



**NEWSLETTER**

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**CT FEAT Donates  
Autism Resource Books  
to Libraries Across the State**

(Denise Buckenheimer)

CT FEAT is undertaking an exciting new initiative to further our goal of helping families learn about and have access to as much information as possible regarding effective autism intervention. We have begun an extensive book donation to public and academic libraries across the state.

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**CT FEAT  
PARENT RESOURCE  
MEETING**

*Thursday, May 12, 2005  
Waterbury*

(Continued on page 3)

**BOOK REVIEW**

**THE SOCIAL SKILLS  
PICTURE BOOK:  
Teaching Play, Emotion, and  
Communication to  
Children with Autism**

By Jed Baker

(Reviewed by Sue Frost Bennett)

A picture is worth a thousand words when it comes to teaching social skills, and this book is packed with them. Parents and teachers will find this book easy to use, with little advance preparation needed. And it's fun!

(Continued on page 21)

## ***In the Next Issue of CT FEAT Newsletter***

Parents Karen Neag (LACASA ) and Roseanne Shea, (CT FEAT) testified as invited speakers at the informational hearing of the *State's Committee on Higher Education and Employment Advancement* on February 10. Both parents, as well as a number of noted professionals, spoke about the need for quality higher education programs to prepare professionals to work with the growing population of people with autism spectrum disorders. The lack of professional development paths in behavioral studies was a key discussion point. A recording of the hearing is available online at [www.ctn.state.ct.us/ondemand.asp](http://www.ctn.state.ct.us/ondemand.asp). ▣

## ***Have You Visited Us Lately?***

**[www.ctfeat.org](http://www.ctfeat.org)**

**ABA Job Connections**

**Updated Conference Listing**

**CT FEAT Newsletter Archives**

**Recommended Resource Materials**

**ABA Programs and Consultants Listing**

**Research Articles on Effective Intervention**

**Info on Joining the CT FEAT PARENTS ONLY LISTSERV**

CT FEAT NEWSLETTER is published two times a year by Connecticut Families for Effective Autism Treatment, Inc. (CT FEAT), a non-profit organization providing information, resources and support for the families of children with Autism Spectrum Disorders (ASD), including Autism (Autistic Disorder), Asperger's Syndrome, and other Pervasive Developmental Disorders (PDD). It is edited by Roberta Daversa with assistance from Sue Frost Bennett, and made possible through the generous contributions of supporters of CT FEAT.

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## ***WHY SUPPORT CT FEAT? Help Us to Help You***

**Your contributions help to pay for costs associated with the CT FEAT web site, telephone hotline, parent meetings, presentations, and other activities designed to provide information and support.**



You can be sure that your contribution will go *directly to provide resources* that will enable families and other interested persons to learn about effective autism treatment and to help children with autism achieve their full potential.

Please consider sending a check to CT FEAT (address below), or participating in any of the following:

### ***SBC COMMUNITY CONNECTIONS***

If you are a SBC customer, SBC will pay CT FEAT 5% of every dollar you spend on long distance calling. You can sign up today by calling 800-635-7638.

### ***The UNITED WAY***

Even though CT FEAT is not listed on the pledge card, it is eligible to receive your donation. Most United Way organizations will forward your gift to us if you write the CT FEAT address (below) and telephone number (860-571-3888) on the pledge card, or write the information in on your electronic pledge (click on "Write-In" on the designation page).

**Donations should be sent to:**

**CT FEAT,  
P.O. Box 370352,  
West Hartford, CT 06137**

**CT FEAT Information Hotline (860) 571-3888**

***Thank You!***

CT FEAT  
**PARENT RESOURCE MEETING**



Thursday, May 12, 2005  
University of Connecticut  
Waterbury Campus (Room 113)  
Main Conference Room, 1<sup>st</sup> Floor

6 PM:  
Parent Resource Browse and Video Preview \*

7 – 8:30 PM:  
Your Role in Your Child's Education  
Questions and Answers with Julie Augeri,  
Child Education Advocate

The meeting will begin at 6 PM with time for parents to browse the CT FEAT resource collection of books, videos and DVDs. Previews of new teaching resources, *Teaching Actions Volumes 1, 2 & 3*, which feature video techniques for language programs, will be shown. \*

At 7 PM, Julie Swanson Augeri will talk about the role of parents in Individual Education Program (IEP) planning and implementation, and will discuss questions from parents regarding IEP issues. Julie is the mother of a child with autism, a disability specialist, and an education advocate. Julie is also the creator of the television program *All About Your Special Child* (see page 10).

