CT FEAT
CONNECTICUT FAMILIES FOR EFFECTIVE AUTISM TREATMENT
12 Years of Families Helping Families
P.O. Box 370352, West Hartford, CT 06137

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Newsletter 2010 Issue

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FEAT Scholarship Winners Transforming Lives

Beth Curry

Connecticut special education teachers, paraprofessionals, speech-language professionals and other educators currently working with children with autism are encouraged to apply for the 2010 *Nancy Leahy Shea Memorial Scholarships for Professional Development*.

By funding these scholarships, CT FEAT actively supports expanding the number of highly trained autism professionals in Connecticut. Established in 2004 in memory of Nancy Leahy Shea, the scholarship provides financial awards to Connecticut educators pursuing advanced academic training and certification in applied behavior analysis (ABA).

Nancy Leahy Shea was the mother of board member Bob Shea and grandmother of his son Jeremiah and daughter Fiona. Jeremiah was Nancy's first grandchild so needless to say she worshiped him. Bob Shea recalls that, "my mom was someone who totally and unconditionally loved Jeremiah - it was hard to lose someone who would have done anything for him. Nancy always wanted the best for Jer and would definitely love the fact that through her scholarship we are training professionals to do the best for all kids with autism."

Previous Scholarship Winners

To date, awards totaling nearly $20,000 have been made to special education teachers Elizabeth Freitas, Stephanie Jacius, Janet Haley and Melissa Dei, school psychologist Margery Stahl, and paraprofessionals Lisa Bosco and Crystal Sacco. With CT FEAT's support, Freitas and Haley were able to complete their training and qualify as Board Certified Behavior Analysts (BCBA), thereby helping to meet the growing need for professionals with this kind of specialized training.

How to Apply

Beginning in 2010, CT FEAT has changed the format of the scholarship program in order to broaden its impact. Instead of annually supporting a single person pursuing certification as a BCBA, FEAT is offering smaller grants to a larger number of recipients studying any specialized autism certification that includes a concentration of training in applied behavior analysis (ABA).

Applications for funding can be submitted at any time. CT FEAT's board of directors reviews the applications on a quarterly basis and makes financial awards based on a variety of considerations, including the merit of the proposed activity, competing requests for funding, and the fund's quarterly budget. The scholarship may cover the entire cost of the proposed activity or some portion thereof. You can request an application by writing to: ctfeat1@ctfeat.org.

Opportunities for studying research-based interventions for autism are available at various educational institutions here in CT as well as in the surrounding region and online. CT locations include Saint Joseph's College in West Hartford, and Eastern CT State University in Willimantic. Many CT students also study at Elms College in Chicopee, MA, and Westfield State College in Westfield, MA. For more information about where you can take courses approved by the Behavior Analyst Certification Board (BACB), including distance learning programs in applied behavior analysis, go to www.bacb.com.


Nancy Leahy Shea

Scholarship Winners: In Their Own Words

2008 FEAT Scholarship Winner Janet Haley is now a board certified behavior analyst (BCBA). She reports:

For many years I have worked for the Simsbury public school system as an Autism Consulting Teacher, serving students from preschool through high school. I realized that training as a board certified behavior analyst (BCBA) would increase tremendously my ability to meet the behavioral needs of these students.

Receiving CT FEAT's professional scholarship allowed me to earn my BCBA and turn this dream into a reality. It also has allowed me to reach out to more individuals on the autism spectrum, and to their families, then would otherwise be possible.

Melissa Dei

Since I was awarded the scholarship I have been selected as Simsbury's Teacher of the Year, made it to the CT State semi-finals for Teacher of the Year, and have had a research article scheduled for publication in a peer-reviewed journal. I've also received Congressional recognition for my "tireless dedication to improving the lives of children with autism" and been appointed to the Greater Hartford Autism Speaks Leadership Team in the role of Autism Education and Awareness Chairperson.

2009 Scholarship winner Melissa Dei is a teacher at the River Street Autism Program at Coltsville. She tells us:

I have worked with autistic children for over ten years. I am also a proud recipient of the Nancy-Leahy Shea Memorial ABA Scholarship, which has enabled me to pursue my Masters degree in autism, and further my expertise in the field.

Janet Haley

I am driven to teach children with autism to lead purposeful active lives, participate in their communities, and strengthen their social abilities to better relate to their families and friends.

This scholarship has assisted me to continue my education at Elms College, and move towards my goal of becoming a Certified Behavior Analyst. I am very grateful to have been chosen for this award. Thank you all at CT FEAT!

Crystal Sacco, a parent of a child on the autism spectrum, works as a paraprofessional and recently received scholarship funding to take an online college course in ABA at the Florida Institute of Technology. Crystal shares:

Thank you very much for allowing me to be the recipient of the professional development scholarship. It is my pleasure to announce that I have finished the first course in the series with an A. Being a parent of a child with autism, as many of you know, changes you. What once seemed like a life sentence, has now become an opportunity for change.

My dream is to be among the great professionals responsible for replacing fear with hope. Hope for a normal life. There is nothing in this world that I want more. I hope to be able to continue on the path to achieving my BCBA certification. What a difference this knowledge would make in the lives of families affected by autism if all parents were given this kind of opportunity.

CT FEAT's Resources

1. ***An Internet Discussion List*** that provides Connecticut parents of ASD children with a supportive forum to discuss issues of concern. To subscribe, go to www.ctfeat.org.
2. ***Free Parent Resource and Networking Meetings.***
3. ***Parent Training Fund*** to subsidize attendance at educational events focused on effective treatment.
4. ***Speaker Events and Conferences*** presenting the latest information on current best practices in autism treatment.
5. ***The Nancy Leahy-Shea Memorial Scholarship for Professional Development in Applied Behavior Analysis*** (ABA) supports CT educators pursuing education and training in ABA.
6. ***A free Newsletter*** reporting on news of interest to our community, including new resources, learning opportunities, research and advocacy.
7. ***A Web Site*** containing extensive resources suggested by parents, including book and video reviews, and professional listings.
8. ***Outreach, Education, and Advocacy*** to increase access to effective treatment

__CT FEAT__ is a non-profit organization staffed by volunteers and funded through the generosity of caring supporters. If you would like to learn more about our activities, or subscribe to our free newsletter: go to www.ctfeat.org; or call (860) 571-3888; or write to P.O. Box 370352, West Hartford, CT 06137-0352; or E-mail ctfeat1@ctfeat.org. We'd like to hear from you!

JOIN CT FEAT'S ONLINE COMMUNITY

Looking to network with other parents of children on the autism spectrum?

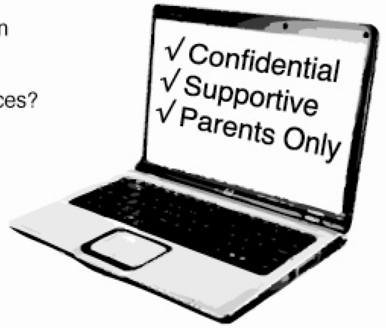
Need more infomation on treatment and resources?

Want to provide support – or just share your story with those who understand?

