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Carol Marcantonio has been a tireless advocate for her son, Evan, 11, who was diagnosed with autism on his fifth birthday. They are pictured in the living room of their Meriden home.

SPECIAL REPORT

Saving Evan

A Mother And Son Navigate The Challenges Of Treating Autism

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van is screaming. Keening, really, because there seems to be anguish

E there.

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“Nooooooooooooooooooooooooahhhhhhh!”

He is a handsome, lithe 11-year-old, the spitting image of his mother, Carol Marcantonio. He's all elbows and knees and long, straight hair, his eyes liquid pools, with a half-smile that can melt hearts. But now he's on the floor of the time-out room here at Adelbrook, a school for children with autism in Cromwell.

His mother had known for several years that he needed to be at a specialty school. After a series of psychiatric hospitalizations for Evan, some violent outbursts and several failed school placements, Carol felt that she and her boy had reached a kind of milestone — joining the fifth grade at Adelbrook in May of last year.

It was a journey that many Connecticut parents of children with autism would recognize.

And those parents would understand this: Even with more supports around them, life for Evan and those who love him is never easy.

Their lives mirror the experiences of thousands of Connecticut families who are navigating the highs and the searing lows of a treatment system that is still in the early stages of development.

These parents see firsthand the fragmentation of services, the variation in quality from school district to school district and the difficulties in accessing the system.

In Evan's case, periods of stability have contrasted with deep depression, thoughts of suicide and bursts of violence that, on a couple of occasions, emptied a classroom. By the middle of Evan's fourth-grade year in 2013, he was being restrained nearly daily, his mother said.

Parents of autistic children would recognize the drop-offs ^{([HTTP://WWW.COURANT.COM/](http://www.courant.com/))} in clinical services (Carol calls them cliffs and gaps) that Evan encountered as he went through the “birth-to-three” developmental program, preschool, elementary schools and some failed outplacements at specialty schools before Adelbrook.

Some Connecticut parents who are financially able have arranged for in-home behavioral and psychological treatment to supplement the services their children receive in school — at a cost of thousands of dollars a month.

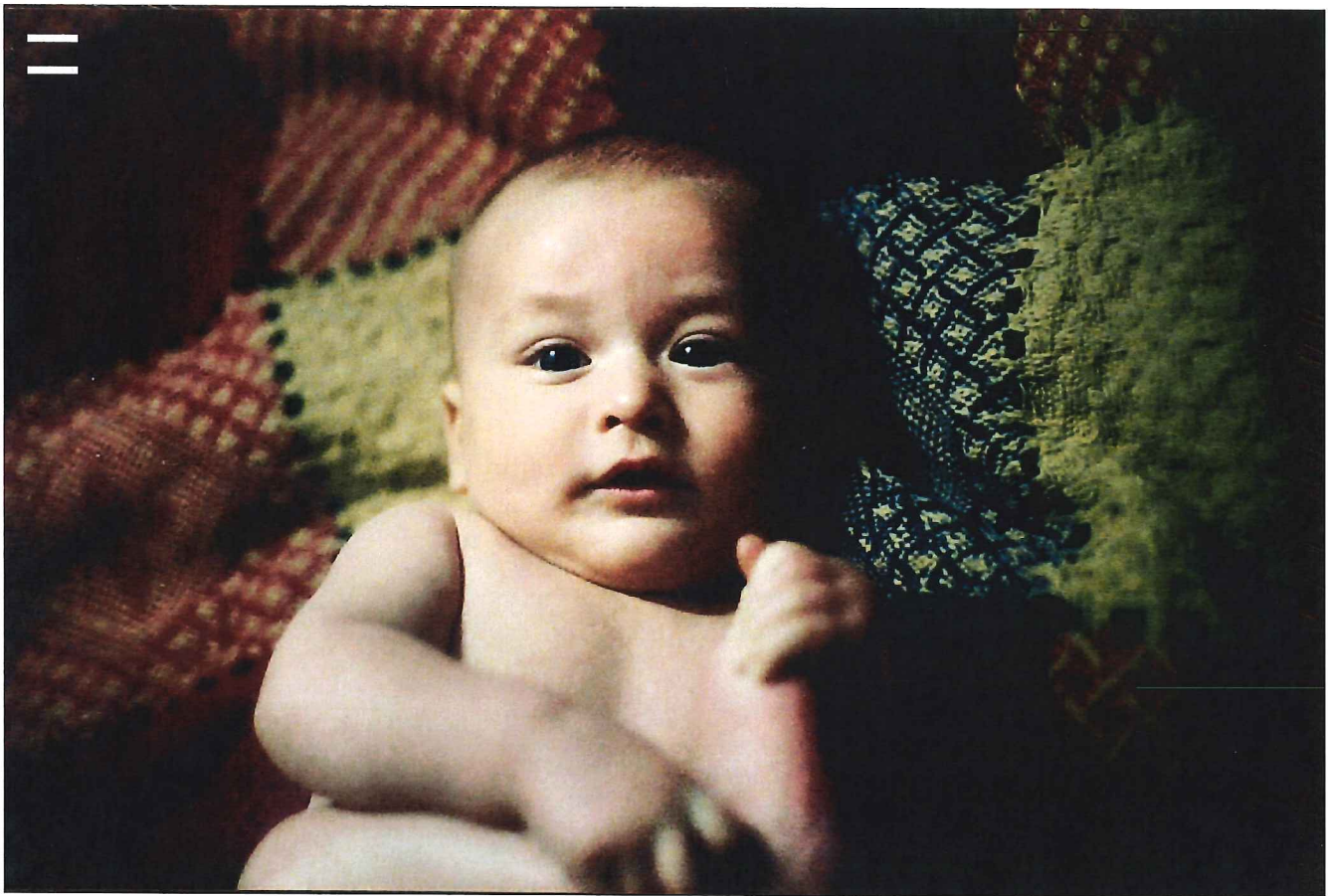
Other parents, like Carol, become tireless advocates for their children and must employ everything at their disposal to try to make the system work.

CHAPTER 1

The First Signs

Learning Your Child is Autistic





After his first birthday, Evan's developmental problems became more obvious. He wasn't speaking, and a social worker suggested that he might have autism.

Carol first noticed that Evan wasn't developing normally after his first birthday. He wasn't close to talking, and a social worker who regularly visited the home to help his cousin Alyssa began watching Evan as well. After observing some of his behavior, including incessant spinning, the social worker said she strongly believed Evan had autism.

"It was the first time I ever heard the word in reference to someone I love," said Carol.

But Evan soon began receiving speech, physical and occupational therapy through the statewide birth-to-three program, and the notion of autism remained in the background for a time.

Then Evan began having a very difficult time.

He was in preschool at the Ben Franklin elementary school in Meriden for five days a week, 2-1/2 hours a day. Then he would be bused to a local day care center in Meriden. He eventually would be kicked out of three centers. (HTTP://WWW.COURANT.COM/)

“I was honest with them each time,” Carol said. “I’d say, ‘My son bites, kicks, screams, and he’s not toilet-trained.’ They would take him, knowing he had all these problems, but he wouldn’t last long.”

This was 2008, and Carol had begun working as a paraprofessional in the Meriden school system.

