

## Residential Schools

Amego Inc.

115 Plymouth Street

Mansfield, MA 02048

Phone: 508-261-1000

Fax: 508-261-1042

Website: [www.amegoinc.org](http://www.amegoinc.org)

Cardinal Cushing Centers, Inc.

Cardinal Cushing School

405 Washington Street

Hanover, MA 02339

Phone: 781-826-6371

Email: [info@coletta.org](mailto:info@coletta.org)

Website: [www.coletta.org](http://www.coletta.org)

Developmental Disabilities Institute

99 Hollywood Drive

Smithtown, NY 11787

Phone: 631-366-2900

Email: [info@ddiinfo.org](mailto:info@ddiinfo.org)

Website: [www.ddiinfo.org](http://www.ddiinfo.org)

Eden II Programs

150 Granite Avenue

Staten Island, NY 10303

Phone: 718-816-1422

Fax: 718-816-1428

Website: [www.eden2.org](http://www.eden2.org)

The Evergreen Center  
345 Fortune Boulevard  
Milford, MA 01757  
Phone: 508-478-2631  
Fax: 508-634-3251  
Email: [services@evergreenctr.org](mailto:services@evergreenctr.org)  
Website: [www.evergreenctr.org](http://www.evergreenctr.org)

Heartspring  
8700 East 29<sup>th</sup> Street North  
Wichita, KS 67226  
Phone: 316-634-8700  
Phone: 800-835-1043  
Fax: 316-634-0555  
Website: [www.heartspring.org](http://www.heartspring.org)

Hillcrest Educational Centers, Inc.  
788 South Street  
Pittsfield, MA 01201  
Phone: 413-499-7924  
Fax: 413-445-2693  
Email: [admissions@hillcresteducationalcenters.org](mailto:admissions@hillcresteducationalcenters.org)  
Website: [www.hec.lsw.com](http://www.hec.lsw.com)

Kennedy Krieger Institute  
707 North Broadway  
Baltimore, MD 21205  
Phone: 800-873-3377  
Phone: 443-923-9200  
Email: [info@kennedykrieger.org](mailto:info@kennedykrieger.org)  
Website: [www.kennedykrieger.org](http://www.kennedykrieger.org)

The Kolburne School, Inc.  
343 NM Southfield Road  
New Marlborough, MA 01230-2035  
Phone: 413-229-8787  
Fax: Fax 413-229-3677  
Email: [kgreco@kolburne.net](mailto:kgreco@kolburne.net)  
Website: [www.kolburne.net](http://www.kolburne.net)

League School of Greater Boston  
300 Boston Providence Turnpike,  
Walpole, MA 02032  
Phone: 508-850-3900  
Fax: 508-660-2442  
Email: [info@leagueschool.com](mailto:info@leagueschool.com)  
Website: [www.leagueschool.com](http://www.leagueschool.com)

May Institute Corporate Headquarters (locations in many states)  
41 Pacella Park Drive  
Randolph, MA 02368  
Phone: 781-440-0400  
Phone: 800-778-7601  
Email: [info@mayinstitute.org](mailto:info@mayinstitute.org)  
Website: [www.mayinstitute.org](http://www.mayinstitute.org)

Melmark  
2600 Wayland Road  
Berwyn, PA 19312  
Phone: 888-MELMARK  
Phone: 610-325-4969  
Email: [admissions@melmark.org](mailto:admissions@melmark.org)  
Website: [www.melmark.org](http://www.melmark.org)

Melmark New England  
461 River Road  
Andover, MA 01810  
Phone: 978-654-4300  
Fax: 978-654-4315  
Website: [www.melmarkne.org](http://www.melmarkne.org)

The New England Center for Children (NECC)  
33 Turnpike Road  
Southborough, MA 01772-2108  
Phone: 508-481-1015  
Fax: 508-485-3421  
Website: [www.necc.org](http://www.necc.org)

Perkins  
971 Main Street  
Lancaster, MA 01523-2569  
Phone: 978-365-7376  
Fax: 978-368-8861  
Email: [admissions@perkinschool.org](mailto:admissions@perkinschool.org)  
Website: [www.perkinschool.org](http://www.perkinschool.org)

Princeton Child Development Institute  
300 Cold Soil Road  
Princeton, NJ 08540  
Phone: 609-924-6280  
Fax: 609-924-4119  
Email: [info@pcdi.org](mailto:info@pcdi.org)  
Website: [www.pcdi.org](http://www.pcdi.org)

# Generation Fragile X

## Family Lives With Genetic Disorder Affecting Two Children

By CAROLYN MOREAU  
Courant Staff Writer

March 13 2004

WEST HARTFORD -- Brian Selinger's teachers and parents worked for weeks to prepare the 10-year-old for his first trip to the movies.

The boy practiced sitting with his class in a room that was gradually darkened. A teacher read "The Cat in the Hat" so they would recognize the words and images in the movie. Administrators at the school informed the theater that a class of children with special needs would be attending a matinee.