Go to

www.ctfeat.org/listservrules

For more details



About CT FEAT

Formed in 1997 by family members, Connecticut Families for Effective Autism Treatment (CT FEAT) is a non-profit organization providing information and support to the families of children with Autism Spectrum Disorders (ASD).

Our Principal Goals

1. To provide educational and networking opportunities to families interested in treatment validated by research.
2. To expand the availability of high quality professional services by supporting education and training opportunities in ABA.

Our Guiding Beliefs

1. Individuals on the autism spectrum should have access to effective intervention throughout their life spans.
2. Treatment should be based on research and produce measurable outcomes.
3. Informed parents make the best advocates for their children.

CT FEAT, Inc.
PO Box 370352
West Hartford, CT
06137-0352

860-571-3888

www.ctfeat.org

ctfeat1@ctfeat.org

We're Proud to Help

Empower Parents

to become more effective advocates for their children with free resources

Raise Public Awareness

by donating thousands of dollars' worth of autism-related books to public libraries and distributing our newsletter to thousands of parents, teachers, doctors and other professionals

Sponsor Conferences and Other Learning Opportunities

for parents and professionals to acquire the most current knowledge about effective autism treatment

Provide Scholarship Funds

to CT educators and parents pursuing training in interventions validated by research.

For more than a decade now, we've never held a single fundraiser. We don't sell anything. We don't accept paid advertising. And our services are free of charge! Help us to continue helping families affected by autism.

Here's How You Can Help Share Information, Resources and Hope

- Donate your tax-deductible contributions securely online at the CT FEAT web site: www.ctfeat.org
- Mail your charitable contribution to CT FEAT, PO Box 370352, West Hartford, CT 06137
- Or designate CT FEAT as the recipient of United Way and employer-matched contributions
- Call us at (860) 571-3888 for more information or email us at ctfeat1@ctfeat.org.

CT FEAT

CT Families For Effective Autism Treatment

Our Gift To You: FEAT'S Annual Holiday Book Giveaway

Every holiday season, CT FEAT selects a new autism book to offer as a free gift to our parent community. A description of the book and how to obtain it is posted on CT FEAT's "parents only" listserv. Over the past three years we have distributed more than 120 books.

In order to be eligible for the gift book you must 1) be a CT parent of a child on the autism spectrum; 2) read the description and decide that you would benefit from the book; and 3) intend the book for your personal use.

FEAT imposes these requirements because there are significant costs associated with purchasing and distributing these books and we want to be sure that they are going to people who want and need them.

We are always looking for book suggestions. Recommendations for our 2010 selection can be made any time up until the end of October. That gives FEAT's board of directors time to review and select the book by November when the gift drive gets underway. Please send any suggestions to: ctfeat1@ctfeat.org.

Our 2009 gift book was Bobby Newman's *Behavioral Detectives: A Staff Training Exercise Book in Applied Behavior Analysis* **(2007).** Though this book is described as a "staff training book," any parent with an interest in behavior analysis would find it accessible and worthwhile.

Newman is a popular presenter and prolific writer whose specialty is translating the sometimes arcane technical vocabulary of behavior analysis in to everyday, easily-comprehended concepts. One of his most well known books is *Behaviorspeak: A Glossary of Terms in Applied Behavior Analysis.*

All of Newman's books share a common purpose to make behavioral thinking and concepts more intelligible. They have the added virtue of being clearly written and are often quite humorous.

Previous gift book titles have included *Right From the Start: Behavioral Intervention for Young Children With Autism* (Sandra Harris and Mary Jane Weiss, 2007), *It's Time for School: Building Quality ABA Programs for Students with Autism Spectrum Disorders and Sense and Nonsense in the Behavioral Treatment of Autism: It Has to be Said* (both by Leaf and McEachin,2008). You will find the reviews of all these books, and more, in the "Recommended Reading" section of the CT FEAT web site (www.ctfeat.org) .

All of these authors are renowned for writing practical informative books of interest to professionals and parents alike. They also have consistently demonstrated exceptional sensitivity to the concerns and needs of parents, making them especially appropriate choices for our special annual holiday gift to parents.

Autism Community Unites for Legislative Victory *Beth Lambert*

Do Connecticut State Senators and Representatives listen to their constituents? Is it possible for parents to make their voices heard when speaking about the need for quality services for their children with autism? Thankfully, the answer to both questions this Legislative Session was a resounding YES!

In an immensely gratifying grass roots effort, parents, professionals, educators, and autism organizations worked together to help our legislators understand the urgent need to enact House Bill (HB) 5425. This bill requires that any person providing applied behavior analysis (ABA) services to children with autism have a specific minimal level of training and experience.

This legislation offers much needed protection to students with autism spectrum disorders by making sure that people who are providing ABA services to them are properly credentialed to do so. Prior to the enactment of this law, providers of ABA services were the only professionals working with our children who didn't need to have some minimal credential requirement.

The new law requires that school districts utilize someone who is either a Board Certified Behavior Analyst (BCBA), a Board Certified Assistant Behavior Analysts (BCaBA) working under the supervision of a BCBA, or another professional credentialed by either the CT State Department of Health or the State Department of Education who has behavior analysis in his or her scope of practice. The bill will take effect on July 1, 2012.

Suzanne Letso, CCCD; Beth Lambert, CT FEAT, Michael Rice, CREC River Street School; and John Molteni, CT ABA, at state capitol after submitting testimony on HB 5425.

Need for the Legislation

Due to the widespread recognition of ABA's unique effectiveness in treating autism, a growing number of parents have been requesting ABA services for their children. Unfortunately, some schools met this growing demand by simply characterizing any kind of behavioral support as "ABA" even when there was no Board Certified Behavior Analyst (BCBA) involved with supervising the services.

In a particularly egregious case that provided part of the impetus for the legislation, a woman named Stacy Lore held herself out to the Norwalk school district as qualified to provide ABA services when in fact she had absolutely no credentials and had even fabricated degrees. The district paid her over a hundred thousand dollars. Meanwhile, this unscrupulous woman cheated many young children out of an irreplaceable treatment opportunity. Lore has been arrested and faces criminal charges.

Upon learning of the situation involving Ms. Lore, the General Assembly's Education Committee asked Attorney General Richard Blumenthal to investigate who has been providing ABA in our state. In an illuminating report that documented the problem, Blumenthal outlined potential solutions. He also testified about the issue before the Education Committee of the Connecticut State Legislature.

The Messy Way a Bill Becomes Law

It is said that democracy can be a messy business. The State Capital is a beehive of interests lobbying for a plethora of causes; many serious issues debated there impact the daily lives of all of us in Connecticut.

Crafting legislation that would effectively define and regulate the application of ABA to our children was a challenge in itself. But passing that legislation in a period of such serious and unprecedented financial problems was an even greater challenge.

After the Attorney General submitted his report, HB 5425 was proposed and the legislature's Education Committee held a public hearing. Testimony before the committee was long and impassioned.

