

A PLACE FOR ALEX: MOM STRUGGLES TO KEEP FAMILY TOGETHER DESPITE SON'S SEVERE AUTISM

By [Cathy Zimmerman](#)



ALEX LOVES TO SWING, OFTEN TWISTING AROUND IN CIRCULAR MOTION. GREG EBERSOLE / THE DAILY NEWS

Young mom, boy on swing, little sister spying bugs in grass. It's a picture so normal it barely snags a glance. The mother is Lacey Cairns, however, and normal is not in her vocabulary.

So explosive and aggressive is Cairns's 9-year-old autistic son, Alex, that the Longview woman is begging the state to provide a separate place for him to live and 24-hour care by trained workers.

While she waits, Alex is being housed at Fircrest Residential School north of Seattle. Cairns, a 33-year-old divorced mother of four, goes up to see Alex every 10 days while her mother watches the other children.

A local house for the boy is close to reality, said Marti Johnson, the director of Residential Resources in Longview, an agency that coordinates housing for the developmentally disabled.

But Cairns only recently allowed herself to feel optimism; it has collapsed on her too many times.

Through her son's nine years, she has struggled to care for him and control him.

Alex expresses frustration at not being able to communicate by biting, pinching, slamming into people and pulling their hair. He also injures himself, gnawing on his fingers and toes.



Lacey pushes her youngest daughter as her son Alex swings at his residence in Seattle. Greg Ebersole / The Daily News

"He'll chew on his feet until he reaches the bone," his mother said. "He's violent if he's upset and violent if he's happy."

She posted pictures on the refrigerator and taught him to touch them to signal what he wants, for instance. But with three other kids, a household to run and Alex's seizures and assaults, she couldn't stick with the exercises enough to train the boy.

"He's gotten so bad, he has to have two people watching him and taking care of him at all times," Cairns said of Alex, who's been called the "Mount

Everest” of autism by his Longview pediatrician, Dr. Blaine Tolby.

“Oh Lord, does she need help,” Tolby said.

“Alex has a poorly controlled, severe disorder, and medication doesn’t handle it well. ... She has other kids who have needs, and her mother doesn’t live with her. Alex is a huge challenge. I look at her smile, and I think ‘How does she do it?’

“To be fair to her, she’s an incredibly strong woman dealing with a challenge way beyond the average.”

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LACEY GIVES ALEX A KISS DURING A VISIT AT HIS RESIDENCE IN SEATTLE. GREG EBERSOLE / THE DAILY NEWS

In May, this got so out of control Cairns took Alex to the Emergency Department at St. John Medical Center, where he spent 12 days before an inpatient bed was found for him at Fircrest, hospital officials said.

The boy was isolated in a room in the emergency area. Cairns knew she couldn’t cope with Alex at home, but she was appalled and distressed that he was alone, sometimes in adult restraints, for such a long time.

“He was having a hard time the night before and became violent the day she brought him in,” said Sheldon Conrad, the Emergency Department’s clinical social worker.

It was obvious that it wasn’t safe to send Alex home, Conrad said. “He would bite himself, bite the staff, strike himself and the staff, and he did that to his mother as well.”

According to Chris Baker, the hospital’s director of women’s and children’s service and care management, “We do not have the level of facilities or expertise to make sure this child would receive the care he needs.”

They couldn’t put Alex in the pediatric unit “with children with asthma and new babies,” Baker said, nor would he be safe in the adult psych unit.

While they treated Alex with medication for his seizures, hospital workers started a daily search for an inpatient bed, said Lynn Van Brunt, regional director of critical care services at St. John.

“We exhausted all the resources in Washington and Oregon,” said Conrad.

Not only is there no adequate long-term care for children like Alex at St. John, Van Brunt said, but there’s no facility in Cowlitz County that fits the bill.

To get the space at Fircrest, Van Brunt added, “approximately nine different individual and county entities intervened.”



AFTER A KISS, ALEX QUICKLY TURNS VIOLENT AND GRABS HIS MOTHER'S HAIR. GREG EBERSOLE / THE DAILY NEWS

Situations like this one are sure to crop up again, she said. “Until something changes drastically, some means of economic support or someone who says, ‘Gee, this is the kind of facility I’m going to build,’ “ the problem won’t go away.

Tolby agrees.

“It’s not St. John’s fault,” the pediatrician said. “They’re a victim in this, too.”

Since the Reagan era, he explained, when “the large mental health system was dissolved and people were sent back to their communities, they tightened down the mental health beds so tightly” that droves of disabled and mentally ill people go begging for in-

patient treatment — and go without.

“Everyone is attempting to provide care,” Tolby said, but “the system doesn’t have the capacity to respond. And that’s what caused Alex to be in the emergency room.

“It’s like having one heart specialist for a million people and needing to wait in line. That is a reasonable analogy.”

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Lacey Cairns has a placid demeanor and a soft voice, but her steely insistence knocked loose the first steps toward a solution.