But when the film started, Brian stood up, stuck his fingers in his ears and moaned. Although his parents and teachers are sure he would have enjoyed the movie, the boy didn't get the chance. An usher insisted that he leave.

For Andy and Tammy Selinger, the trip to the movie would have added a basic childhood experience to their son's narrow world. Instead, it was another reminder that Brian, who is mentally retarded and autistic because of a genetic disorder called fragile X, is viewed by much of society as a burden.

Partly because of those views, and partly because neither Brian's parents nor the West Hartford school system can provide him the kind of care he needs, the Selingers are sending Brian to a residential school in Massachusetts.

It was not an easy decision for the Selingers. In addition to the guilt that accompanies the decision to send a child away, there's the price tag - \$233,000 a year, to be paid by the town and the state.

There are children such as Brian in virtually every school district - children with needs so great that the public schools are unable to provide an appropriate education.

Connecticut spends more than \$200 million a year to send such special needs children to out-of-state residential schools. But behind the shocking price tags are usually stories of suffering families.

Brian's condition was fated almost from the moment of conception. A slightly mutated gene carried unknowingly by his mother became a full-blown mutation in the developing embryo. Nine months later, when Brian was born, the mutated gene could not produce a protein crucial to connecting his brain cells. He seemed like a typical newborn to his doctors and parents, but his ability to learn and memorize was greatly diminished.

A family wouldn't normally find out about such a disorder until a child showed developmental delays, perhaps around 18 months or older. But when their 3-year-old daughter Jodi was diagnosed with fragile X - when Brian was 8 months old - the parents insisted on DNA testing for the entire family.

"We had to figure out where this came from and where it was going," Andy said. "Being genetic, there were other people at risk."

A doctor read a strand of Brian's DNA, and based on the size of the gene mutation, made a grim prognosis, which the family captured on a cassette recorder.

"It does not mean we can predict his IQ and it does not mean he is going to be autistic," the doctor tells

Andy and Tammy, who can be heard sobbing in the background. "But he has a significant chance of mental retardation. It is a very big chance."

Brian's symptoms became obvious around age 4, when he became obsessed with doors. He would open and close each one compulsively, fighting whoever tried to pull him away. When he was anxious, he vomited, which made it difficult for teachers in West Hartford's preschool special needs program to help.

"There were problems moving him around and through the building because of the doors," Andy said. "Everyone that worked with Brian said, 'You do not know how many doors there are in this world.'"

Andy and Tammy pulled most of their doors off the hinges. Doors they couldn't remove - like the one in their bedroom - they locked and hid the key. They paid \$8,000 for locked windows, signing a waiver for the contractor who warned them they couldn't escape in a fire.

The worst period began when Brian turned 8 and became too strong for his mother to restrain.

"He would do things like fill up the stairwell with every item in the house that he could find," Andy said. "He would literally fill the stairwell full of things just because he was displeased at staying home."

To give Tammy a break - she couldn't leave Brian alone even to use the bathroom - Andy drove the boy around in the car, sometimes for 10 hours a day. It kept Brian restrained, but the peace never lasted.

"He was doing things like urinating intentionally to get out of the car so he could go get at doors," Andy said. "I got to the point where I had had enough. I said to Tammy that I just can't deal with this getting bitten all the time, getting so depressed about riding around all the time, living in the car."

After picking Brian up at school one day, Tammy drove around the neighborhood for several hours because Andy wasn't home and she couldn't wrestle Brian from the car to the house by herself.

Tammy would get only a few hours sleep at night because Brian often woke up and wandered. She coped by focusing on the things she could control, like making sure her son always had clean clothes. But that meant at least three loads of laundry every night, because Brian soiled his pants and vomited several times a day.

In a Vernon doughnut shop one day, an employee saw Andy wrestling Brian through the front door to change his diaper in the bathroom. The employee called police, fearing the boy was being abused. The authorities didn't act after they saw the bite marks on Andy's forearms and understood the boy had to be restrained.

But it was clear to Andy that the family couldn't go on much longer. Feeling suicidal, he called the state Department of Children and Families and told officials he was scared that he would hurt the boy if the family didn't get help. He'd recently been laid off after taking a medical leave for depression. "I was concerned for my own mental health and if I was going to be able to weather the storm," he said.

They then began the long process of finding a residential school for Brian through the DCF's voluntary services program, which allows families of troubled children to seek expert help without giving up custody. The program was not designed for families of special needs children, nor was it intended for children to remain in residential care for years. But for families with the most extreme children, who cannot persuade their school districts to provide residential placement - sometimes costing more than \$100,000 annually - it is the only way.

Connecticut does not have a wide range of services for mentally retarded children with extreme behavioral problems, said Karen Andersson, mental health director for the DCF.

The state closed most of its training schools for the mentally retarded in favor of group homes, public school special education programs and community-based services.