The legislators heard from parents, professional educators, autism organizations and parent advocates about the great need to set clear standards for providers of ABA. CT FEAT President Beth Lambert, Autism Speaks CT Advocacy Chair Shannon Knall, CT Center for Child Development CEO Suzanne Letso as well as Providers from ACES, CREC and Birth to Three all took time to submit testimony.

Our Senators and Representatives sat up and took notice that a tremendous number of parents from the autism community found the time to testify either in person or through written testimony. You can read this testimony yourself at the Connecticut General Assembly's web site: http://www.cga.ct.gov.

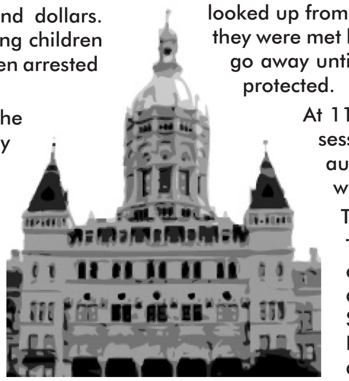
We were thrilled when the bill was approved by the committee but that was only the first hurdle. It still needed to be passed by the House of Representatives, passed by the Senate and signed by the governor. All this in a year when the state is facing a historic fiscal crisis which understandably was consuming most of the legislators' time. Focusing their attention on this important issue was not easy.

On April 7, at the Autism Awareness Day at the state capitol organized by the CT Autism Action Coalition, CT FEAT President Beth Lambert and Autism Speaks CT Advocacy Chair Shannon Knall thanked Rep. Graziani, Rep. Lyddy, and Sen. Gaffey for sponsoring HB 5425. You'll find a complete list of sponsors at the CT General Assembly's web site.

CT FEAT Parents Provide the Final Push

The contribution made by many of the 300 members of CT FEAT's "parents only" listserv played a critical role in the success of this legislation. In the course of our daily lives parenting children with autism, it is not easy or comfortable to find the time, or the words, to write letters and make phone calls to our legislators. But clearly many found the energy and the passion to make that contact, make that call, and send those e-mails, thereby calling our legislators' attention to the critical importance of this issue in our lives. That push from the trenches made all the difference.

Ultimately the bill passed the House of Representatives and on May 5th, the very last day of the legislative session, it was still awaiting action in the State Senate. As the hour grew late, a stubborn contingent of supporters waited in the Senate gallery. When the eyes of Senators looked up from their last minute finessing of the legislative process, they were met by the eyes of 20 stubborn supporters who would not go away until the rights of our most vulnerable population were protected.



At 11:53 PM, 7 minutes before the end of the legislative session, HB 5425, requiring that ABA for our children with autism be administered by qualified ABA professionals was passed by the Connecticut Senate.

Thank You, Thank You, Thank You

The list of people that should be thanked for their efforts in passing this bill is too long to include in this article. However, special mention needs to be made of Suzanne Letso from the Connecticut Center for Child Development (CCCD), whose tireless leadership drove the entire effort; Shannon Knall from Autism Speaks, whose savvy with the legislative process and characteristic determination played an indispensably critical role; and Bob Shea from CT FEAT, whose understanding of the process and players got us over the finish line.

And a special shout out to everyone who wrote letters, e-mails, phone calls, or sat in the gallery and kept the heat turned up on the state legislators. Your passion about this cause, and the heroic effort to it, were indispensable to the success of this effort. Thank you for caring so deeply about our children!

Have You Visited Us Online Lately?

NEW at the CT FEAT Web Site: www.ctfeat.org

*Dr. Mayville on Evaluating Educational Programs for Children With Autism Spectrum Disorders

Read this comprehensive report on Dr. Eric Mayville's enlightening presentation at the recent CT ABA conference. Dr. Mayville, Ph.D., BCBA-D, from the Institute of Educational Planning in Milford, describes the essential elements required to produce the kind of meaningful evaluation needed to develop and implement a truly individualized education plan.

According to Dr. Mayville, "Evaluation of educational services should go beyond descriptions of standardized test data and surface descriptions of behavior, and should be detailed enough to inform specific educational and treatment directions."

Topics covered include the purpose and content of an independent educational evaluation, standardized testing, document review, data collection, classroom observation, discrete trials, incidental teaching, small group instruction, inclusion, social programming, content of the report and recommendations.

*Dr. Zane on Who are You Going to Believe, Me or Your Own Eyes: The Use of Pre--•Post Test Designs to Evaluate Effectiveness of Autism Treatments

Thomas Zane, Ph.D., BCBA-D, provides guidance on how to assess treatment research. According to Dr. Zane, "All research is not equal in quality. Just because a research study has been conducted and shows positive changes in some aspects of autism does not necessarily mean that the treatment was responsible for those changes.

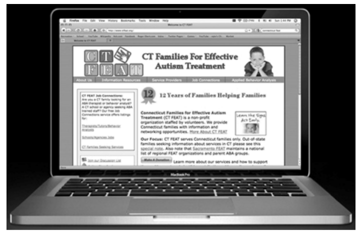
"Since autism is said by some to be a "fad magnet" parents and other consumers must critique any research study that purports to show a positive effect of a treatment and try to determine if the positive changes could be due to other explanations, or could be due to the treatment.

"By activating their "baloney detectors" parents, care givers, and service providers can avoid adopting treatments that have no proof of effectiveness, and thus be more likely to embrace treatments for which there is a body of well-designed research supporting a cause and effect relationship." (Read the rest of Dr. Zane's thought-provoking article at www.ctfeat.org.)

Plus…

Recommended Resources
Conferences and Workshops
Sign-up for FEAT's Online Parent Discussion Group
Scholarship Information
Service Providers
Job Connections
Newsletter Archives
Parent Perspectives
Autism Newsfeed

Have You Visited Us Lately?



Open Letter from CT FEAT President –

Helping Us to Help Others

This is an appeal for your support. Most of CT FEAT's work is accomplished by volunteers. If we paid people to do what our volunteers do, the cost would be astronomical: writing and editing this newsletter, maintaining our website, answering requests for information, organizing conferences and parent meetings - to name just some of our activities.

Despite the extraordinary work of our dedicated volunteers, we still have expenses. For example, we:

- provide a Listserv where parents can exchange ideas and find help in advocating for our children. The Listserv quickly "gets the word out" about social opportunities in the community, important legislative action, and informative workshops.
- donate books to guide the parents of newly diagnosed children.
- sponsor parent meetings where professionals share their expertise on important topics like toilet training, transition to adult employment, and the use of medication.
- subsidize parents to attend trainings in effective treatment methods.
- award substantial scholarships to support educators learn more about applied behavior analysis (ABA) so that they can better help those with autism.

As a statewide organization that doesn't accept any form of paid advertising, CT FEAT speaks with an independent voice that is heard in the Capitol.

All these things are priceless but not without cost.

Please join us in making a big difference in the lives of families all across our state. Contributions are tax deductible. All donations large and small are appreciated.

Thank you.

Beth Lambert
President, CT FEAT

To help support the work of
CT FEAT, you may:
✓ Send a check made out to CT FEAT to:
CT FEAT
P.O. Box 370352
West Hartford, CT 06137-0352
✓ or go to our website:
www.ctfeat.org
Click on the yellow "Make a Donation" button to use your credit card to make a donation.

