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The New England Center for Children

Leading the Way in Autism Education, Research, and Technology Development

JANET MENDELSOHN writer



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is an infectiously happy 18-year-old who loves music and 1,000-piece puzzles. At age two, he was diagnosed with autism, a disorder that research indicates is probably caused by genetic abnormalities in brain development. Every autistic child is different, but Jacob's disabilities mean he will never be able to live independently. His parents, Bella Wong and Steve Brand of Weston, hoped and assumed he would stay with them until, as an adult, he moves into a group home. Until the situation changed.

"By the time Jacob turned 14, he became sensorially interested in breaking glass," said Brand. "He was fascinated by the way it shatters. We removed every picture frame, all the glassware; then it moved to windows. When he needed stitches, it wasn't so much about property damage as it was fear that he'd hurt himself."



Since fifth grade, Jacob had been a day student at a school for children with Autism Spectrum Disorders (ASD). He sometimes worked with a therapist at home, as well. But when he began shattering glass at night and on weekends, it was more than his parents could handle. On the advice of his medical team, Jacob's parents searched for a residential program that could give him the education, services, and attention he needs around-the-clock.

"It was devastating. We couldn't keep him safe," said his mother. "We were tremendously disappointed but there really wasn't any other choice."

At The New England Center for Children (NECC) in Southborough, Jacob has now been a residential student for four years. He lives in one of 16 supervised

group homes in neighboring communities. NECC applies the principles of Applied Behavior Analysis (ABA). Teachers and staff identified his repetitive disruptive behaviors, figured out what was behind them, established protocols to change his reaction to triggers, and helped him master more appropriate conduct.



Before NECC, he frequently grabbed his brother's food and threw it away to get his attention. Now he is learning teamwork and socialization in different settings. Learning to read is going smoother. He enjoys activities with his roommates; previously he only had his twin brother, who is a college freshman this year, said his parents.

"Jacob needs those protocols reinforced 24/7 and we weren't able to do that," said Wong. "We didn't realize how exhausted we were until he became a resident student."

NECC is internationally known as a leader in autism education, research, and technology development. Since 1975, when it was founded by President and CEO Vincent Strully, Jr., its teachers, clinicians, and researchers have played pivotal roles in the lives of more than 13,000 children, ages 18 months to 22 years, and their families worldwide. Services provided include home-based therapy, day and residential programs, more than 60 public school partnerships and 35 collaborative classrooms in the U.S., consulting services in 15 countries, and support services for family members.

A new venture for NECC came about at the direction of the Crown Prince of Abu Dhabi with the opening of what is now known as the Mohammed bin Rashid Center for Special Education in 2007. What started with a referral from Boston Children's Hospital for a private program for a child from the United Arab Emirates (UAE), is now the first of its kind in the Persian Gulf region. MRC-NECC currently serves more than 200 children, with plans to triple that number over the next decade.

In New Delhi, working with the Autism Center for Excellence, NECC created the first center in India for treating children with ASD.

Cathy Welch, executive director for NECC in Southborough, compares NECC to a teaching hospital. "We are unique because of the research conducted on-site with our students and because of our graduate degree programs in partnership with Simmons and Western New England universities."

More than 1,500 professionals have received master's degrees in special education or behavior analysis at NECC since 1992. Hundreds of other educators have completed online ABA or Registered Behavioral Technician training through the institute's ABAplus® curriculum.

education "he's proud to show us his progress"

Its ACE® ABA Software System is a cloud-based assessment and teaching tool used on both campuses and in hundreds of schools in 28 states and 13 countries including Argentina, Canada, Iceland, and Ghana, currently serving 6,400 students. Based on the principles of

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ABA, ACE (Autism Curriculum Encyclopedia) software gives educators tools they can easily access over the Internet to assess a child's skills, create lesson plans, find teaching materials, and create up-to-the-minute student performance reports.

The Centers for Disease Control and Prevention (CDC) estimates that one in 59 children has been diagnosed with Autism Spectrum Disorder. It occurs in all racial, ethnic, and socioeconomic groups and is four times more common among boys than girls.