**Please Note: This meeting is for parents and family members only; Unfortunately, childcare is not available.** The only requirement for participation is that parents agree to respect each other's confidentiality. Directions to UConn Waterbury can be found on the CT FEAT web site, [www.ctfeat.org](http://www.ctfeat.org). For more information, call the **CT FEAT Hotline** at (860) 571-3888.

**\* Teaching Actions Vols. 1, 2, and 3**

These DVDs aim to improve language development in children with language deficits. The *Teaching Actions* DVDs are collections of short action scenes (30-60 seconds) used to teach children how to label actions. Each disc also includes footage of a behavior analyst demonstrating assessment and teaching techniques. Photographs from the DVDs are included on CD-ROMs, to be used as flash cards. Data forms to monitor the child's learning are also provided, making *Teaching Actions* an innovative tool for language enhancement. ■

CT FEAT Announces

*Nancy Leahy Shea Memorial Scholarship*



The CT FEAT Board of Directors is honored to announce the third CT FEAT ABA Educator Scholarship. This award has been made possible through generous memorial contributions to CT FEAT on behalf of Nancy Leahy Shea.

The scholarship will be awarded to a CT teacher or paraprofessional interested in pursuing national certification as a Board Certified Associate Behavior Analyst. It will cover the cost of online undergraduate university courses in applied behavior analysis (ABA), required by the national Behavior Analyst Certification Board (BACB).

Applicants must be currently working with children with autism and have a bachelor's degree in a related area. Non-degreed students who are currently working toward a bachelor's degree are also eligible to apply for the scholarship.

Nancy Shea is the grandmother of a child with autism. She was a devoted family member and a graduate of Aquinas College of Milton, Massachusetts.

The CT FEAT Board of Directors deeply appreciates the overwhelming generosity of the family and friends of Mrs. Shea, and the thoughtfulness of their contributions. Their vote of confidence in our work, to provide resources to the autism community, is a touching tribute to Mrs. Shea. We are grateful to the many people who have made this award possible, and are especially grateful to the family of Nancy Shea for directing these very special contributions to CT FEAT.

For more information about the Nancy Leahy Shea Memorial ABA Scholarship, please e-mail Roberta Daversa at [editorCT-FEAT@aol.com](mailto:editorCT-FEAT@aol.com), or call the CT FEAT Information Hotline at (860) 571-3888. ■

**Teaching Social Communication Skills:  
The BASIC Curriculum**

**B**uilding  
**A**ppropriate  
**S**ocial  
**I**nteraction and  
**C**ommunication Skills



The River Street Autism Program provides intensive early intervention for children with autism, using evidenced-based practices for the development of Social Communication Skills through The BASIC Curriculum.

Evidenced-based practices provide scientifically derived interventions that fall on a continuum of adult directed activities in structured, distraction-free contexts, to child directed activities in natural contexts, and are provided through repeated, planned teaching opportunities.

Nationally recognized experts in autism, including Kathleen Dyer, Ph.D., Clinical Director of the River Street Autism Program, developed the procedures used in the BASIC Curriculum using principles of Applied Behavior Analysis (ABA).

Dr. Dyer has collaborated with Dr. Robert Koegel at the University of California – Santa Barbara, to develop child-directed procedures to reduce core deficits including social avoidance behavior, repetitive behavior and communication deficits. These procedures are integrated with other evidenced-based practices for intensive early intervention and result in increases in positive affect, social approach and spontaneous communication with Autism Spectrum Disorders.

The BASIC Curriculum addresses core deficits and develops relationship skills, social emotional reciprocity, joint attention

social approach and initiation, spontaneous speech, group participation and generalized communication.