Knowledge is Power: Conferences, Workshops and Lectures

Attending conferences and other educational presentations is an efficient way to keep current on the latest autism treatment developments. The new research often presented in such forums can take a long time finding its way into the mainstream of information.

FEAT accepts no advertising for these listings and only includes those which appear to have particular merit. For the most part, FEAT's listings are focused on treatment practices that have been validated by research. If you know about an event that may be suitable for inclusion, kindly send the information to ctfeat1@ctfeat.org.

ASCONN's Blogspot

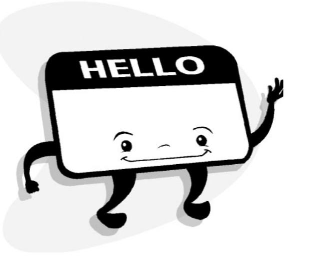
The Autism Society of Connecticut (ASCONN) provides a more comprehensive listing service through its "Autism in Connecticut" blog (www.autisminconnecticut.blogspot.com). The blog format permits people to post information on a broad range of autism related presentations, support groups, and activities.

Opportunities at SERC

Connecticut's State Education Resource Center (SERC), a non-profit organization primarily funded by the Connecticut State Department of Education, holds "professional development" workshops every school year, some of which are of interest to parents as well. You'll find upcoming events listed at their web site, www.ctserc.org.

SERC doesn't organize the listings by topic so you'll need to scroll through all of them to find workshops pertaining to autism.

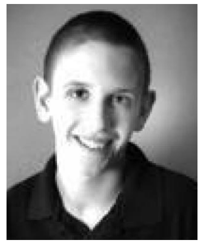
Pre-registration is required. The events tend to be very reasonably priced. SERC also offers scholarships to parents. SERC is also home to the Connecticut Parent Information and Resource Center (CT PIRC) which presents workshops on more general topics of presumed interest to families.



SAVE THE DATE!

Autism New Jersey's 28th Annual Conference, October 7-9, 2010, Atlantic City. New Jersey's statewide autism organization, "Autism New Jersey," (formerly known as COSAC) sponsors educational events throughout the year, as well as an outstanding, three-day, annual conference now in its 28th year. For more information, visit www.autismnj.org.

Berkshire Association for Behavior Analysis and Therapy (BABAT) Conference, University of Massachusetts, Amherst, MA, October 14-15 2010. This popular annual conference is primarily focused on professionals but many parents as well find it extremely worthwhile. BABAT is an affiliated chapter of the Association for Behavior Analysis International and of the Association of Professional Behavior Analysts. Learn more at www.babat.org.



Tyler's Gift

By Linda Jones, Tyler's Mother,
and edited by Catherine Bailey

Tyler,
From Harvard to Heaven all in one leap,
Your memory is ours to cherish and keep
Living with autism you had much to endure
Now through your precious gift you will be part of the cure

By Helena Clancy

The daily living with an autistic child can be filled with challenges and triumphs. Then the worst and unexpected happened; our family had to cope with the sudden death of our 16-year-old autistic teenager.

Tyler's journey began as one of twin boys born in October 1992. In November 1994 our twins were both diagnosed with autism. One son recovered and Tyler maintained a diagnosis of severe autism.

Supported by Birth to Three resources, Tyler started an Applied Behavior Analysis (ABA) program with Rutgers University supervised by Dr. Mary Jane Weiss. Our family was fortunate enough to be a part of an early ABA program offered in Connecticut for a limited number of six children. Tyler received intensive one-on-one training seven days a week learning how to learn.

In 2002 we started consulting Dr. Margaret Bauman, a neurologist specializing in autism from LADDERS in Massachusetts, for Tyler's medical concerns. She diagnosed a mitochondrion deficiency which was treated with vitamin supplements.

Throughout his life Tyler suffered from chronic constipation. Dr. Bauman referred us to Dr. Timothy Buie, a gastroenterologist. The two-year wait for an appointment was well worth it as Dr. Buie's input changed Tyler's life –medically and behaviorally. Dr. Buie diagnosed gastric reflux and treated it successfully with medication. Many of Tyler's maladaptive behaviors were a result of the pain he felt from these medical conditions.

In the summer of 2008, Tyler started a beading program and his jewelry business T.J. Designs was created. We started with random semi-precious stones that did not require a pattern and had Tyler put them on a piece of elastic using a needle. He was very good at it and it seemed to calm him. At our first craft fair in October 2008 we sold approximately 150 bracelets! Tyler, two of his teachers, and I were tickled to tears when we realized our success. Tyler made an average of two bracelets per day over the next year.

On September 18, 2009 Tyler did not get up to go to school. He passed away from unknown causes. There are so many memories to record. He struggled to learn and to communicate but he never struggled to love.

Tyler adored his twin brother and older sister. They spent time together playing basketball, listening to music, or playing instruments—his brother on the piano, his sister playing the violin, and Tyler drumming. His smile and gentle "butterfly" kisses let you know that no matter how bad his behavior he still loved you. Tyler loved to go to school and could hardly wait to walk down to the van in the morning. He loved to learn and he loved to make people proud of him.

Tyler's life was a learning gift. We learned patience; we learned if Tyler could not learn something it was our responsibility to learn how to teach him; we learned to never give up.

Our family made the decision to contact the Harvard Brain Bank to donate Tyler's brain to Dr. Bauman. We hope that the donation of his brain will serve as a medical gift for all future generations.

Donations in Memory of Tyler Jones can be made to:

AUTISM RESEARCH FOUNDATION
c/o Anatomy and Neurobiology, Dr. Margaret Bauman
Boston University School of Medicine
750 N. Albany Street, Boston, MA 02118

Editor's Note: a longer version of this article appears in the "Parent Perspectives" section of the CT FEAT web site, www.ctfeat.org

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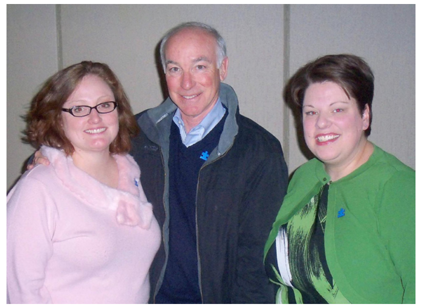
Autism Votes! Legislative Update

by Shannon Knall, Autism Speaks Connecticut Advocacy Chair

The New Year began with a sigh of relief for many parents when Connecticut's new law requiring insurance coverage for the diagnosis and treatment of autism spectrum disorders went into effect. Yes, my friends, autism insurance reform came to the Insurance Capital of the World making ours the 13th state in the country to do so.

It was a Herculean effort but, above all the clatter, our voices were heard. We succeeded in achieving important change. Is it everything we need? Absolutely not. Most disappointing is the fact that self-funded insurance plans are exempt from its reach.


Shannon Knall of Autism Speaks, Congressman Joe Courtney, and volunteer Sherry Pardy

But is it progress? Yes. Does its passage send a message to state and federal legislators? Heck, yes! For more information on the details of Connecticut's new autism insurance law (Senate Bill 301) visit www.autismvotes.org/connecticut.