“I tried to get a day care in Cheshire that had more experience with children like Evan, but Meriden wasn’t going to bus him to Cheshire,” she said. “You have to pick your battles; I just had to accept my losses. It was stressful. I cried a lot. But I had to plow through.”

Baby Steps

After a normal birth, Carol Marcantonio slowly noticed developmental delays in Evan.



When Evan was 4, Carol made an appointment with a developmental ^{([HTTP://WWW.COURANT.COM/](http://www.courant.com/))} pediatrician to have Evan evaluated for autism. It took more than six months to get the examination — and Carol was one of the lucky ones.

“For those appointments, you can wait a year,” said Miriam “Mickey” Kramer, of the state Office of the Child Advocate. “That’s when the weight of the world is on these families. They are saying, ‘I can’t even understand what I’m seeing.’ Meanwhile, the kid is going to school, and you’re hoping the school has expertise to meet the needs — access to a behaviorist, a neuropsychologist, clinical support.”

Carol’s next battle would come soon enough.

“Kindergarten was a major cliff for Evan,” said Carol. “He’d been evaluated and had his diagnosis. I made a draft of the services that he would need. I wanted occupational and behavioral therapy and a one-on-one paraprofessional. This is how children with autism learn, through constant reinforcement and repetition. I was told, ‘Oh, we’re not required to do that.’”

She recalled a time when, after taking Evan out of school for an appointment, she brought him back to his kindergarten classroom.

“The teacher looked at me, pointed, and said, ‘Oh no, he doesn’t belong here. He belongs in the special-education classroom.’”

Carol cries now, recalling the words she felt were hurtful. Evan was an early reader, and was ahead of some of his kindergarten mates academically.

“Then they were going to put Evan on a regular bus without an aide. He’d had Hunters [Transportation Services], which provided an aide. On the regular bus, he would have to be restrained in his seat. The restraint was something you had to put on before you sat down. This would have been just one more thing that made Evan different. I wasn’t going to have that.”

Eighteen people came to support Carol at a meeting with school administrators

about retaining the bus with the aide.

[\(HTTP://WWW.COURANT.COM/\)](http://www.courant.com/)

“The principal saw everyone, there was no question I was keeping Hunters,” Carol said. “I didn't win the one-on-one [paraprofessional], and I came out crying. But a staff member said to me, ‘Carol, sometimes it has to get worse before it gets better.’”

CHAPTER 2

Riding the Highs and Lows

Episodes of Violence, Moments of Joy



Evan's mother, Carol Marcantonio, sometimes has to help him start getting dressed while he's still in bed to make sure that he is ready for school on time.

A difficult three-year period spanning first to fourth grade culminated in January 2014, right before a psychiatric hospitalization led to Evan's being placed at The Children's Center of Hamden, a "step down" facility where children can go to get some stability back after a psychiatric break. (HTTP://WWW.COURANT.COM/)

"He flipped out over homework we were doing," Carol said.

Mother and son had ended up in a narrow hallway at home, with Evan alternately kicking at a door and at Carol. Moments earlier, he had pushed a table against Carol, pinning her against a wall, and threw paperwork and his medications all over the floor. He laughed, which unnerved her further. Then he threw a steel water bottle at Carol. She called the police, and her last memory, before he was taken away by ambulance, is of the officers pinning him down.

Carol has come to understand Evan's occasional violent outbursts.

"It happens for a reason," she said. "When Evan's needs could not be met, and he could not pragmatically communicate that to adults, he would become violent. Another reason may be that he is overloaded, sensory-wise, and doesn't know how to cope with it."

Even though autism is not generally associated with violent thinking, Professor John Molteni recognizes the pattern in some children with autism.

"We see a high level of aggressive or self-injurious behavior in children on the [autism] spectrum," said Molteni. He is director of Autism and Behavioral Studies at the University of St. Joseph in West Hartford and a psychologist and behaviorist at the Hospital of Special Care's Autism Center in New Britain.

The violent response "often comes from a difficulty in communicating wants and needs," said Molteni. "There is a functionality to it, a purpose. It tends to be momentary and situational."

Through the years, Carol has strongly encouraged clinicians and counselors to help Evan with daily living and coping skills, and to look closely at situations — the classroom, his relationships with other children — to identify triggers and make the necessary changes. (HTTP://WWW.COURANT.COM/)

“That's why I like working with [Evan's current in-home therapist]. She helps me by teaching us how to extinguish maladaptive behaviors and encourage positive behaviors,” Carol said.

Evan's hospitalizations came after a golden period in third grade, a time during which Evan was the happiest he had ever been.

Carol thinks the calm period was the result of the self-contained classroom that Evan was in at school. He was placed with other special-needs children of various ages.

Carol never stopped advocating, successfully pushing for something she and a few other parents called “lunch bunch.” Children from Evan's class would eat together in a quiet room, with none of the sensory overload of the cafeteria, and be joined by some regular-education students. Teachers would prompt Evan and his classmates to carry on conversations and to socialize.

Also during that third-grade period, the Marcantonio family had settled into a routine at home. Carol was still working as a school paraprofessional, and her schedule allowed her to be home in the afternoons. She would cook dinner, and the family would sit down and eat together. When the dishes were cleared away and Evan was done with his homework, he would join his stepfather, John, who worked long hours as a machinist, and the two would watch sports on TV. When Evan went to bed at 7:30, the couple had time to themselves.

This period contrasted sharply with what had come before, and what would come after.

In first grade, Evan cleared out the classroom three times with violent outbursts, and stabbed his teacher in the hand with a pencil.