BASIC intervention strategies include discrete trial training (DTT) for initial acquisition of skills, and other evidence based techniques, including modeling, Picture Exchange Communication, choice and preference, visual supports, child-directed activities, Pivotal Response Training, paced instructions, social stories, and natural language generalization.

The BASIC model of social communication involves a systematic, individualized intervention plan for each child, designed according to a comprehensive social and communication skills assessment. Baseline skill level and ongoing data collection are maintained to monitor and adjust ongoing program development. Instruction begins with one-to-one teaching of BASIC skills and expands into carefully planned small-group environments to facilitate generalization of learned skills. Careful manipulation of positive reinforcement and other data-driven, sophisticated teaching techniques are utilized to move the child toward independent social interaction and communication. ■

**Teaching Social Communication Skills  
Using Systematic Interventions**

**A Series of CT FEAT Workshops  
for Parents and Educators**

**Fall 2005**

**Details Will Be Made Available on  
the CT FEAT Web Site,  
[www.ctfeat.org](http://www.ctfeat.org).**

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**ORGANIZATION FOR AUTISM RESEARCH**

**AN EDUCATOR'S GUIDE TO AUTISM**



Free Publication for Parents and Educators  
Available Online or In Print

*An Educator's Guide*, the second book in the *Life Journey through Autism* series of resource guides published by the Organization for Autism Research (OAR), is now available. OAR, a national nonprofit organization whose mission is to apply research to the daily challenges that people living with autism and their families must face, is distributing the *Guides* free of charge to education professionals and parents of children with autism as part of their national autism education initiative. *An Educator's Guide* provides parents, teachers and education professionals with a six-step plan for teaching a child with autism in the general elementary classroom setting.

**“With the current emphasis on teaching children with autism and developmental disabilities in the inclusive classroom and the increasing numbers of children being diagnosed on the autism spectrum, more and more general classroom teachers are teaching children with autism for the first time,”** said Michael V. Maloney, Executive Director of OAR. “With this goal in mind, we have developed *An Educator's Guide* as a resource to provide a working understanding of autism and a practical approach to establishing the most beneficial learning environment for the student with autism and his or her typical peers. Based on the feedback we have received so far from educators who have viewed the *Guide*, we are confident that it will prove to be a useful resource.”

*(Continued on page 23)*

**APPLIED BEHAVIOR ANALYSIS  
FOR AUTISM**

Gina Green, PhD, BCBA  
San Diego State University  
University of North Texas

Recent years have seen a surge of interest in applied behavior analysis (ABA) in the treatment of autism. Scores of programs and practitioners claiming to "do ABA" have popped up, some seemingly overnight. Many stories about ABA for autism have appeared in the electronic

*Overusing discrete-trial procedures tends to produce skills that do not carry over from the training situation to other everyday situations... effective ABA programming blends discrete-trial procedures with a variety of other ABA methods, including child-initiated instructional sequences... There is a heavy emphasis on making learning enjoyable, and on engaging the learner in positive social interactions.*

and print media, and various task forces and committees have undertaken to evaluate published research on ABA and other approaches to autism treatment. Yet misconceptions about ABA – including some that have been around for years – persist, and many treatment programs that claim to be "doing ABA" really are not. How can families, professionals, and funding agencies differentiate genuine ABA programs and practitioners from posers? It is difficult to paint a picture of

genuine ABA treatment for autism in words, especially in a limited space, but this article attempts to describe some of its key features.

Behavior analysis is a natural science approach to understanding behavior; ABA is the use of behavior analytic methods and research findings to change socially important behaviors in meaningful ways. Autism is only one of many arenas in which behavior analysis has been applied successfully. Since the early 1960s, hundreds of researchers have documented the effectiveness of ABA principles and methods for building a wide range of important skills and

*(Continued on page 22)*

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**RESEARCH REPORT:**

**Early Intensive Behavioral Works  
and "Eclectic" Doesn't**

A Comparison of Intensive Behavior Analytic and Eclectic Treatments for Young Children with Autism

Jane S. Howard\*, Coleen R. Sparkman, Howard G. Cohen, Gina Green, Harold Stanislaw

**Abstract**

We compared the effects of three treatment approaches on preschool-age children with autism spectrum disorders. Twenty-nine children received intensive behavior analytic intervention (IBT; 1:1 adult:child ratio, 25-40 h per week). A comparison group (n = 16) received intensive "eclectic" intervention (a combination of methods, 1:1 or 1:2 ratio, 30 h per week) in public special education classrooms (designated the AP group). A second comparison group (GP) comprised 16 children in non-intensive public early intervention programs (a combination of methods, small groups, 15 h per week).