Implementation of SB 301 has not come easily and we have received significant resistance from insurance providers. Most problems have been addressed; however, if you are still experiencing difficulty, please contact Maureen Smith in the Office of the Healthcare Advocate.

I thank our state legislative champions Senators Looney, Crisco and Harris, Speaker Donovan and Representative Abercrombie. And now we must keep the momentum moving forward. For all the progress Connecticut has made, it is not enough to keep up with meeting the needs of the escalating number of children being diagnosed.

Federal Initiatives

On the federal level, coverage for the diagnosis and treatment of autism exists in both the House and Senate versions of health care reform recently signed by President Obama. Additionally, Autism Speaks is working on three federal legislative initiatives:

First, the Autism Treatment Acceleration Act (ATAA). There are currently 12 sections of the ATAA, each focusing on a different aspect of autism. But Section 12 is of particular interest to the insurance movement because if passed, it will require all insurance companies to provide coverage for evidence-based, medically necessary autism treatments and therapies.

Second, the ABLE Accounts Act of 2009. The ABLE Act , a follow up to Senator Dodd's originally proposed Disabilities Savings Act of 2008, would encourage individuals with autism and other disabilities and their families to save, tax-free, for disability-related expenses.

Third, HR 4247, The Preventing Harmful Restraint and Seclusion in Schools Act. On a general level, this act would establish guidelines to protect children with autism and other disabilities from abuse in schools

For information on ANY of these initiatives, please visit www.autismvotes.org. You can also check there to see if your federal legislator has co-sponsored this legislation.

Congressional Forums

Throughout the winter months, Autism Speaks has been hosting Congressional forums around the state. The goal of these is twofold; first, to serve as a resource to our community and second, to educate our federal and state policy makers about the issues we face. By and large, they have been successful. Forums were hosted by Congressman Murphy, Himes, Courtney and Congresswoman DeLauro.

Were any immediate problems solved? No. However, the goal of educating both our community and our policy makers was attained. Again, we can't let the ideas posed in those forums disappear. The one clear message from all legislators was this: work together and be one voice.

This is not natural to us. In our quest for information, our fight for services, insurance, providers, what have you, we do not easily unite behind one voice. But we have no choice but to do so now.

One Word, One Voice

The fact of the matter is that autism unites us and in that reality, we need to unite as a community. Around one word. Autism. Not a message. Not an organization. Not a therapy. One word. Autism.

Imagine if we all went to the Capitol on Autism Awareness Day and all we said was the word, "Autism," with all the need for help and understanding that that single word implies. All of us packed in that one room, overflowing in to the hallway, saying only "autism" over and over until it was as familiar to our legislators as it is to us and to our families. Just imagine the power of that one word, broadly and deeply understood.

New Incentives to Hire the Disabled

Advocates for the disabled achieved an important victory this legislative session with the passage of Public Act No. 10-75, "An Act Concerning the Recommendations of the Majority Leader's Job Growth Roundtable."

This groundbreaking new law provides employers with tax credit incentives ($200 per month) for hiring people with disabilities. The bill was co-sponsored by State Senator Martin Looney of New Haven as part of the overall job growths bill he championed.

To be eligible, the new employees must be registered with the Bureau of Rehabilitation Services. Other details about the bill can be found at the Connecticut Legislative Assembly's web site: www.cga.ct.gov.

We thank all the legislators who supported this legislation as well as the family members and professionals who helped articulate the tremendous need for it. We also want to express our great appreciation for the vigorous advocacy of CT FEAT's Bob Shea, Autism Speaks' Shannon Knall, and all the other individuals and organizations that worked so hard to pass this important legislation.

Parent Training Funds: Applications Being Accepted!

The *Frank D. Craemer Memorial Parent Training Fund* was established in 2008 to support parents seeking information about current best practices in autism treatment. Mr. Craemer was the father of CT FEAT board member Rosie Shea and a loving grandfather, known as "Poppy," to his grandchildren Jeremiah and Fiona Shea.

According to Rosie, "Poppy had a special bond with Jer; we see Poppy in Jer when he sits on the patio by himself, legs crossed, looking at the trees. Jer has traded a stronger drink for a seltzer, but definitely embodies the "Frankster" while relaxing after a demanding day."

To date, this special Parent Training Fund has paid out over $2,000 to help parents defray the costs of attending educational events (e.g. lectures, training workshops, conferences, courses) focused on interventions validated by research. Parents learn about the most effective methods for teaching specific skills and achieving positive behavioral changes.

Some recently sponsored events include presentations by the River Street Autism Program and the Connecticut Association for Behavior Analysis. Monies from the Frank D. Craemer Memorial Parent Training Fund also were used to underwrite the cost of the two-day 2009 Basics of ABA Conference sponsored by CT FEAT and held at the University of Hartford. (Editor's note: read more about that conference in "Dynamic Presenters Deliver More than Just the Basics" elsewhere in this newsletter.)

Applications for funding can be submitted at any time. CT FEAT's board of directors reviews the applications on a quarterly basis and makes financial awards based on a variety of considerations, including the merit of the proposed activity, competing requests for funding, and the fund's quarterly budget. The scholarship may cover the entire cost of the activity or some portion thereof.

Frank Craemer and Grandson Jeremiah Shea

If you would like to be considered for a Parent Training Scholarship, please provide us with the following information: 1) Your contact information (full name, address, phone number and email); 2) Your child's age and date of diagnosis; 3) a description of the proposed educational activity (including names and background of presenters, location, date, and cost); 4) how you heard about the scholarship; and 5) a brief statement as to why you believe the activity would be beneficial to you.

Please send your scholarship funding request to: ctfeat1@ctfeat.org. Be sure to put "Parent Training Fund" in the subject line of your email. CT FEAT's board of directors typically act upon a request within two weeks of receiving it.

Treating Mild Autism

Book Review by *Beth Curry*

Parents of young children on the milder end of the autism spectrum (i.e. Asperger Syndrome, PDD-NOS, or other "high functioning autism") often have an especially difficult time finding appropriate ABA-based intervention.

The standard interventions provided by Birth to Three or the local school system may be too "prefabricated," and not tailored to the child's specific and sometimes subtle deficits. Or the intervention may be insufficiently intensive and systematic due to some vague hope that the child will "improve" on his or her own.

Either way, these children often fall through the cracks and never reach their full potential for social competence and independent learning.

Autism expert and author Mary Jane Weiss, Ph.D., has written a book focused on the special and often misunderstood treatment needs of such children. Like all of Weiss' books, Practical Solutions for Educating Young Children with High-Functioning Autism and Asperger Syndrome (2008) is written in such a way as to make it accessible to both professionals and parents.

For more than a decade, Weiss has been a director of the nationally renowned autism research and treatment center at Rutgers University. She has personal hands-on experience working with all kinds of children (across the whole range of impairment) and in all kinds of settings (e.g. home programs, schools, etc.).