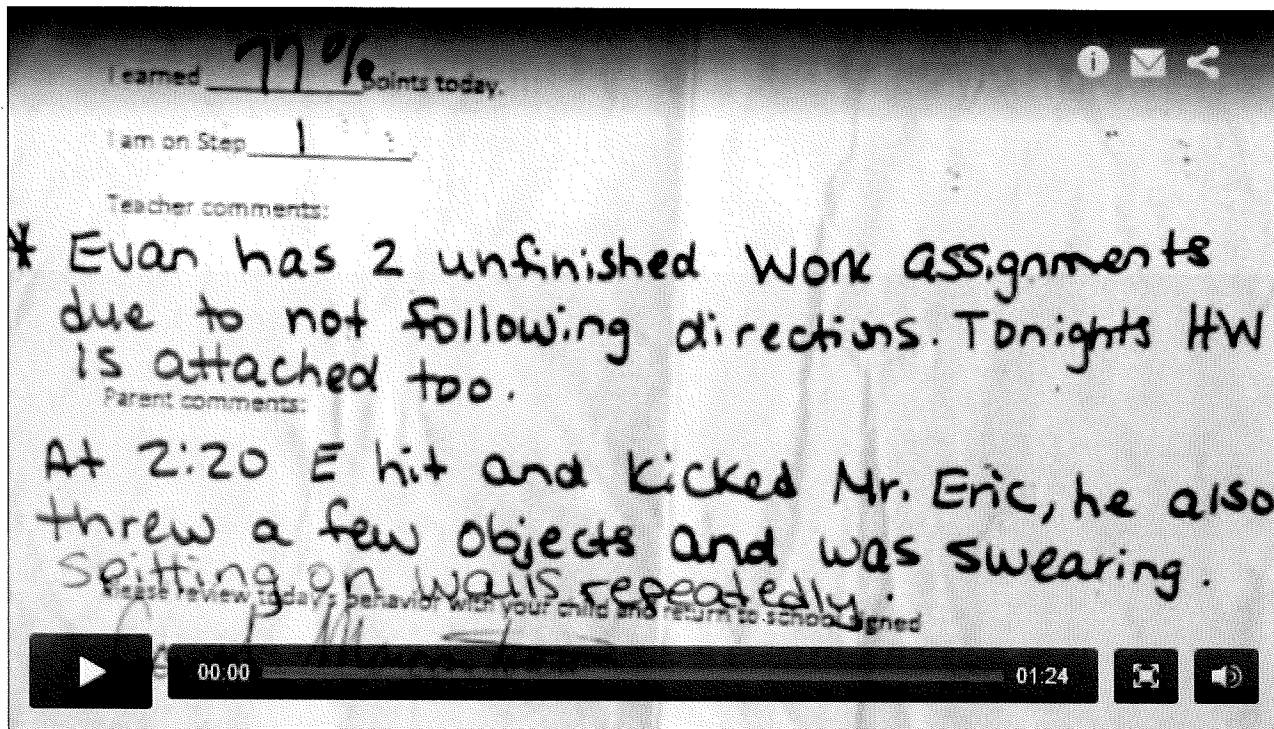
And when Evan was in the fourth grade in 2012 and 2013, ^(HTTP://WWW.COURANT.COM/) he slipped backward, and squandered the stability he had gained the year before. He began to act out aggressively again, and was being restrained almost every day.

Carol thinks it is partly because she had entered Lincoln College of New England and begun a rigorous course of study to gain her certification as an occupational therapy assistant. At one point, she was taking seven classes and studying on the weekends. There were far fewer family dinners.

“As that part of my life was finally working out, my son's life was falling apart,” Carol said.

Behaving Badly

Carol's advocacy for Evan intensified when he entered public school. Evan's disruptive behaviors forced Carol and the Meriden school system to look for solutions. Midway through first grade, Evan transferred to a school where he went to class with other students who had special needs. Evan remained in the public school system, in spite of his difficult behaviors, until the fourth grade, when Carol finally persuaded the district to agree to an outplacement at the Webb School in Cheshire, a therapeutic day school run by the Institute of Living. His behavior would later lead to hospitalizations at the pediatric psychiatric unit at Yale New Haven Hospital.



And then came Dec. 14, 2012.

The shootings at Sandy Hook Elementary School put a face and name to the fear and concern Carol had already been feeling about Evan's increasingly aggressive behavior at home and in school. ([HTTP://WWW.COURANT.COM/](http://www.courant.com/))

In December 2012, Evan was a fourth-grader at Ben Franklin School in Meriden. His school year was marked by restraints, violent outbursts and tantrums.

A day after the shootings, Carol was doing homework for one of her occupational therapy classes. Facebook was on in the background. A story came up on her news feed. The Sandy Hook shooter, 20-year-old Adam Lanza, was said to have been diagnosed with Asperger's, an autism-spectrum disorder.

“Evan is on my mind. His behaviors. I'm staring at the picture of Adam Lanza, looking into his eyes. They were empty, and I remember, before one of Evan's hospitalizations, seeing that empty look in my son's eyes. Evan wasn't Evan. Something had taken over, I felt. And now he was biting and punching and scratching ...

“So it was the timing. I didn't discount that Evan wasn't capable of more extreme violence. You heard that Adam Lanza was socially awkward, that he spent a lot of time on his computer. Some of this described my son — I mean I was limiting his computer time but he was still obsessed with Minecraft — so I felt a particular connection to Sandy Hook.”

In the year after the shootings, the number of visits to emergency rooms and therapists increased markedly as parents sought evaluations of children on and off the spectrum who were struggling.

Acting Out

While working on a math assignment with Adelbrook behavioral associate Kellina Flanagan and one-to-one aide Quiana Wallace, Evan grew frustrated and angry to the point of disrupting the classroom. After being directed to the time-out room, he continued to act out in the hallway. He was escorted to the time-out room to cool down before being allowed to return to class.

(HTTP://WWW.COURANT.COM/PROJECTS/RAISING-CHILD-AUTISM/)



CAPTION —

Behavioral associate Kellina Flanagan, left, tries to calm Evan as he gets frustrated with an assignment in his fourth-grade classroom at Adelbrook. Quiana Wallace, Evan's one-to-one aide, looks on.

For Carol, the tragedy inspired her to become even more active in Evan's life. She arranged for more frequent planning and placement team meetings at Ben Franklin School, and by the early spring of 2013, with Carol and Evan's teachers and counselors having reached a consensus, Evan was transferred to Webb School in Cheshire, his first placement outside the Meriden school district.

Carol arranged for PPT meetings every six weeks during that fourth-grade year.

“We would sit at the table and literally say, ‘What are we going to do?’“

Carol worked with counselors to adjust Evan's medication. He was taking, at various times, Risperidone, Intuniv, Concerta, Seroquel 400 for moods and Depakote 750 to help mute his aggression.

During fourth and fifth grade, Evan often took the aggression home with him, and he periodically expressed thoughts of suicide, according to Carol. Despite the out-of-district placement in a specialized school, Evan struggled and Carol was forced to take him to the hospital on several occasions in response to his deteriorating behavior. (HTTP://WWW.COURANT.COM/)

On Dec. 23, 2013, toward the third of four psychiatric hospitalizations at Yale-New Haven Hospital, Evan came home for Christmas.

“We kept the Christmas tree bare until he came home,” Carol says. “We couldn't stand decorating it without him there. We have a nice video of him putting the lights on the tree. That was when he knew it was me buying the presents, so the Santa thing was done.”

Carol cries recalling that Christmas scene, something she rarely does. She talks in great detail about her struggles and Evan's journey but only certain episodes bring tears.

She cried when she recalled going to the psychiatric unit at Yale as Evan was being discharged. She brought a T-shirt and had all the other children in the unit sign it. She did it because it was what Evan's fifth-grade classmates did at school, and it tore Carol up inside that Evan couldn't be there with them.

And she cried when she talked about the times that she picked up Evan while he was still at The Children's Center of Hamden, and took him swimming at the physical therapy center in Wallingford. It was mom and son, back together, on Thursday afternoons for 30 minutes of swimming and then a Mexican dinner at Moe's Southwest Grill.

“Oh, did I milk the times at Moe's,” Carol said, her voice breaking. “I didn't want to give him back.”

CHAPTER 3

Mom vs. The System ([HTTP://WWW.COURANT.COM/](http://www.courant.com/))

Fighting for Services is an Ongoing Battle



Carol Marcantonio takes part in a planning and placement team meeting at Ädelbrook with then-director Amy Gates, center, and behavioral analyst Brian Heslin. Marcantonio chose Ädelbrook for Evan in part because it uses applied behavioral analysis therapy.

It was a serendipitous combination of brains, hard knocks, and life ambition that equipped Carol Marcantonio to raise Evan.