Independent examiners administered standardized tests of cognitive, language, and adaptive skills to children in all three groups at intake and about 14 months after treatment began.

The groups were similar on key variables at intake. At follow-up, the IBT group had higher mean standard scores in all skill domains than the AP and GP groups. The differences were statistically significant for all domains except motor skills.

There were no statistically significant differences between the mean scores of the AP and GP groups.

Learning rates at follow-up were also substantially higher for children in the IBT group than for either of the other two groups.

These findings are consistent with other research showing that IBT is considerably more efficacious than "eclectic" intervention.

Research in Developmental Disabilities 26(2005)  
359-383

*The complete article may be viewed at the CT FEAT web site, [www.ctfeat.org](http://www.ctfeat.org) (see "ABA"). – Editor ✉*

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**ESTATE PLANNING  
FOR PARENTS OF CHILDREN  
WITH DISABILITIES**

by Thomas D. Begley, Jr.  
and John F. Kearns III  
© Special Needs Alliance, LLC



Harry, 48, and Sally, 46, have a child with autism, Bill, age 21. Bill lives with his parents. The couple is concerned about Bill's welfare after they die. Harry and Sally always thought that Bill would live with his sister, Joan. Joan has three children and it is apparent that Joan's husband, Andy, will not be happy with Bill living in his home.

Harry and Sally have a home, retirement plans, and \$100,000 in investments. They have life insurance. Bill receives SSI and Medicaid, and he can have no more than \$2,000 of assets. Any income Bill receives will reduce his SSI benefit dollar-for-dollar, and if he loses his SSI, he loses his Medicaid. Bill would be eligible for a group home.

Like all parents of children with disabilities, the critical question in Harry and Sally's mind is, "what will happen to our child after we die?" Families are fearful that, after the parents die, there will be a loss in the quality of life of the person with disabilities. The child will lose his parents as his most effective advocates, his parents' financial resources, and the child's lifestyle in the parents' home.

From a legal and financial standpoint Harry and Sally are anxious about how to protect Bill in the future.

*(Continued on page 24)*

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Did You Know?

Special Passes at  
Disney , Other Parks,  
for Children with Disabilities



(Danielle Green-Barnard)

Families of children with disabilities are eligible to receive a special pass so that they do not have to wait in line for rides and other amusements at all 4 Disney parks in Florida. The *Fast Pass* can be obtained after entering the park at the Guest Services Office. Families visiting the parks with a child with disabilities may use the pass for the entire family at Magic Kingdom, EPCOT, Animal Kingdom and MGM (now known as Disney Studios).

Needless to say, this feature was a wonderful advantage for our family vacation. All we did was bring a letter from our child's pediatrician confirming the disability. We also had a letter regarding our son's special dietary needs so that we could bring food into the parks.

My husband and I did the same at Universal and Sea World, and we were accommodated though their guest services as well. You really can see a lot more of the theme parks without waiting in those long lines.

It's a good idea to contact Disney to confirm that this program is still in place before you visit if you plan to do so. You can reach them by telephone at 407-939-6244, or by using the guest relations contact page on the Disney World web site, [www.cure.disney.go.com/wdw/contact/contactUs?id=ContactUsPage](http://www.cure.disney.go.com/wdw/contact/contactUs?id=ContactUsPage).

You also might want to check with the airline carrier that you plan on using, regarding special accommodations for avoiding long security checkpoints for children with

**BOOK REVIEW**

**THE CHILD WITH AUTISM  
GOES TO TOWN:**

*The Go-Anywhere Guide*  
By Kathy Labosh

(Reviewed by Roberta Daversa)

Taking children with autism out into the community can be a challenge. In this handy little guide, Kathy Labosh, the parent of 2 children with autism, shares the many, insightful tips she has learned along the way. She attributes the collection to professional advice, trial and error, and that familiar, often harsh teacher, hindsight.