Weiss draws upon this extensive experience to provide examples of how the principles of applied behavior analysis (ABA) can be used to remediate the social deficits characteristic of these children. She also explains how to incorporate other teaching approaches and materials in to ABA programs and, perhaps most importantly, how to use ABA methods to empirically evaluate the effectiveness of all such interventions.

Editor's Note: Dr. Weiss is also the co-author of various treatment oriented books recommended at the CT FEAT web site (www.ctfeat.org).

My Unexpected Move into Special Education: A Parent/Teacher's Perspective

Randy Ewart

When I packed up and moved to Connecticut two years, I was expecting big changes in my life. I was finishing up a job as a math teacher in South Carolina and getting ready to move north to pursue a doctoral degree in math education at the University of Connecticut (UConn). My wife and I were looking forward to the birth of our second child.

Two years, and an autistic disorder diagnosis, later I find myself living a somewhat different new life than I had envisioned then. Instead of a doctorate in math education, I'm now pursuing a master's degree in special education and autism.

I had always been amazed at the patience and dedication shown by the best special education teachers but I hadn't ever expected to find myself joining their ranks. Now I'm glad to be there. I wanted to share with my fellow parents in the autism community what this transition has been like for me.

Currently, I am in the Autism Spectrum Disorder certificate program at Saint Joseph College as part of a master's in special education. The certificate is comprised of five courses: Intro to Autism, Managing Behaviors, Assistive Technology, Assessment, and Instruction. The director is Dr. John Molteni, Ph.D., BCBA, a behavior analyst who, in addition to his work developing and directing the program at Saint Joseph, is a popular speaker at informational workshops in the community.

Molteni and the other instructors are practitioners who have tremendous practical experience addressing the issues our kids commonly have with social skills, organization and planning, empathy, and communication. What I learn from them has often been useful to me in my personal life.

For example, while out walking one day my wife I happened to meet a 10-year-old girl whose behavior struck me as being on the spectrum. When I agreed to let her push our stroller, she asked "if the stroller falls over, is that funny or is that serious?" I immediately understood from my course work that, lacking a well developed sense of empathy and perspective taking, this little girl had instead learned to make sense of the world by systematically going through the possible outcomes of a given situation.

My autism related courses are providing me with a kind of expertise that is often missing in our schools. Dr. Molteni shared that, due to the lack of this specialized knowledge in many schools, someone who had taken only the introductory autism course might find themselves being the most "expert" person in a school.

Indeed, in the PPT meetings concerning my son, I am often the only one with any knowledge of autism. I know that we parents are the greatest "experts" when it comes to our children but I hadn't expected to find myself being the main "expert" when it comes to my child's education.

While pursuing my degree, I continue to work as a teacher. In that capacity, I already have found opportunities to use the knowledge about autism that I am acquiring. For example, I have two students on the milder end of the spectrum (PDD-NOS and Asperger). I realized that one of my students needed extra help in organization and planning in order to complete his science fair project. He won and is moving on to the regional competition!

Randy Ewart

My students also have found it helpful when I use color coding to break down steps in math topics. I am expanding this intervention by addressing what we call universal design - creating an environment that is useful for ALL students. A familiar example is the use of ramps built into curbs to allow wheel chair access.

My education in autism, both personal and professional, has led me to recognize that our current special education system usually falls far short of achieving its purpose. The legal purpose of special education is to help kids learn academic, daily living, and employment skills. However, schools typically concern themselves only with very narrowly conceived "academics" not appreciating that they must teach all the skills necessary for independent living and employment.

For example, I personally know of a case concerning a child with glaring adaptive functioning deficits of the kind that definitely would interfere with employment and daily living. The principal of the child's school considered him ineligible for any kind of special education services because he had scored adequately on the CMTs.

Sadly, this kind of negligence and neglect is not uncommon – or so I've learned from other parents who participate in CT FEAT's "Parents Only" listserv discussion group. There is a lack of long-term planning to prepare our kids for the inevitable transition into the real world. Those kinds of "real world functioning" skills should be addressed from the first day of treatment. But too often those skills aren't dealt with at all until high school – a classic example of too little too late.

Though many teachers and administrators are very caring about our children, too often our schools lack in-house experts with sufficient expertise. To address this deficit, schools need to invest more in leadership and training. And, if parents are to be true partners in their children's education, that training should include parent training as well. Parent training should focus not only on how parents can generalize at home the lessons learned at school but also on how to help articulate educational objectives and assess the progress being made in attaining them.

There certainly is a lot more "autism awareness" these days but not enough awareness about what to do about it. I think that some of the suggestions I've made could go a long way towards improving our children's lives both now and in the future when they are living the independent lives that school is supposed to prepare them for.

Dynamic Presenters Deliver More than Just the Basics

Beth Lambert

CT FEAT's conference about the basic principles of applied behavior analysis (ABA) was aptly titled The Basics of ABA. Sounds drier than a Sahara rock garden, doesn't it? But dynamic presenters Greg Smith (BCBA) and Patricia Bush (BCaBA) of the River Street Autism Program knew how to juice up the topic for their mixed audience of 30 parents and professionals.

By the end of the two-day conference, which took place last year at the University of Hartford, many of the participants talked about having had a "eureka" moment regarding the power of ABA to positively change behavior.


Patricia Bush and Greg Smith of the River Street Autism Program and Beth Lambert, president of CT FEAT

According to one psychologist in attendance, "Greg and Trish's knowledge, personable nature, and humor made me re-think some of the misconceptions I had about ABA." A parent evaluating the conference wrote: " I loved this workshop! We need more people like Greg and Trish educating parents and school staff. It was worth the 100 mile trip!" And a paraprofessional declared "I've been doing [ABA] without really getting the "big picture." Now I do. Thank you!"

Using lectures, videos, group interaction and role playing, the presenters worked with a diverse audience of teachers, paraprofessionals, psychologists and parents to show them how to "think like a behavior analyst." By the end of the conference, the audience understood how ABA is used throughout the day – not just in discrete trial training - to improve a child's functioning in all areas of his life.

Greg emphasized that this is called applied behavior analysis for a reason: teachers can't sit in an office and have an effect. In order to determine what drives a child's behavior, and positively change that behavior, they need to conduct behavior analysis in every environment, be it the classroom, playground, school bus, grocery store or home. Only then can they formulate an effective plan to build and reinforce positive behaviors and extinguish negative ones.

Participants were provided with the opportunity to share specific examples of students' challenging behaviors and then led through the steps of formulating an effective behavior plan. That process begins with questions like: Why is the child doing it? How is the behavior reinforced? What would be a more appropriate behavior? According to Greg, there are always answers if you are asking the right questions.

By the end of the two-day conference, Greg and Trish had provided the audience with solid techniques to improve the lives of people with autism and their families. The evaluations by the participants were overwhelmingly positive. CT FEAT was proud to have had this opportunity to help all these caring professionals and parents learn more about how to help our children with interventions validated by research.