She refused to take Alex home. Medical professionals saw the boy in action and scoured the region for a bed. Fircrest opened up. And Residential Resources stepped in to find a permanent place.

It’ll be a godsend for Cairns, but bittersweet. She has always wanted him at home, with her.

“Two years ago,” she said, “if you would have asked if we plan to put him in a group home, I would have said ‘NO!’ But I have three other children, and it’s hard to keep them safe, and myself safe.”

Cairns knew something was amiss early on.

“He hit all of his milestones in the first year, but he was always sick with ear infections, she said. “Right after his first birthday, he stopped having eye contact. He wouldn’t sleep, he was screaming all the time, and he started having seizures. I couldn’t take him anywhere.”



TWO STAFF WORKERS HELP ALEX TO HIS LIVING QUARTERS AFTER PLAYING ON THE SWING. GREG EBERSOLE / THE DAILY NEWS

Doctors diagnosed Alex with severe autism, and Cairns's journey began.

She taught the boy to look into her eyes, a major accomplishment. She treated his skin rashes and painstakingly adjusted to his numerous food allergies, which caused vomiting and chronic diarrhea.

Cairns put a trampoline in the house for the repetitive exercise he needed even on rainy days. Her attention had to be on him constantly; left unattended, he would crawl on kitchen counters,

throw things, flood the room.

They lived in California in his early childhood, with ready services for the disabled at regional centers. Then her marriage fell apart, and Cairns returned to her native Northwest to enlist the support of her mother, Carol Peterson of Rainier, with Alex and his brothers, Zach, who's now 8, and Aidan, 11.

Cairns has since had a daughter, Chloe, but the little girl's father is no longer in the picture. The family relies on Social Security allotments. Public funds also cover Alex's treatment in special needs classes, respite care, and Cairns's transportation to Fircrest.

At the Shoreline facility, Alex has good days and rough ones.

One afternoon in early June, he seemed content, although off in his solitary, jittery world. He showed affection to his mother in their ritual of rubbing noses. But seconds later, he grabbed fistfuls of her hair and fiercely yanked, knocking her sideways with his other arm.

In the throes of aggression, he's very strong, and two attendants hurried to separate mother and son.

"Safe hands! Safe hands!" They all used the same cue to remind Alex not to strike.

While at Fircrest, Alex has been taking clonidine and thiorazine, his mother said. Clonidine relaxes the heart to slow the heartbeat; thiorazine controls schizophrenia and the hyper-energetic phase of manic-depressive illness. Both medications are powerful; the side effects of thiorazine alone fill 21 lines of text on one Web site.

Even on those powerful meds, Alex showed frenetic energy while visitors were there. He will swing for hours, then jump off suddenly and lunge a bystander, making his breathless, grunting sounds.

He's in holding pattern. But the path may soon open to move him closer to home.

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At Residential Resources, Johnson has worked for 30 years coordinating housing for adults who are developmentally disabled. The growth in autism, now estimated to affect one child in every 160, has begun to involve her agency.

Alex represents “those who are in the extra-severe range,” Johnson said, or up to 20 percent of autistic children who are so disabled that they act out in destructive ways.

With help from a task force on children in crisis and agencies with which she has forged ties, Johnson found a house and the funds to rent it.

“This is on the fast track,” she said early this month. “The state has asked us to set up a home for him, and we are paying rent on a place.” Several staff members have expressed interest in working with Alex, she added.

“Our best hope is to license the home in 90 days.”

At first, no other clients will live in the house, Johnson said, but other developmentally disabled youths might live there as Alex gains skills and becomes safer to be around.

“We don’t know what the world sounds like or looks like to someone with autism,” she said. “They can’t filter stimulus to be able to focus on something.

“You and I can hear the fan, or the squeak of a chair, or laughter in the next room.” It doesn’t affect us, but an autistic person “might feel really, really out of control. They behave as if they are uncomfortable or in pain. And they can’t tell us what the problem is.”

Those who work with autistic people “become expert observers,” Johnson said, “like moms do with tiny infants. You watch so carefully you get a sense of what the behavior means.”

As soon as Alex is in a house with trained staff, they can concentrate all their energies on him.

“We want (disabled clients) to get what they need without aggression and violence,” Johnson said. “A lot of families locally are exhausted. They could take every bit of their time just working with the autistic child, but they have other children, and their own needs. They need help, and encouragement.”

Cairns does feel supported by the movement to bring Alex back here.

“I go up there to see him, and it’s so emotional,” she said. “He can’t talk; he doesn’t understand. It’s so hard to leave him. I’m a wreck.”

Last week, she came back from Fircrest with a blue bruise on her upper arm. It’s the size of a tennis ball, but in the incongruous shape of a heart.

“Alex bit me,” she said with a lopsided smile. “A love bite. I almost miss ‘em.”

If the house comes to fruition, she can see her son every day, Cairns said, bringing her hands together in a gesture that started as clapping and ended as prayer. “I will be so glad.”