"In the area of mental retardation, there has been a real push to keep kids home. Schools have done an admirable job crafting special education programs," Andersson said. "The flip side is there are not enough resources. We have dug in our heels to avoid residential care whenever possible, but obviously, with 1,500 kids in residential care, there is still a need."

### **Common And Costly**

The real mystery of fragile X is not the cause - the mutated gene was discovered in 1991 - but rather why the public is unaware of the nation's biggest inherited cause of mental retardation. Studies suggest that fragile X syndrome could affect one in 2,500 males of all races and ethnic groups, according to the national Centers for Disease Control and Prevention. No study has determined the prevalence of the full mutation among females in the general population, but the CDC estimates the number of Caucasian women such as Tammy Selinger, who are symptomless carriers of the gene, may be as high as one in 250.

Mary Jane Clark, a popular mystery novelist and television producer at CBS news, said she thought fragile X would become part of the public consciousness 13 years ago when "48 Hours" devoted a program to the disorder.

"But it did not," said Clark, whose 15-year-old son David has fragile X. "It's more common than muscular dystrophy and cystic fibrosis and everyone has heard of those."

To raise the profile of the disorder, Clark dedicated some of her thrillers to people with fragile X and cast a character with the disorder in her first book, "Do You Want to Know A Secret?"

Despite that lack of awareness, however, it is the public's money that pays for the special education required for many children with fragile X. About one in 400 males receiving special education services nationwide are affected by the fragile X syndrome, the CDC reports.

Brian's stay at the New England Center for Children, a year-round residential facility in Southborough, Mass., will cost Connecticut taxpayers about \$233,000 a year. If he remains at the school until he is 21, as is expected, the care for this one child would cost taxpayers more than \$2.5 million.

"This is a costly initiative. There is no getting around it," said Andersson.

Because DCF ordered Brian's transfer, the agency will pay \$128,000 a year for his board and care. The West Hartford school district agreed to pay \$105,000 a year for his education, although all but \$11,000 of that will be reimbursed by the state Department of Education under a complex formula, said Glenn McGrath, the district's director of pupil services.

"Kids like this have extreme needs," said John D'Amico, whose 17-year-old, mentally retarded daughter is also at New England Center for Children, at the expense of the Hebron school district. She was placed after chronic vomiting and compulsive fecal smearing landed her at age 5 in a psychiatric ward at Yale-New Haven Children's Hospital, he said.

"In order to provide them with educational opportunities, you have to have infrastructure in place. In Connecticut, that infrastructure is not available for our extreme kids," said D'Amico.

### **Leaving Home**

When a vacancy finally opened this year in the intensive unit at New England Center for Children, it was tempting for the family to say they would try to manage Brian at home.

His behavior had improved. At 10, he'd said his first words and switched his obsession from opening doors to snatching the glasses off his parents' faces.

"There is a sense of 'Gee, why can't I do this? I am a parent. I should be able to take care of my own children,'" Andy said.

But as Brian grows older, stronger, and more difficult to restrain, so does the danger that he could be admitted to a psychiatric ward instead of a residential school.

The parents also realize that while they've been absorbed with Brian, they haven't been able to give Jodi, now an autistic 13-year-old who chatters incessantly, the attention and structure she needs. Unlike Brian, Jodi was never violent. Nothing about her is urgent, so the parents tended to leave her alone while they worried about changing Brian's diapers and making sure he didn't smash the computer.

New England Center for Children won't take children much older than Brian because it becomes too difficult to change the behavior of older children, said Vincent Strully, the center's executive director.

"For kids with autism and related disorders, if you intervene effectively and early, you will alter the outcome," Strully said. "Around age 14 or 15 you see nightmare cases that we do not really take anymore. Those kids are sent to a state facility where they are restrained mechanically or medically."

Some students at the school deliberately injure themselves. Teachers, who wear thick denim jackets to protect themselves from getting bitten, sometimes carry helmets and plastic face shields to put on students if they start smashing their heads or gouging their eyes.

The intensive residential program where Brian is placed is expensive because it provides students with one-on-one care and teaching for most of their waking hours. There are 26 students in Brian's unit; four of them have fragile X.

Teachers work in the classroom and in the residential unit to maintain consistency. A teacher can expect to work one weekend day and one to two evenings a week. The school, open 365 days a year, has a curriculum based on a kind of teaching called Applied Behavior Analysis, which has proven effective in helping autistic children overcome the learning and communication handicaps and behavioral problems associated with the disorder.

The hope for Brian is that, as he gets better at communicating, he will learn to moderate some of his excessive behavior, develop some life skills and eventually enjoy a less restricted life.

"There is no way, given the intervention he was receiving, that he was going to develop," Strully said. "I do not see how he was going to gain independence to live and work and get control of his own things."

Brian's parents were forced to accept some abnormal behaviors, such as keeping him in diapers and letting him eat the same thing at every meal, because it was beyond the family to try to change him.