Jacob's parents, Wong and Brand, said NECC is a holistic place. They are grateful for parent support groups and guidance, especially given their son will age out of state-funded services at 22.

Wellesley resident Elizabeth May has two children diagnosed with autism. Her son, Charlie, 15, is a resident student. Charlie was diagnosed at age three.

"In public school, he was the weird kid, the outcast," said May. "He spent a year at the Collaborative Learning Center, which offered more support but, when he was 12, we found NECC and things fell into place. Charlie went from being marginalized to normalized. He was elected class president. Field trips are all designed for kids like Charlie, instead of him needing an aide."

"Kids on the spectrum are trying to fit in just like the rest of us," said May. "They struggle to understand social norms. What works for one child on the spectrum doesn't necessarily work for another. Charlie needs one-to-one care. He comes home on weekends. It's still challenging but he was able to come off six medications and is doing much better without them. We're able to do more as a family, even go out to dinner or movies. He has good friendships at NECC, a new experience for him. He couldn't learn to read when other kids did because of his emotional outbursts. Now he's proud to show us his progress."

NECC moved to its Southborough location on Route 9 in the 1980s. Facilities built in the past 20 years include the Michael F. Downey Center for Childhood Development, providing day care for staff members' children; the John and Diane Kim Autism Institute, which houses administration and research; and the Dillon Arledge Student Center, with





"a positive experience"

students may serve others, one of many skills taught in a vocational training program that includes such job placements as Sun Life in Wellesley, Walgreens, TJ Maxx, farms, and animal shelters.

Music and art classrooms, a gym, and several playgrounds are spacious and wellorganized, with all materials stored inside cabinets. Health Services includes sensitivity training to help students overcome

their fear of dentists or doctors. Everywhere you go, people greet students and co-workers by name. No piles of backpacks or equipment clutter the wide hallways or classrooms where they could become projectiles or cause someone to fall.

"When Mike Dukakis was a State Representative," said Welch, "he

classrooms dedicated to music, art, career development, a library, and leisure. The Michael S. Dukakis Aquatic Center, opened in 2008, is named for the former Massachusetts governor who serves on the NECC Board.

In the school building, during mealtime in the sunny cafeteria, some students are taught to feed themselves while behind the counter. Older

Information for Families and Friends about Autism Spectrum Disorder

■ THE NEW ENGLAND CENTER FOR CHILDREN

33 Turnpike Road, Southborough, MA

508.481.1015

www.necc.org

■ FREQUENTLY ASKED QUESTIONS ABOUT AUTISM FROM NECC

www.necc.org/wp-content/uploads/2015/08/AutismFAQ.pdf

■ ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

www.asatonline.org

Science-based information, research, and recommendations online, on Facebook and Twitter, and in a quarterly newsletter.

■ ABA INSIDE TRACK

www.abainsidetrack.com

Podcast, website, and Facebook page run by three former NECC employees about Applied Behavior Analysis (ABA) and recent research.

■ BEHAVIOR ANALYST CERTIFICATION BOARD (BACB) video summarizing the history of Behavior Analysis, an explanation of ABA, and areas where it has been applied.

http://youtu.be/HnyYwWlenJg

■ AUTISM SPEAKS

www.autismspeaks.org

Widely known source for information on autism, causes, accessing services, FAQs; includes some treatment approaches that have not been scientifically evaluated.

SOURCE: NECC

was appalled when he saw the medieval conditions for children and adults with developmental disabilities at the state's Fernald School. He promised if elected governor, he would make things better and he has ever since. Because of him, 40 years ago we received a Department of Mental Health \$30,000 grant that enabled this school to open."

Tuition, therapy, and room and board for most NECC students is paid by a combination of their local school district, their home state's department of education, social service agencies, and private individuals. NECC has no endowment or scholarships.

"We've had such a positive experience with NECC," said Wong. "It's about Jacob's education but also the staff understands what it's like to raise a child like this. We focus on what he can do, not on what he can't. Having a child on the spectrum is isolating. We want people to know we just want to be included."