Editor's Note: The 2009 Basics of ABA Conference was subsidized by the *Nancy Leahy Shea Memorial Scholarship for Professional Development* and *the Frank D. Craemer Memorial Parent Training Fund* as part of CT FEAT's commitment to increasing parents' and professionals' knowledge of effective autism treatments. To learn more about this scholarship visit the CT FEAT website – www.ctfeat.org

Hilton Employees' Generosity


HILTON EMPLOYEES PHOTO: *L to R: Waterford Group General Manager Jeff Roike, CT FEAT Vice President Donna Cohen, daughter Rachel, CT FEAT President Beth Lambert, son Lawrence, Hilton employees*

This past December the kindhearted employees of the Hilton Hotel in Hartford surprised CT FEAT with a generous donation collected by means of voluntary payroll deductions. The Hilton employees gathered together with CT FEAT members to witness General Manager Jeff Roike present CT FEAT's delighted president, Beth Lambert, with a check for $1,000.

Lambert, who was accompanied by her son Lawrence, expressed her deep gratitude to the Hilton employees for recognizing the importance of CT FEAT's work on behalf of families of children with autism spectrum disorders. She stated that the money will be used to support the educational and networking opportunities that CT FEAT provides.

The Hilton is managed by the Waterford Hotel Group which has created a private charitable foundation that supports the communities in which associates of the Waterford Group live and work. The donation to CT FEAT came from the foundation.

The Waterford Group Charitable Foundation's mission is to improve the quality of life of others through monetary and gift-in-kind donations, as well as volunteering at various events. Donations are provided to not-for-profit organizations that support health and well-being, youths, arts and cultural activities, and other community initiatives.

Once again, thank you Hilton Hotel employees and Waterford Group!

Stares

L. to R.: Sisters Rachael (17) and Naomi (14) Cohen

Rude people
Looking at her
Just because she's different
Mothers, fathers, children, and more
"She talks funny," I hear them say
Sixteen years old; carries a teddy bear
Sixteen years old; watches Barney
Sixteen years old; screams in public

Loving people
Hugging her
Just because she's different
Aunts, uncles, cousins, and more
"I love her," I hear them say
Sixteen years old; carries a teddy bear
Sixteen years old; watches Barney
Sixteen years old; loved by family

Clueless people
Staring at her
Just because she's different
Grandmothers, grandfathers, children, and more
"She looks funny," I hear them say
Almost seventeen; eats children's meals
Almost seventeen; watches Sesame Street
Almost seventeen; yells in public

Caring people
Kissing her
Just because she's different
Grandma, Grandpa, friends, and more
"I adore her," I hear them say
Almost seventeen; eats children's meals
Almost seventeen; watches Sesame Street
Almost seventeen; loved by all

-by Naomi Cohen

Recovered - DVD Review *by Sue Frost*

Twenty years ago, Doreen Granpeesheh founded the Center for Autism & Related Disorders, Inc. (CARD), one of the first private agencies providing autism intervention services grounded in the principles of applied behavior analysis (ABA). Today, CARD is headquartered in southern California and has offices around the country and throughout the world.

Granpeesheh, a board certified behavior analyst (BCBA) with a Ph.D. in psychology, studied with Ivar Lovaas at UCLA. Her documentary about autism treatment, *Recovered: Journeys Through the Autism Spectrum and Back*, is dedicated to Lovaas and another pioneer in autism treatment, the late Bernard Rimland.

CARD's earliest clients are now teens and young adults, and Granpeesheh has video tapes documenting the early treatment progress of some of them. In 2003 it occurred to her to try to track down some of those children and see how they are doing today.

She managed to contact six of the children, five of whom had recovered from autism. Four of these families agreed to participate in this documentary, with parents and children alike agreeing to be interviewed to describe their lives today and how they had been affected by their treatment experiences.

Some of the parents alluded to the fact that much of the medical community is unaware of the prevalence of recovery and therefore unlikely to alert parents to that possibility. "The very devastating thing about autism is not only dealing with the autism but also with the ignorance among health professionals." They wanted to help fill that information gap by providing hope to families of newly diagnosed children that recovery is indeed possible for some children.

What is "Recovery"?

Dr. Granpeesheh defines recovery as normal scores on intelligence tests, language tests, adaptive functioning tests (including social functioning), and attending regular education school without support. A psychologist assessing the child would not be able to tell that the child had ever had a diagnosis of an autism spectrum disorder.

Of course, not all children recover and therefore "recovery" is not the goal for every child. According to Granpeesheh, "At CARD, we strive to teach our children functional skills necessary to live independent and productive lives" and for some children that path leads to recovery. Granpeesheh states that "hundreds" of CARD's clients have recovered and that treatment has greatly improved the lives of "thousands" more.

The Children

The film tells the stories of Janna, Brett, Ruffin, and Nick ("Deke"). The children all have positive recollections about their years in therapy but some also remember how difficult it was at the outset.

Janna was diagnosed with autism and an IQ of 73 (mild mental retardation) at age 2 years 7 months. After an average of 28 hours/week of intervention for 3 ½ years, her IQ at age 6 was 106 and her adaptive functioning was in the normal range. She was recovered.

Brett was diagnosed with autism and an IQ of 75 (mild mental retardation) at age 2 ½ years. After an average of 31 hours/week of intervention for 5 years, his IQ at age 7 was 110 and his adaptive functioning was in the normal range. He was recovered.

Ruffin was diagnosed with PDD and an IQ of 50 (moderate mental retardation) at age 3 years 3 months. After an average of 27.3 hours/week of intervention for 2 ½ years, his IQ at age 6 was 112 and his adaptive functioning in the normal range. He was recovered. By age 12, his IQ had increased to120.

Nick ("Deke") was diagnosed with autism and an IQ of 83 (within borderline of intellectual function) at age 4 ½. After an average of 26 hours/week of intervention for 5 years, he had lost his autism diagnosis but still had some residual adaptive functioning issues. His intervention continued, though gradually faded out over the ensuing years, and by the age of 13 his IQ was 109 and his adaptive functioning was in the normal range.

The Children's Intervention

According to Granpeesheh, all the children who recovered had parents who were highly involved in their treatment. Parents were trained to help teach and generalize adaptive skills.

Each child received interventions from CARD, including assessments, supervision, parent/teacher training, and one-on-one behavioral therapy.

The interventions began with an assessment of the child's strengths, and what skills needed to be taught. If the child had problems sleeping, eating, was in pain or had any other physical problems that would interfere with treatment, those issues were addressed first. Then an individualized ABA program was begun to teach the child the skills needed.

During the first year of intervention, the children received 30-40 hours of intervention at home. They had about 5 different therapists, each doing 2-3 hour sessions.

During the second year, the children were mainstreamed into a regular pre-school for about 9 hours/week. One of their therapists went with them, to help them focus on applying their recently-acquired skills with their peers. The children continued their home therapy in the afternoons.

During the third year, the children spent about 6 hours/day at school. By now, they had mastered their language skills, and were working on cognition, other people's perspectives, and executive functioning. During the last year, the hours of therapy were faded out.