"I do not know how we can call on any family to deal with a child that requires supervision 100 percent of the time," Strully said.

Shortly after Brian arrived in early January, Strully said he hoped the boy could be moved to a less restrictive - and less expensive - program in a year or so. Ideally, Brian will leave at age 21 with a vocational skill and hobbies so he can live as typical a life as possible, most likely in a group home.

"The early returns indicate he is quite responsive and he will do better than we hoped," Strully said. "Certainly this offers the best hope for his long-term independence." Copyright 2004, [Hartford Courant](#)

## CAN A BROKEN HEART BE MENDED

By Avis Premack

Because of a catastrophic medical emergency my grandson Adam had to be placed in a house for the developmentally delayed. Early on the family realized that eventually he would have to live in a facility. Little did we think that the time would come so soon!

Adam's family immediately went into a spin, what can we do, where do we turn? Fortunately Illinois has the PUNS program. Based on the information you provide during the family interview; the Coordination agency will complete a "Prioritization of Urgency of Need for Services" (PUNS) form, and categorize your need for services as one of the following:

Emergency - need immediate services

Critical - need services within 1 year

Planning for need - need services in 1 to 5 years.

We started working with a crisis manager who literally walked and ran us through the system. He was a captain in rough waters and sailed us into calm seas. He helped us find an appropriate placement for Adam, and that is when my heart broke.

It seemed impossible to turn my grandson's life over to stranger. What did they know about my sweet Adam – Adam, a youngster who is non-verbal.

Did they realize he liked to sleep with two pillows, that he liked rye toast not white bread! That he loved to go to Wal-Mart and he knew where every item in the store is located. That his favorite thing to do is play with his dog Sugar, loves to chase her around the house with a dust-buster. Endless other little bits of information that made Adam the boy that he is today.

Oh my poor broken heart! He was going to leave his loving home to live elsewhere. Adam had so much – a secure home and his loving and devoted family. Then I realized that he lacked more than he had. He lived a life that was planned minute-to-minute; nothing was spontaneous. After school and his various therapies he was home with his family and dog. So would life be

better for Adam in his new environment?

With help from the PUNS program, Adam was placed in Rocvale Children's Home, located in Rockford Illinois. Finally the dreaded day arrived, it was a beautiful bright fall day, and the leaves were glorious in their beautiful colors. It helped relieve the feeling of doom and gloom. We had packed and labeled all of Adam's belongings, he picked out a new quilt for his bed, gathered his favorite books and pictures of animals; mostly bears.

Did Adam know where he was going? I'm not sure – he had spent a few says at Rocvale during the summer, he thought he was at summer camp. What he thought now no one can answer. We explained what was going to happen, but there was little response. Less than an hour and a half later we arrived at Adams new house.

Adam seemed quiet when we first arrived, but he was fairly calm. After spending a few hours filling out and signing various forms; we then took Adam out for lunch and a trip to his favorite place, Wal-Mart. Then back to Rocvale. Adam was then visibly upset and of course we all tried to keep from breaking down. As we were getting ready to leave, Adam tried to block the door. He had to be pulled away we left in a big hurry. Trips back to Rocvale at the beginning were very hard, leaving Adam again for other people to take care of him.

Adam was able to make good friends with his housemates. He and his roommate, another non-verbal young man, have become the best of friends – as you can see by the photo. In fact, when Adam comes home for a weekend his roommate has trouble going to sleep and so does Adam. Adam attends a wonderful school where he is learning some much needed life skills, along with academic studies.

Adam participated in The Special Olympics, where he won a silver medal for Baseball throws. He is also in a program with the Boy Scouts, where they visit a Nursing Home on a regular basis. He loves to push the patients in their wheel chairs, sit next to them as they watch a show. I thought Adam needed special attention, but what a joy to see that Adam can give comfort and support to someone with greater problems than his. This is good for many stitches for my broken heart.

I never thought I'd see Adam attend a dance with a beautiful young girl – and

that I would pin a boutonniere on his tuxedo. More stitches for my broken heart. Adam's life is so rich with his activities and his housemates. He enjoys jogging, bike riding and showing off his skills at swimming. He is truly a different young man more capable and willing to try new adventures. Day by day life changed for Adam – and stitch by stitch my broken heart was being repaired. Now when Adam returns to Rocvale he jumps out of the car. Runs up to his room, puts his stuff away, goes to the front door and waves us off.

At first I called Rocvale his house. I wanted to delineate house from home. However, as time has passed I have come to think of both places as home to Adam. So again, stitch by stitch by stitch my broken heart has been repaired – except for a tiny little tear that will always remain. But that is life with a Fragile X child.

## **Placing Your Child in a Group Home - A Dad's Perspective**

**By Jay Goldsmith**

All parents of special needs children dread and most avoid the thought of placing their loved ones into a private or state run child care facility. Worse is when the child approaches their 18<sup>th</sup> birthday and then the placement must be into an adult facility. The waiting list for Illinois children can be quite long; for adults the wait can be sometimes more than 8 years unless an emergency situation occurs. This is how our family life came to face this decision and how life changed and we moved forward and progressed since then.