The daughter of Polish immigrants, Carol learned English by watching children's programs. She grew up in Hartford and Newington and graduated from Newington High School in 1997.

She worked as a waitress at Friendly's and Denny's to pay for courses at Central Connecticut State University. She loved cars and she wanted to become a shop teacher. (HTTP://WWW.COURANT.COM/)

What she described as an abusive relationship interrupted her education at Central.

She was healing, physically and emotionally, when she met her first husband. They were married in April 2003 and Evan was born three months later, in July 2003.

"The marriage never really began," Carol says now. "I still had some life lessons to learn."

By September 2003, Carol and her first husband were separated, and Carol began dating John Marcantonio, who had been a cook at Denny's.

In 2004, Carol and Evan moved into John's 45-year-old, ranch-style house at the end of a quiet street in Meriden. John, a kind, sensitive man with a heart as big as Carol's, also struggled with anxiety. He came to rely on Carol as a wellspring of support, and she drew strength from John. They married four years later, in September 2008.

Carol and John also took care of John's niece, Alyssa, and eventually the couple became her legal guardians. John's brother, Alyssa's father, also spends time at the house.

Along the way, Carol has learned to be proactive in dealing with any potential problems when it comes to managing Evan's education and treatment.

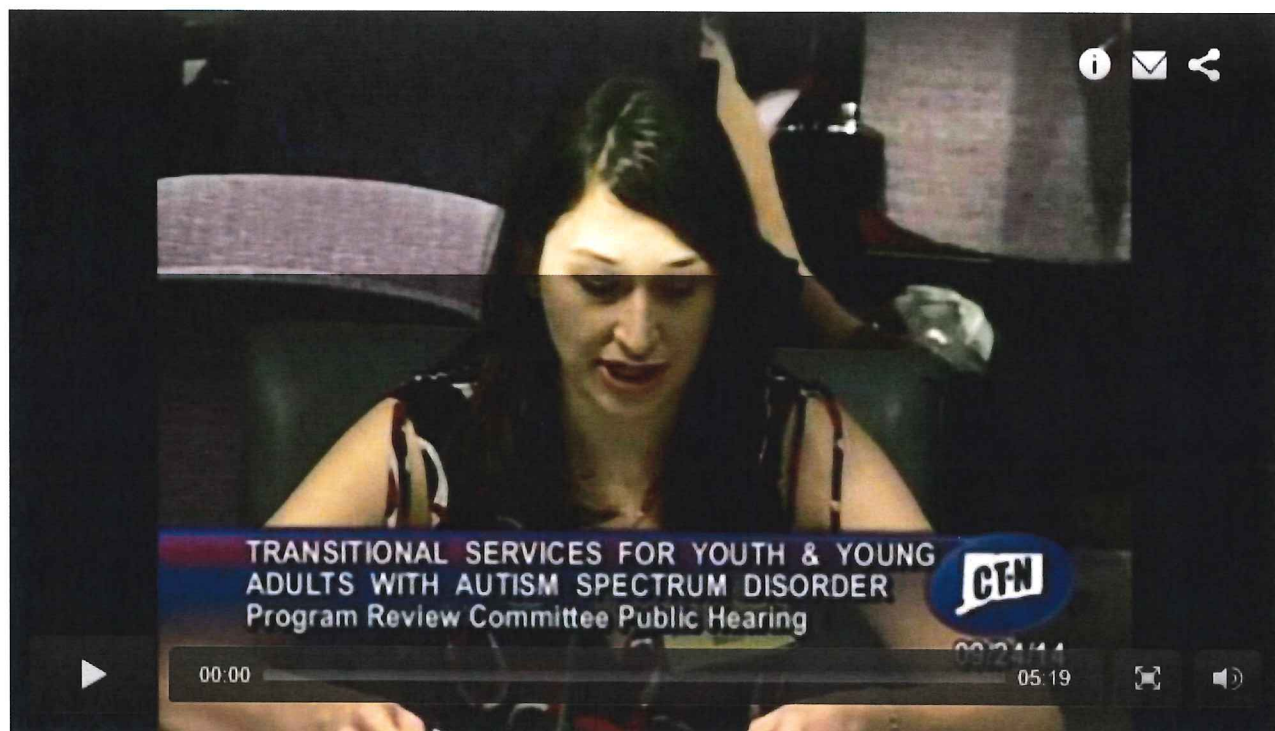
After Evan's discharge from Yale, early in the spring of 2014, Carol was consumed with improving his care at The Children's Center of Hamden. She wrote a four-page email to the center's administrators, outlining the role that each should play in improving Evan's stay at the center. She picked apart his overly generic treatment plan, and suggested to the social worker some areas to

focus on, such as life skills and daily hygiene. And she made formal complaints (HTTP://WWW.COURANT.COM/) to the state Department of Children and Families and the Office of the Child Advocate about instances where she believes Evan was bullied. She also swore that she would cobble together school and treatment programs for Evan and get him out of there weeks before his scheduled discharge date in late June.

But beyond her advocacy, Carol said she had a story to tell, one that would be helpful to other parents of autistic children making their way through Connecticut's treatment system.

A Plea For Help

Carol testifies at a public hearing of the General Assembly's program review committee, saying that her son needs more services to succeed in school and in life.



It quickly became clear that this petite woman, 35, who works as a certified occupational therapy assistant at a nursing home, had learned to hold her own with the alphabet soup of Ph.D.s and LCSWs at various planning and placement team meetings. She didn't tolerate excuses and blind adherence to convention. She was not prone to drama, throw away lines or big pronouncements.

“They tell you your child has autism, then they walk away. ^{([HTTP://WWW.COURANT.COM/](http://www.courant.com/))} It's up to you figure out what to do. Your child goes to the hospital with a medical condition and you have to beat off the doctors and nurses and clinicians with a stick. But for autism, there is no road map.

“I had to work hard to understand the system, and that has had an influence on my advocacy for Evan. When he was 7, at PPT meetings, I was concerned that unless he was being set up in the right way, he wouldn't be successful in the later transitional programs. They said, ‘He's only 7.’ But even then, I was set on doing the best I could do to position him to one day be independent.

“I know he can do it. The numbers say he can. If he had a low IQ and was non verbal, I'd be making sure he was comfortable and I wouldn't be pushing as hard.”

Extra Help

Evan receives various therapies at Ädelbrook, including speech and occupational therapy, but he also is treated by a behavioral optometrist in Woodbridge and a psychiatrist at the Hospital for Special Care's Autism Center in New Britain.





