this story were not returned.

Maryellen Bucci, the administrator at Easter Seals Therapeutic Day School, where Colin used to attend, thinks doctors' reports regarding Colin's allergies contributed to the difficulty in placing him. She said she believes the reports may have characterized the allergies as more severe than they were.

She said there are some cases at her school where children have such severe allergies, the staff can't even risk having the child in the same environment as their allergens. But that wasn't the case with Colin, she said. To be safe, the school had an epinephrine pen to counteract the reaction in case Colin ate one of the foods to which he was allergic.

"We may have had to seat Colin further away from kids who were eating peanuts or other foods he was allergic to. But it wasn't like he couldn't be in the same environment," Bucci said.

"None of us here felt that his allergies should have been the deciding factor for these facilities to reject him," Bucci said. "But these are

a unique set of circumstances. I've never come across a case like this one."

Bucci credited Kathleen and Mark's tenacity in getting Colin placed. She said they did everything they possibly could to be heard and did not take "no" for an answer.

Kathleen and Mark said Colin is getting used to his new environment and has had some incidents. But over time, they believe Colin's behavior will continue to improve under the right guidance.

The family's outlook on the state's system for helping the disabled isn't as rosy. They're convinced it is broken and needs to be fixed.

WHY WAS COLIN TURNED AWAY?

Dr. Peter Nierman, a child psychologist, assistant professor at the University of Chicago and the medical director at Chicago Lakeshore Hospital, said it's not unusual for a family to face rejection when trying to find a residential treatment facility for a loved one with developmental disabilities.

The state of Illinois has gotten out of the practice of running such facilities, leaving them to the private sector. The state's role is as a potential funding source, Nierman said, with the Department of Human Services providing the funding. Nierman thought it was unusual that Colin's family was rejected by private residential facilities based on Colin's allergies. He said facilities should have been able to adjust to accommodate Fenlon's dietary restrictions. But he said he also sees why a private facility would be wary.

"When kids have language barriers or are impulsive, extraordinary measures, extraordinary individualized care may be necessary. Staffing may be a problem. It may come down to, 'Can we provide what this child and his family needs?' The answer might be 'no' because there is so much risk involved in his impulsiveness," Nierman said. He said neurobiological research indicates autistic teens going through puberty have shown spikes in aggression, making them "almost impossible" to deal with, and Colin's increased aggression and allergies may have been factors in his being turned away. If a scenario comes down to four kids applying for one opening, Nierman said, a candidate such as Colin may be the fourth out of four likely to be accepted.

WHAT IS AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder is a disorder in which the different areas of the brain fail to work together, resulting in a person's inability to communicate and interact with others.

The Autism Society of America states that symptoms begin to appear from birth to age 3. They often manifest themselves in delayed speech, repetitive movements or behaviors, lack of eye contact, a fixation on certain objects and a lack of interest in relationships with others.

Children do not outgrow autism. However, the society states that early diagnosis and intervention can result in better quality of life.

The Centers for Disease Control in Atlanta released its Autism Prevalence Report in 2009, indicating that autism occurs as frequently as 1 in 110 births.

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