My son, Adam, is a non-verbal Fragile X boy who is currently 15; but at that time was 13 years old. He has a very pleasant personality; a great sense of humor; comprehends all of what he hears (but does not always comply with what is requested); and does not exhibit behavioral issues. My wife, mother-in-law, and I had always worked as a team with his therapists, teachers, and other educators; for setting up my son's IEPs', as well as his therapy, and social goals. All of this was done to provide him with the best opportunities to experience a full life and to have a social life.

We had registered Adam for the Illinois PUNS (Prioritization of Urgency of Need for Services) program some years ago (~2005 - 2006). This is something that many special needs parents are not willing to do. It does not take much time to do and can be very helpful if any emergency situation arises. Many parents think it is not necessary, but if not registered in Illinois and a crisis situation occurs; any actions for the child or children's immediate future can be stalled.

Now back to our story. Over the past few years some serious life threatening medical issues occurred that made us realize that we needed to make some important decisions that would affect our family situation; but were in our child's best interests. My wife was severely ill in 2007 and in 2008 our situation went to crisis mode. My wife could not care for my son and I was at work. We had exhausted our savings and my 401K savings on medical expenses and care-giving for both my son and my wife. During this time; we contacted our PUNS Case manager to help us. He started searching for potential facilities for my son, because of our crisis circumstances. Jody and I were very scared, unsure of what would happen, and thinking that we were bad parents for doing this. We began to doubt ourselves and had many moments of anger and sadness during this time. This was our egos' getting in the way of our son's best interest.

We were fortunate enough to find a facility in Rockford, Illinois. We met with the staff and administrators; and filled out the appropriate paperwork during meetings, where we discussed our son, his life, and his potential. They allowed him to have a trial visit for three days in August of 2008. He had a wonderful three days there as we called it camp. We were called in October that Adam would be accepted into the group home (Rocvale Children's Home – a part of the Milestone Organization). We packed up enough of his clothing, books, videos, and other comfort items for his move to the home on November 4, 2008. This was not all of his things; just the seasonal items for the late fall and early winter. We set out for Rockford and arrived after a 100 minute drive.

When we arrived Adam did not want to get out of the car and when he finally did he was very nervous. I think that he sensed our apprehension and fear; even though we tried to keep the mood light. We described Rocvale as his house for school. After we

met with the staff and administrators; and signed off on many papers; we then met the house staff, Adam's house-mates and his roommate. We proceeded to unpack his belongings and make the room comfortable for him. The three of us then took Adam out for lunch and went to Wal-Mart for a TV and DVD player and some extra personal bedding items for his room.

We drove back to Rocvale and got Adam into the house and then prepared to leave. He was trying to prevent us from leaving and was crying his eyes out. With much trepidation, guilt, and fear; we left. As we drove home, we were crying and were extremely depressed. We did not see Adam for 2 weeks. We called daily; but the administrative personnel thought that he needed some time to settle before we saw him next. He then came home with us for the weekend; late Friday afternoon and returned on Sunday afternoon. Each weekend the separation was easier for him to accept but still very difficult for us. My wife and I found the people that worked there: treated all of the children with much respect; handled them with care, and gave us peace of mind about their care (especially my son). He was in a safe, protective place and we felt much comfort from this. My son also felt this. My wife and I learned to take our egos out of the situation and look at the big picture; that this was for my son's future and was providing him the best opportunities to adapt to life and to grow as an individual. Our egos were our fears, anxieties, and the guilt feelings for being bad parents for doing this to our child. Getting these negative feelings out of the way made life better for us; but did take time and much patience for us. Adam was doing so well there. Adam also made the transition to a new school (8<sup>th</sup> grade) with new teachers, new classmates, and new schedules. His IEP was followed to the letter and he was adjusting well. Our initial meeting and then the IEP meeting with the school personnel had Rocvale personnel with us. That was extremely helpful in forging a positive team network.

Over the first month and a half, our fears about Adam were very much relieved. Initially, we both felt much guilt and angst about putting him into this situation. We were very tense and sad each time we took him back; and this lessened a little each time. Adam seemed to adjust better than we did. When the winter holiday break arrived, my wife and I picked him up for an extended stay at home. Unfortunately, my wife passed away during this time. This was a very difficult time for the entire family and my son and I went had to adjust to this and we both got into a depressed state for a short while. My anxieties, fears, and the guilt of putting Adam into this situation had to be re-handled. My ego again got in the way. Adam was flourishing in this environment and seemed happy with his life.