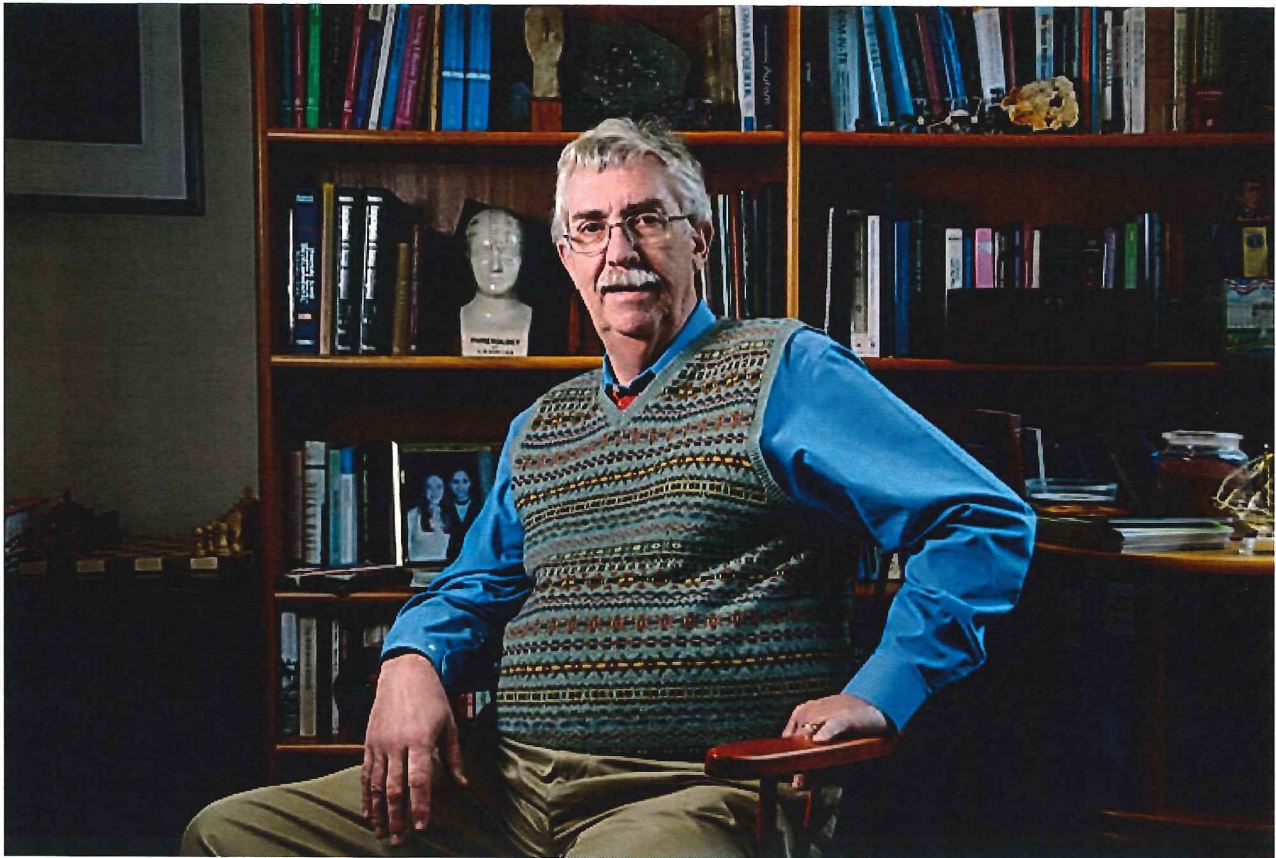
Carol and Evan are not among the relative few families lucky enough to have landed a spot in the autism program at the state Department of Developmental Services. Each slot provides up to \$60,000 worth of counseling, life-skills training, clinical treatment, job coaching and other services. But there are only 114 spots in the federally funded program, and more than 400 Connecticut families are on the waiting list. It will take years for some of the families to move up the list. Evan is somewhere on it, having qualified for the services.

Still other families simply struggle, waiting a year or more in many cases to get the initial diagnosis of autism spectrum disorder and then contending with public-school programs that vary wildly from town to town. It often breaks down to money — towns with more of it have better services for children with autism than towns with less.

Carol, for example, is supportive of her hometown of Meriden and its school system, but she said that as an urban district, “it limps along with the bare minimum.” As savvy as she had become in working the planning and placement

team meetings to her and Evan's advantage at times, her ^(HTTP://WWW.COURANT.COM/)pleadings for assistive technology, occupational therapy, certain behavioral approaches and special sensory equipment for children with autism were mostly futile.

Dr. Fred R. Volkmar, head of the Yale Child Study Center, said there is a tremendous disparity among school districts in the quality of autism services.



Dr. Fred R. Volkmar is head of the Yale Child Study Center. He specializes in autism and related disorders.

“I can tell you the good towns and I can tell you the bad towns,” said Volkmar, a professor of pediatrics who writes and lectures widely on autism. “The variation is amazing, but that’s Connecticut and its history of town rule. It’s part of the reason why services are fragmented.”

A statewide shortage of trained behaviorists who work inside and outside the school system contributes to the imbalance. There just aren’t enough of them to go around. Carol has requested an ABA (applied behavioral analysis) specialist in every grade and in every school that Evan has been in, but rarely encountered one until Adelbrook.

At the University of St. Joseph, Molteni said, the faculty is ^(<http://www.courant.com/>)trying to turn out new behaviorists as fast as it can.

“Our mission is to train more professionals to go out and do this work,” said Molteni.

As it stands now, he said, “there are many holes in the system. The major issues are access and capacity. Many thousands of children aren't being served.”

CHAPTER 4

A Loving Boy

A Child Who Loves to Run and Play



Carol carries Evan on her back after getting up off the floor from helping him clean up his Legos before

bedtime.

([HTTP://WWW.COURANT.COM/](http://www.courant.com/))

A lot of the time, Evan doesn't look like he needs any special help. The boy loves Hubbard Park in Meriden, a classic urban green space, with a pond, winding roads, a pool, tennis and basketball courts, and a big playground. Carol has brought Evan to the playscape ever since he was a baby.

On a beautiful morning recently, Evan leaps through the playground's gate. His sneakers hit the cedar with a crunch, and he's off and running toward the climbing rock.

“Stay in sight, Evan!” Carol's voice trails behind him. Evan scales the glacial boulder in three hops and perches at the top like a frog, then scampers down, comes out from behind the rock and approaches a curly-haired toddler.

He leans down and reaches out his hand to the boy, who is crouching. The child reaches up, and touches the tips of Evan's outstretched fingers.

The other child's mother is a few yards away, striding back and forth while talking on her cellphone. She glances up, and stops, watching the interaction between the brown-haired boy and her little son.

Carol watches, too. She gives Evan space, but is wary. That is her general posture when she is out in public with Evan, shopping, taking him to appointments.

Sometimes he'll bolt, and if he's in or near a parking lot, that's a problem.

Tough Times

Following his release from Yale-New Haven in early 2014, Evan was placed at The Children's Center in Hamden for a four-month stay. It was a place where he could practice the skills that he had learned during his latest hospitalization before going back to home and school. But Carol realized early on that it was the wrong place for Evan, and she worked to find a place that was better-suited to him.



[\(HTTP://WWW.COURANT.COM/\)](http://www.courant.com/)

“When you have a child on the spectrum, you're that much more watchful for them,” Carol said. “When he was small, and another child brushed him the wrong way, he turned his head and bit. ... I would be mortified. He's gotten past that now.”

On occasion, some planning is necessary before Evan goes out.

When Alyssa's fifth-grade graduation came up, Carol called ahead to get an aisle seat for Evan. And the principal was nice enough to offer the use of the media room in case Evan needed a quiet place to go.