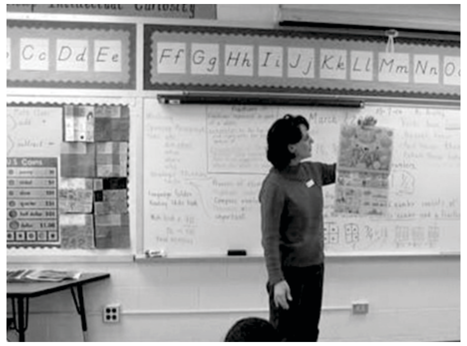
Advice From The Children's Mothers

One mother in the film says that what worked most was hard work: repetition, one step at a time. She says, "Find the best provider—the one getting results."

Another mother urges parents to do "whatever it takes. Do it quickly, do it early, do it hard in the beginning. The payoffs are enormous… It's very important to get an early diagnosis, and to move, do whatever you have to do financially to make it possible to do something between ages 3 and 5, 4 and 6."

This 2008 film by Granpeesheh and Jacquis is available through CARD at www.recoveredautism.com for $29.95 plus shipping. It runs for approximately 57 minutes. Also included is a second disc, providing more information about the children, autism, and CARD.

BEING A TEAM PLAYER:
OBSERVING YOUR CHILD IN THE CLASSROOM *Beth Lambert*



Whenever a parent expresses concern about their child's lack of progress at school or home, my first piece of advice is to get into the classroom to see what is happening. Over the 13 years my son has been in school, I have learned a tremendous amount by observing him there.

Why do I go into the school? I need to see what my son is and isn't doing there. Like many children on the autism spectrum, he has difficulty generalizing skills to new people, new areas and new materials.

Sometimes he does things in class that I didn't know he was capable of. Sometimes he is not doing things there that he is capable of doing at home. By observing him at school, I can help him generalize skills across all settings: in the school, home and community.

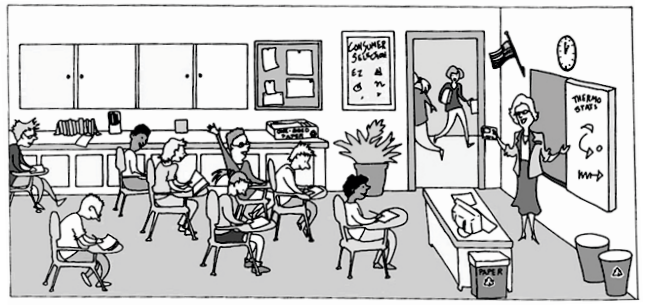
Requesting Permission to Observe

How do parents get permission to visit their child's classroom? Most schools have a written policy about parent observations/ visitations. The policy usually includes notifying the staff ahead of time, signing in and out of the school, and picking up some type of badge to indicate you are a visitor. Sometimes they may want another staff person to accompany you throughout your stay.

Before requesting permission to observe my son, I determine just why I need to visit. I look over the Individualized Education Program (IEP) to see which objectives seem to be mastered at home and which have not. Then I ask myself: About which skills am I most concerned? Which teaching approaches would I like to see demonstrated?

I usually deal directly with my son's teacher in setting up the time. I might say "I'd like to come in and observe him doing X. When would be a good time?" or "I'd like to observe him during story time. Would Monday or Wednesday be better for you?" Note that both ways you're not asking for permission; you are asking them when a good time is.

I also respect the teacher's answer. If she tells me that some of her staff have asked for a day off so she'll be shorthanded or will have substitute paraprofessionals in the room, I choose another day. I want to see my son on a typical day.



A Teacher's Perspective

I taught school for many years and I know that there are parents who don't know how to behave appropriately in the classroom. But in my experience, they are the exception and not the rule.

I always make an effort to demonstrate, by my overall behavior, that I am not interested in critiquing the staff or in observing anyone's child but my own. I'm there purely as a member of the pupil placement team (PPT) with the goal of making a constructive contribution to my son's educational program.

If a teacher or a school were to refuse me permission to observe, it would be a HUGE red flag for me. Of course, a parent should cooperate with the overall schedule and routine of the school and abide by all reasonable suggestions as to when to attend and where to place yourself in the room.

The key to being welcomed into a school is to have respect for the staff and to conduct yourself appropriately. If you word your request politely and make your legitimate intentions plain, no school or teacher should refuse you. If they do, ask to see the written policy about school observations or visitations.

If the teacher tells you that your visit will disturb the rest of the class, reassure her that you won't be interrupting. Find a place to sit in the room where you can see/hear and then just sit quietly.

Some parents report that teachers have tried to discourage them by claiming that the child would be upset and distracted by their presence. My son's first therapist from CREC told me, "If it bothers him to see you in the room, then you need to come in more often. He should be able to look up, say 'hi mom,' and go back to work/play."

Other parents have found it worthwhile to observe their children by volunteering in the classroom. Teachers are often grateful to have extra hands preparing class materials and otherwise helping out as needed. Working under the teacher's direction, parent volunteers help all of the children in the class and not just their own.

How to Observe

In order to see and hear what is happening, I have not always needed to be physically in the classroom. Some schools will have a remote camera and microphone set up in the classroom that allows you to watch and listen from another room. Others have observation rooms where you can see and hear what your child is doing.

But sometimes that may not be adequate. For example, my son's current classroom has an observation room with a two-way mirror. But I am not able to see the materials well enough to really understand what he is or isn't doing. Therefore I go in the classroom and observe there.

A parent has the right to be in the classroom. As part of the PPT team you need first- hand knowledge of what your child is and isn't doing there. If you prepare and behave appropriately, the experience will be pleasant and constructive for all concerned.

Four Easy Rules for Successful Classroom Observation

1. Don't interrupt the teacher or the lesson.

If I see something I don't understand, or would do differently, I make a note to talk to the teacher at some more appropriate time. Many teachers are concerned that you're really in the room to judge them and will get flustered if you interrupt what they are doing. That's not fair to the teacher and it's especially not fair to the children.

2. Observe only your own child, not the other children in the room.

I'm not looking around to see what skills the other children are working on or to determine what services they get. I wouldn't want a stranger observing my son for such improper reasons so I won't do it to others. I respect the privacy and confidentiality of every child in the class.

3. Let the teacher know ahead of time the skills you'd like to see.

Often, time is limited so if there's a certain skill I want to see my child perform, I let the teacher know. Sometimes my son will do things for the teacher that he won't do for me. Seeing it done, I know I can make him accountable for bringing those skills home. Likewise, my son may have skills at home that he's not demonstrating at school. When I share that fact at the monthly meeting, the school staff can then increase their expectations of him at school.

4. Take notes about what you are seeing

I have one notebook dedicated solely to school observations. This helps me share what I've learned with the teacher and my husband. Otherwise it can be hard to remember the important details until the next monthly meeting or opportunity to speak with the teacher.

WILL YOU RECEIVE CT FEAT'S NEXT NEWSLETTER? ?

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In order to save paper and money, future issues will be mailed ONLY to those who sign up by writing us at ctfeat1@ctfeat.org;
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This issue of the newsletter was edited by CT FEAT volunteer Beth Curry, with original graphic art contributed by Joe C-S.

The Newsletter also can be found online at www.ctfeat.org.

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