Over the next few months, we met with the staff and started Adam on a low-sugar diet in order for him to lose weight and they also started to work to toilet train him. We tried and tried at home without success. Adam changed roommates after a few months. This was a staff decision and not due to anything else. They thought that this new roommate was a better fit for Adam. They got along very well. Adam was starting to lose weight and was adapting to the house life. During this time, I found myself telling Adam that this was Adam's school home and that his housemates were his house family. On weekends, he would come back to our home and be with his daddy and his dog Sugar. We would visit his Nonnie (Avis) and Papa, and his aunts, uncles, and cousins. Adam was becoming more confident in himself and it showed. I was becoming adapted to this way of life for him and became more involved in Rocvale and his house activities.

When the school year was ending; we had a new IEP meeting for his transition to high school in Rockford. It was like passing a baton flawlessly in a relay race. The Rocvale staff was with us during this meeting and we were all on the same page. We felt excited about Adam's high school future from this meeting. Also Adam was losing weight and was doing so much better in his toilet training. Adam attended his first dance in May 2009. It was called "A Night to Remember" and was hosted by a local Rockford church. There were about 150 special needs individuals attending. The boys/young men wore Tuxes and the girls/young ladies wore dresses. It was so cool to see my son dressed up and really enjoying being with his housemates and friend and their dates. I never was so proud!!

Adam had a wonderful summer; he went to an overnight camp in Iowa for 5 days and spent weekends home with me. He was showing more self-confidence in himself and was becoming a fine young man. His roommate left the home and one of his housemates became his new roommate. They are now best of friends and have such a great time together. My son is experiencing life much better than I could have ever imagined.

His freshman year has been a wonderful experience for him and he has truly grown from his life at Rocvale. He is a member of a local Boy Scout troop and he likes it. He just had his second prom dance "A Night to Remember" this past May. This year over 230 special needs children attended. He has lost about 50 pounds since November 2008 and grown a few inches. He looked great in his tux this year and had a fantastic time with his date (from the Church). His Nonnie attended with me and we both had such a great time seeing Adam and all of the attendees enjoying themselves. This summer Adam will: attend summer school; go to after-camp, go to a weeklong overnight camp as well as a weeklong Boy Scout camp. He will also do activities with his housemates and the other residents. He is gaining so much self-awareness of his abilities and his self-confidence has grown tremendously.

I am always amazed at how much the decision we made to put him into this home; has been an ideal opportunity for him to succeed in life. He has experienced so much more than I could have ever done for him. Yes, it is still hard for me to say goodbye to him; when I take him home after the weekend. But I know that he is in a great place and I have no anxieties, fears, or any guilt when he is there. People are commenting at how well he is going and how great he looks. I am so proud of this young man and how much potential he now has. I have no regrets for our actions and have become a spokesperson and advocate for the Rocvale Children's home and the Milestone Organization.

The hardest thing a special needs parent(s) can do is to have to place their children into a facility. It is not an easy decision and should not be taken lightly. Many parents experience this when their child or children leave to attend college. My wife and I did not look at it this way, but now this is my son's life experience. He will not go to college (?). But for him to experience the positive life opportunities that he encounters; is giving him the tools to face life in the future with self-confidence, pride, and respect for himself and others. I look forward to his transition to an adult facility when he gets older. Not with trepidation or fear, but with love, with his happiness, and with a sense of his success in life in mind!

Derek, Woods Services Placement, Langhorne, Pennsylvania  
By Cheryl Cook

Derek went away to school when he was 12. At the time, we were planning our move to Simsbury, which would have meant a change in residence and schools for Derek regardless. Prior to that, we had experienced a steady decline in Derek's ability to function in a "public" or in his case, semi-public school. He was completely unable to function in any normal childcare facility and even the home care person who had welcomed Derek into her home for years finally said she could not do it any longer. This left me at home with Derek every hour he was not in school. We spent a year this way and it was not a satisfactory arrangement for any of us. My other 2 children did not get what they needed from me and Derek and I were miserable. We could not go to a store, pool, restaurant, party, anywhere, without some type of incident. At this point Derek was not toilet trained and this added to the stress. Add this to the stress of the move and it was not a good situation.

In our search for help, we first got some respite time from DDS. This was good, but we could only get one weekend every 3 months. Then we arranged, through DDS, for a private pay respite provider. This man was great with Derek, and allowed me to get out once a week and go to girl scouts with my daughter. He also helped us out with some childcare at other times, including keeping an eye on Derek when we had family events, etc. We continued to look for some help and someone suggested the voluntary services program through DCF to me. It took the case worker about 15 minutes in our home to accept us. We started the search not really knowing what to expect. Derek was turned down by many institutions because he did not fit their profile. (In other words, he was too hard to deal with.) When the case worker called and said that Woods was expanding their program with 35 more beds in the boys unit she said we should get ourselves down there right away because this opportunity was not coming back. We visited and immediately saw that this was a place Derek could be comfortable, well supervised and learn as much as he is capable of learning. I think it is like visiting colleges with other kids, you get a feeling when you walk on the campus that is either right or wrong for you. The case worker said she understood that we were not planning on sending him away just yet but that this was an opportunity we should not pass up. She was right. It was great for everyone and the people who did not take the opportunity are probably still on the waiting list. I have talked to a few families here in CT who are on the waiting list for Woods.