“It turned out fine. We packed his favorite toys and charged up the iPhone,” Carol said.

At the park, Evan bends and picks up the young child, and holds him to his chest. The little boy's mom starts to walk over and Evan gently puts the boy down. As the mom leads the little child away, Evan skips toward Carol.

“He loves children. He can be really gentle,” Carol said. “But he has to be reminded about personal space.”

Evan can be a loving boy — so much so that it is hard to picture him in some of the situations he's been in.



Evan gives his friend Toby Carino a hug while Toby works on an assignment on the periodic table of elements in a science class at Ädelbrook. Evan had finished his work sheet and was trying to encourage Toby, one of the kids at Ädelbrook that he has made friends with. Rebecca Cutter, a teacher's aide, works with Toby.

CHAPTER 5

Fixated On The Future

Carol's Determination to Make Evan Independent





At his mother Carol's prompting, Evan uses a fork to eat salad at dinner at home in Meriden. Some of Evan's motor skills are still developing, as evidenced by the way he holds his fork.

Carol and John's home is dotted with paper signs, reminders for Evan to follow certain rules about table manners, hygiene and behavior.

“Everything with Evan has to be manually taught, and he has to have an internal motivation to learn. Use your utensils, that's a big one. My son fists his fork. I may have to accept that he'll always fist his fork. There's other things: sit nicely, answer when you name is called, say ‘thank you’ and ‘please,’ ask to be excused, flush the toilet, turn off the light. ... We are constantly reminding and prompting.

“If he didn't wash his hands, and if I said, ‘Go back and wash your hands,’ he would stomp, and we'd be off on a downward spiral. But if I say, ‘Did you follow all of your bathroom rules?’ he'll stop, think, and go back and wash hands.

“Everything I do, everything I say, has a direct effect on Evan. ^{([HTTP://WWW.COURANT.COM/](http://www.courant.com/))} That's true for every other parent, but more so for Evan. He sees the world through a magnifying glass, and every day, you have to be willing to compromise.”

And then there is the token board.

“Evan starts out each day with six tokens Velcroed to the board. Each is worth 20 minutes. He can earn up to an hour of TV and hour of video every day.

“If he doesn't listen, or is disruptive, a token comes off the board and he loses time. We've found that it is a high motivator for him.”

Carol never relaxes her grasp on a certain vision: Evan in the future.

“When he's a grown-up and working, there is going to be no one to tell him how to do his job all day. That's why I'm always thinking in terms of life skills, of how he'll go further in school, in a job, how he'll function in an emergency. I mean, if he doesn't respond to his name because he's engrossed in a video, that's potentially serious. You don't want to think in those terms, but it's kind of how my mind works with Evan. That's why I've always advocated for more occupational therapy in school.”

Carol's principle concern is this: Will Evan, in his post-high school years, as a young man in his late teens or early 20s, be able to have any kind of an independent life? Will he get a job, have a family, or will Carol still be calling the shots?

“Every parent wants their child to be successful, so for me, planning for my son's future is no different than other parents,” Carol said. “It's just that my son's future is so much more complicated than a neurotypical child. I feel I have to be that much more keen on it because I don't know if he'll be college-bound or even able to live an independent life. If he can't follow my directions, how will he follow directions at work? I cater my directions so closely to him, what he responds to, and I'm still repeating myself 10 times.”

The transition to adulthood for young people with autism ^{([HTTP://WWW.GOURANT.COM/](http://www.courant.com/))} remains the most daunting cliff and the biggest gap along Connecticut's landscape of services, advocates say.

But it's not the only part of the system that needs attention.

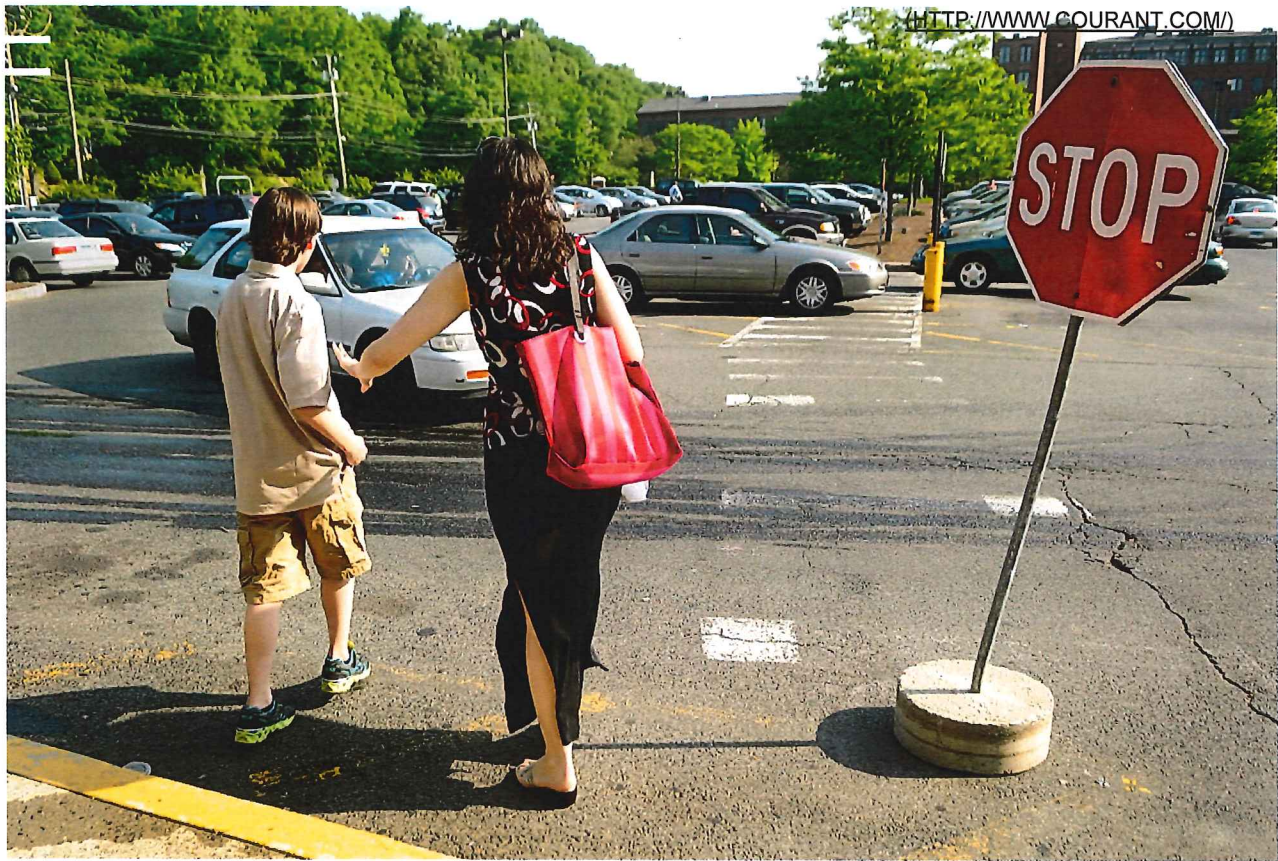
Molteni, Volkmar of Yale and Child Advocate Sarah Eagan all say there must be a more consistent, more specialized array of services available in schools, as well as a bridge between what happens in schools, in the community, and inside the family household.

“What we are really talking about here,” said Molteni, “is a unified, statewide system, where you can set standards for care, as much as possible, and the level of service in the northeast section of the state is the same as it is in Fairfield County.”

Volkmar said that would require more sharing of resources among state agencies and better coordination between the state and the private sector, as well as a greater emphasis on “early and intensive intervention.”

A state task force of advocates, health professionals and parents is working to develop a central listing of quality programs and qualified service providers in Connecticut, as well as identifying gaps in the system and trying to close them.

Molteni, who sits on the task force, said that, at the moment, there is no single entry point into the autism service system, and parents find that to be a source of tremendous frustration.



Carol keeps Evan from running into the parking lot at Stop & Shop in Meriden, where they had stopped to buy ice cream after Evan got home from school. Evan often bolts ahead of Carol, making it hard for her to keep him safe.

CHAPTER 6

Well Versed In Evan

A Turning Point for Mother and Son





Evan gets instruction from his new fifth-grade teacher, Ann Johnson, at The Learning Center at Ädelbrook during his first week at the school. Several staff members, including occupational therapist Tania Pesce, right, keep an eye on students in the classroom.

After years of struggle, Carol lobbied successfully to have the Meriden school district pay for Evan's placement at Adelbrook — the school in Cromwell with specialized services and staff members trained in responding to crisis.

On this morning back at Adelbrook, Evan's time-out is being handled in the flow of the school day. In public school, it surely would have gone down as a restraint, an incident report, a call to Carol and perhaps a meeting.

Four staff members position themselves around Evan. He scoots further back in the time-out room, and screams for Ellen, his “one-on-one” aide during the regular school year. But this is the summer session, three weeks in, and the staff is trying to wean him off Ellen for now, help him learn to adjust to other people, and help him to figure a way out of these fixes on his own. (HTTP://WWW.COURANT.COM/)

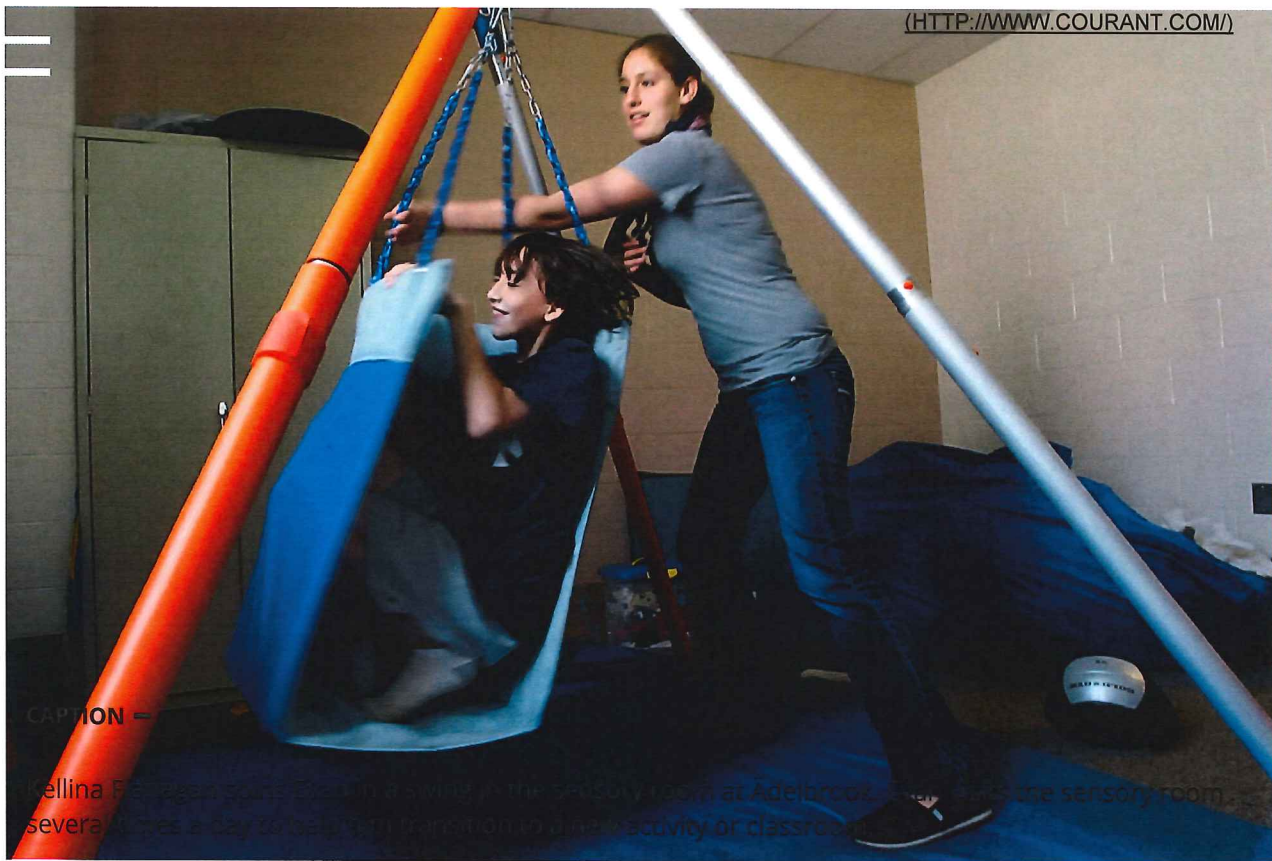
He's in time-out this morning because he didn't want to do his reading-comprehension exercise in the classroom. Instead he scooped up an iPad that had inadvertently been left within his reach and started playing it, thumbs dancing, in his absorbed way, drawing the screen close and tilting it fore and aft, as if he's driving a space ship. He had to be “redirected” and lost control, as often happens with Evan first thing in the morning at Adelbrook.

Another scream gives way to a choked but reasonable proposition: “I won't yell if you don't close the doooooorrrrr.” The door stays open. Quid pro quo.

Relieving Tension

Adelbrook provides a sensory room for students to use while transitioning between classes and activities. The room helps students relieve tension and anxiety with various sensory tools such as swings, body socks, fitness balls and other objects. Evan typically visits the sensory room for five to ten minutes between classes to help with his transition.





Then Kellina Flanagan comes over from somewhere else in the low-slung, pleasant building that hums with sounds of bouncing basketballs from the gym and zigzagging aides escorting children of various abilities.

“Evan, it's one minute of being calm. Then we come out,” said Flanagan, a behavioral associate at the school who works closely with Evan.

He scoots into the hallway, just outside the room.

Reason is creeping further back into his sentences.

“I know. I already did it. I'm done ...”

When a minute of calm actually passes, Flanagan helps him up. She extends both hands, grasps his, and pulls him up — but he digs his nails into her wrists.