It was hard to let go, and it is hard to bring him back after a visit, but he is so much better and had so many more opportunities he would not have had at home with me. He has all of the professional help we could not get here and it has paid off both in his behavior and skill level. He is toilet trained, less aggressive, more verbal and more social than he has ever been. And for the rest of us, we can now look forward to seeing Derek without the stress, my other children can have some type of relationship with him and not be afraid of him, and we know he is safe and cared for 24/7. I can attest that while sending a younger child to a residential school is more difficult, the payoff is greater. Getting all of that care earlier, rather than waiting until he was 14 or 15, was the best choice. No matter how much we would all like to think we can take care of our own kids better than anyone else, I don't think that is always the case with a special needs child. I will be the first to admit that I cannot stand social workers and I have a hard time listening to school psychologists, but I have tried very hard to see Derek through their eyes too and listen to suggestions. It does not always work and I still disagree sometimes but now I have a whole team of people to help me and that is a good thing.

Our Daughter  
By Denise & David Helm

In looking back, as the parents of a daughter on the Autism Spectrum who has intense anxiety and behavioral challenges, it was the most difficult decision for us to place her in a residential school out of state. For 18 years we struggled as parents to always try our hardest, be committed 150% to keep our daughter at home and provide every type of intervention that we could find. After exhausting all our options, attempting 10 to 20 different medications over a 10 year period, 4 hospitalizations for 30-plus days at a time, because she was becoming increasingly difficult to manage at home and in the school setting, and 2 outplacements at local private day schools, (she was asked to leave both by administration because they couldn't provide what she needed), it was time to pursue the unthinkable - a residential setting for her. We just hoped it wasn't too late.

We knew it was the only option left in which she would receive the best supports, care, and available resources, along with a highly trained staff that could give her what she needed most: the opportunity at a chance for a better life when she becomes an adult. We realized that we couldn't be selfish and keep her home just because we wanted her to live at home with us. We aren't the professionals; as much as we strived to do right by her, we had to let go for her sake.

Today she is thriving and had been there for 18 months. She likes her environment and her friends. As much as we miss her, she has everything she needs to be successful at her home and school. She is re-learning the correct way to handle her frustration and learning new strategies and techniques. Instead of being contained and maintained, she is able to be taught with the expertise of her school and residential staff and be part of a community. Her opportunities are more than we could give her, and the possibilities for her future are endless, given the ways she learns. We see maturity and independence, and above all she is happy. So we are happy! (Not to say she still doesn't have a ways to go to improve).

Monday, April 20, 2009  
Almost a year after entering residential school...  
By Holly Nappi Collins

This week I thought I would stretch back to my archives and pull some oldies from when I first started blogging 10 months ago. As you know I started this blog to help me deal with the reality of sending Meghan to a residential school. And over these few months, many people have found me (this blog) for that very same reason: they are facing the same reality of having to send one of their own children to a residential school.

It's interesting because back then I definitely thought that some visitors to this blog would condemn me. I thought they would tell me that I was "giving up" or "how could I send my child off to residential school," or an "institution" for those who didn't understand. I thought this because I, too, thought it of others who preceded me and had done it to their own children when my daughter was still very young.

Back then I had no idea what laid ahead for me, for my family, and for Meghan--and it scared me to death. The "not knowing" about our children is the horror in anyone's story--as in any difficult situation or traumatic event. I can honestly say that I thought of myself as a fighter for my daughter (for my children) and was determined to make her a success story. But by sending her off to a residential school was surely the start of just giving up and surrendering.

This was the main reason for writing this blog: A form of therapy, reaching out to others, helping others, seeing my words reflected back at me to completely comprehend what was going on...all of it. And I found myself pulling away from Meghan—physically and emotionally, as if to protect her and to protect me. I would find myself searching for an escape—reading books, spending time with friends... anything to detach myself from my failure. Failure. It's interesting to see this word and think of it as a common word used when one is failing at school, or a job, or a project...but not parenting. Failing your child is inexcusable. And no matter what anyone said to me in support of this decision, I believed it was a failure on my part and an end to her success story.

And now, after almost a year, I realized something that I wasn't sure I would. I realized that I was wrong—terribly wrong. I realized that NOT sending Meghan to her residential school (and I'm stipulating *her* school) would be the true act of failing her. By not sending Meghan to residential school would be saying that I didn't believe in her, her future and her ability to succeed. What I thought was selfish on my part—sending her away to school and in the care of strangers who could do the job better—was instead sending her away to a school with "many" trained teachers who could help her. I realized that this was a gift with a disgusting name in a cold and uncaring disguise. A gift to her, and to me, and to our family. It was gold.

I also came to realize during this crazy, surreal and transformational year, that this was just the start of her success story—not the end of it.