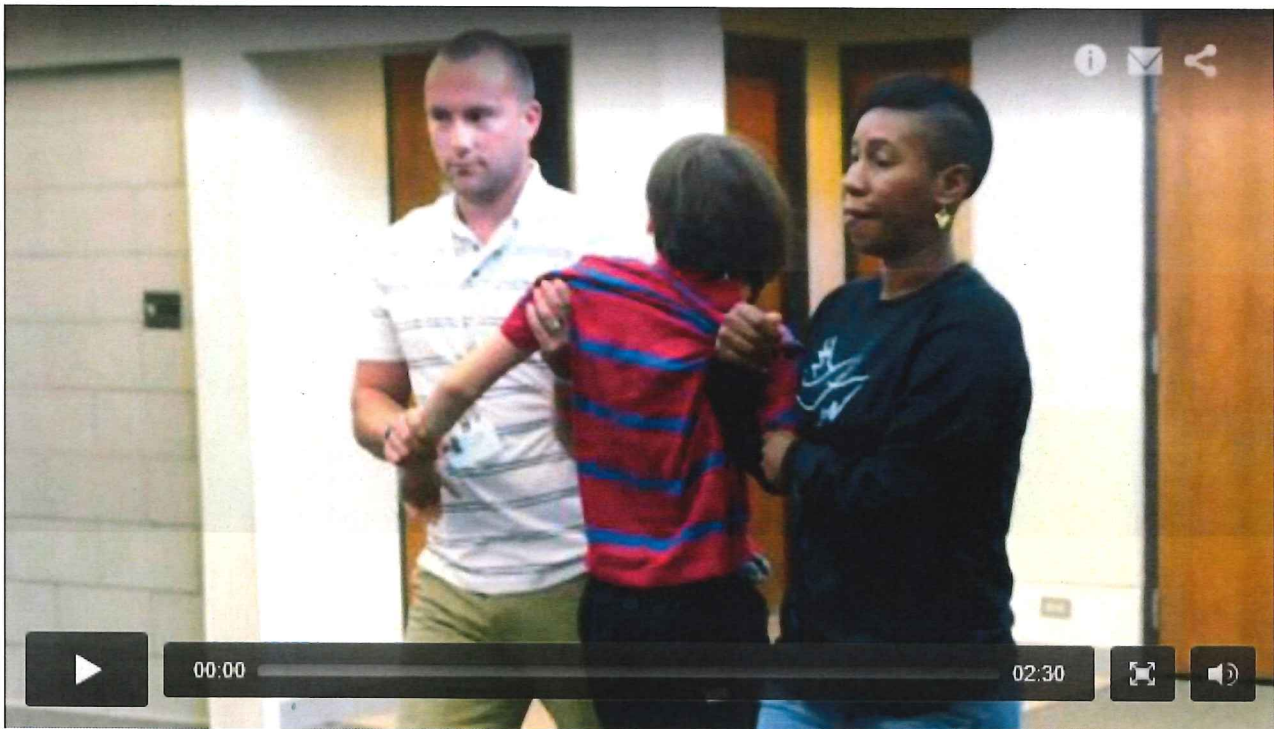
“Ow. Ow. You are hurting me. See what you did?”

“Sorry, I'm pissed,” Evan says.

Sulking, Evan goes back into the classroom. But he sits at a table, hunkers down over his reading-comprehension exercise, and completes it so quickly that Flanagan has to scan it to make sure he did the questions. He did. (HTTP://WWW.COURANT.COM/)

A Good Fit

While Evan was at The Children's Center, Carol's mission was to find an appropriate and effective school for him. She learned about Adelbrook, a private school that specializes in ABA (Applied Behavioral Analysis) therapy, and persuaded the Meriden school system to place him there.



“He is so smart,” Flanagan said later.

He turns to Flanagan and makes “an appropriate request” — he calmly, politely asks if he can go to the computer room, where he is allowed to watch simulations of the Minecraft video game under a strictly enforced time limit.

The answer is yes, and he's off at a run, showing the speed he displayed when Carol had him in travel soccer a couple of years back, though it turned out he got teased big time when the other kids on the team realized he was different. In the cool, quiet, high-ceilinged computer room, he instantly dons headphones, leans

into a monitor, and is lost in the images of Minecraft, his ^(HTTP://WWW.COURANT.COM/) mouth open. Flanagan sets a timer for 10 minutes and puts it down next to him, so he can see the time ticking away.

And she explains that this progression is “typical Evan in the morning.”

The afternoon before, in the inflatable water slide, Evan was one of the stars, sliding like a skinny white seal, going down in pairs, and then attempting three across before a staff member reinforces the one-at-a-time rule.

On that afternoon, he wanted to be in the computer room after lunch, but Flanagan blocked him physically from going in the door, and walked him to the bathroom so he could change into his bathing suit. Then out to the water slide.

“See how social he's being, and his laughter?” Flanagan said, gazing at Evan on the slide. “I want to make sure everyone is well versed in Evan, so they know what a character he is. He's not just the kid on the floor of the hallway. He is so much fun; like now, just a goofball.”

CHAPTER 7

The Journey Continues

Finding Validation Through A New Medical Plan





Evan rides his bicycle on the dead-end street in Meriden where he lives with his mother, stepfather and cousin.

Evan began his first full year at Adelbrook this fall. He is comfortable there, Carol said, and his behavior at home is improving. Carol, of course, is keeping close tabs on him. She calls the social workers to make sure he is safe, supervised, and doing enough school work to keep him engaged and moving forward.

Carol has found a private behavioral-health service that accepts Husky insurance. This means a therapist trained in applied behavioral analysis visits the home to supplement the work that the Adelbrook staff is doing with Evan.

Last month, doctors at the Hospital of Special Care in New Britain ran a battery of psychological and neurological tests on Evan. He scored average and above in the intelligence categories. Among the doctors' recommendations: a heavy focus

on his daily-living, hygiene and coping skills to build his independence, and as much swimming and other therapeutic activities outside of school as he can handle. (HTTP://WWW.COURANT.COM/)

Carol couldn't have said it better herself.

“I feel so validated today,” she said on Dec. 11, after the six hours of testing. “I was told that everything I wanted in a program is exactly what Evan needs. The doctors are going to stress the need for an [occupational therapy] evaluation for daily living skills and make more suggestions for programming that would help Evan. He needs a one-on-one, so his options for the outside activities are somewhat limited.

Forward Thinking

Carol's biggest fear is that Evan won't be able to live independently when he grows up, but she remains optimistic when she hears him talk about his future.



“We all also agreed that his behavior is the most important concern and everyone needs to be on the same page; something that is extremely hard to do ...”

She has arranged with Washington School in Meriden, ^{([HTTP://WWW.COURANT.COM/](http://www.courant.com/))} where Alyssa goes, to allow Evan to go there so he can participate in social functions with his cousin.

“When I went to Alyssa's orientation, I went to see the special-ed teacher and asked for permission for Evan to go to dances and social events, so he would be with regular kids, too. You know, I haven't given up hope that he goes to a regular high school.”

Carol said she has reached stable ground.

“The challenges are more manageable now,” she said. “The stress is definitely much less than what it was, and I feel more secure, I feel I have the supports that I need from Adelbrook — they want to know Evan's home life. No one before had connected the school and home life.

“It's getting there. It's always a work in progress.”



Evan and Carol sit on the trunk of the car while waiting for Evan's school bus on a spring morning.

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Saving Evan

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