<http://fearlessfolks.com/>

## Words from a Former Residential Teacher

By Jessica L.K. Rosado, MA

In my current work, conducting psychiatric level of care assessments, I'm faced with hospitalizing children on a regular basis. One of the hardest parts of this process is talking with the parents about the need for this level of care. As the parents are the guardians of clients who are minors, though the doctors do have the ability to override their decisions if there are glaring safety concerns, the decision to hospitalize a child lies with the parents. My experience working at the New England Center for Children (NECC) with the boys who live at the Oak Street residence and their families, has given me a perspective that I find very helpful in sharing with parents who often are forced to make a decision to hospitalize their child. What I have learned is that it takes the strongest parents to recognize their need to ask for help and get their child the services the child needs. Sometimes that means residential care. The job of a parent is to do what is best for their child. Though as a parent, it is extremely difficult to entrust the care of your child to other people, what may be best is what other people have to offer to your child. Residential staff are trained to function as a team in capacities that affect every aspect of the children's lives. What residential treatment is able to provide for your child is often impossible for parents to provide, given their responsibilities to other children, significant others and other family members, to their careers and to themselves, to mention a few things. Parents cannot watch and teach a child every moment of the day and expect to function in any other capacity. In a residential setting, the parents add a group of trained professionals to create a team of caregivers for their child. I would like to emphasize that residential staff are an "addition" to a "team" of people working with the child. There is a common misconception that parents are forced to give up complete control in allowing others to be primary caregivers of their children in a residential setting. Residential treatment isn't about "giving up" a child to an institution and removing them from the parents. Though there is, of course, some control lost when a child no longer lives in the parents' home, by no means does this mean that parents no longer have control in their child's care. Tammy and Andy are a wonderful illustration of this point. The Selingers are a wonderful example of a family who have a son in residential care who have

a great deal of control over their son's treatment. Of course, there are rarely rights or wrongs when it comes to these things, but if you ask me, they are doing it right. Tammy and Andy have managed to maintain a powerful relationship with their son despite his living in another state. They not only bring Brian home regularly for visits, but they also call Oak St. daily to speak with Brian before he goes to bed. Tammy and Andy take an extremely active role in their son's care. In addition to participating in IEP planning and all of the other educational aspects of Brian's treatment, they speak with Oak St. staff every day before speaking with Brian each night. Tammy and Andy's level of involvement extends beyond care of their son as well, as they are active members of the Parents Organization at NECC and do such wonderful work with education pertaining to Fragile X. And they do this all and care for their daughter Jodi as well! Residential staff have respect for all parents as the primary decision makers for the children for whom we care, but when parents are as involved as Tammy and Andy are, the power of the role of the parents cannot be ignored. The Selingers collaborate with the Oak St. leaders and staff to get Brian's needs met in every aspect of his life, they are incredible advocates for their son's needs. Their dedication has played a tremendous role in the amount of success Brian has had in his care at NECC. There are countless examples of Brian's residential treatment being a success, I cannot even think of an example to choose that would appropriately convey how far he has come.

### **Global System of Education for Children with Autism**

Accessing and developing curriculum to meet the vast needs of children with autism is often an overwhelming task. Few curriculum guides fully address the complexities inherent in teaching children with autism across ages, abilities and learning styles. Children with autism typically have uneven patterns of development, resulting in a wide range of functioning levels. Many are easily distracted, have difficulty organizing information, and often fail to generalize and maintain what they learn. It is important for curriculum to allow flexibility for individual differences in learning profiles.

The New England Center for Children is internationally recognized as a leader in the field of education for children with autism. For the past thirty years, NECC has been developing curriculum to teach children with autism using the principles of Applied Behavior Analysis. This curriculum is based on sound and systematic research conducted at the NECC or elsewhere, and published in peer reviewed journals. Recently this curriculum been translated into a comprehensive computer program, the Autism Curriculum Encyclopedia®.

The Autism Curriculum Encyclopedia, or the ACE®, is an interactive database that holds assessment tools, lesson plans, teaching materials, data sheets, graphing protocols and progress reports for over 1000 skills. Each curriculum template is accompanied with a video clip demonstrating key features of the teaching procedures used. Data sheets and related materials such as pictures or worksheets are also included with every curriculum sheet. All documents, once modified for the individual, can be printed and brought to the classroom for teachers to use as they work with each student.

The ACE® is effective in teaching critical skills to individuals with autism across all NECC programs. From children aged two receiving instruction at home, to students in our day and residential programs, to students in public schools and adults working in the community, the ACE® provides the tools which guide teachers to design highly effective individualized curricula. Data from the ACE® show our students making progress towards mastery of core skills and educational objective each year (Core Skills - 81% in 2007, 86% in 2008, and 89% in 2009, IEP Objectives - 86% Progress or Met). Overwhelmingly, we have found the ACE® to be an invaluable teacher resource that has significantly improved the quality of educational services offered at NECC® and has increased the rate of our students' progress.