The booklet is filled with simple, insightful techniques to help children succeed in public places and to head-off difficulties that can sabotage family outings, from the playground to the movie theater.

Also included are sections on going to the barber or hair-dresser, doctor and dentist visits, and advice on how to prepare your child for hospital stays.

Many of the 15 topics begin with suggestions on pre-teaching at home, before going to the event, like having your child watch a favorite video in an increasingly dark room and slowly adjusting the volume, in order to acclimate him or her to some of the elements of the theater.

*The Child with Autism Goes to Town* is part of *The Child with Autism* series by Labosh Publishing ([www.laboshpublishing.com](http://www.laboshpublishing.com)). The 48 paged, pocket-sized booklet costs only \$5.00 and is loaded with practical, do-able advice for overcoming the challenges that children and their families often face in everyday life. It is available through Different Roads to Learning ([www.differlearn.com](http://www.differlearn.com), or 800-853-1057). ISBN 0-9744341-1-6. ❧



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**The  
Outreach  
Program for  
Soccer**



**National TOPSoccer Program Offers  
Training and Fun!**

(Donna Cohen)

The Outreach Program for Soccer (TOPSoccer) is a national soccer program for children with special needs who are between the ages of 4 and 19 years old. The program is run as community-based teams, staffed by local volunteers. TOPSoccer is affiliated with the US Youth Soccer Association (USYSA), and shares their mission "to foster the physical, mental, and emotional growth and development through the sport of soccer at all levels of age and competition."

Emphasis is on skill-building and meaningful participation (rather than competition), in a caring coaching environment. TOPS coaches are trained to build on the strengths of each child and to assess the player's progress in order to provide appropriate ongoing playing situations. This can also include placement on other teams, as appropriate (e.g. Special Olympics or non-disabled teams).

The USYSA encourages the continued development of TOPSoccer teams and has published a comprehensive manual on how parents and other interested persons can organize a TOPSoccer program. It is available at no charge from the Connecticut Junior Soccer Association (CJSA). Contact them by phone, (203) 761-0676, or e-mail at [office@swdcjsa.org](mailto:office@swdcjsa.org).

To find a TOPSoccer program in your area, or for information on volunteering or beginning a team, please call Marc Glass at 860-644-2930, 860-568-5690, or e-mail Marc at [mlkabglass@aol.com](mailto:mlkabglass@aol.com). ▣

# Rhythms of Grace

*Torrington Church Continues  
Child Centered Worship Service*

(Roberta Daversa)

On the first Sunday of most months, the Trinity Episcopal Church in Torrington welcomes children with special needs and their families to an informal, non-denominational worship service.



The service starts with a relaxed get-together during which children and their families "hang out" and welcome one another. The Church's auxiliary chapel is prepared with play items and children are encouraged to explore and interact during the gathering. Then a short, adapted Bible story sets the theme for supported play time in several learning centers, which have included favorites like a water table, shaving cream art, parachute toss and various musical activities.

Worship with music and the breaking of bread follow for those who wish to participate.

The services, which start at 1 PM, offer families an opportunity to introduce children to group worship in a supportive environment.

The program is open to all families. It is lovingly run and skillfully adapted by the Reverend Audrey Scanlon, Curate, and Mrs. Linda Snyder, Director of Children and Youth Ministries of the Trinity Episcopal Church, 220 Prospect Street in Torrington.

Directions and service schedules are available at the Trinity Episcopal web site, [www.trinitytorrington.org](http://www.trinitytorrington.org). You can call Audrey or Linda with further questions at 860-482-6027. ▣

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## Parents Needed for a Focus Group on Learning the Basics of Behavioral Intervention



An Opportunity to Share Your Experience  
to Help Other Parents

(Beth Lambert)

Dr. Richard Fleming, of the E. K. Shriver Center and University of Massachusetts Medical School, has begun work on the development of a multi-media, online introduction to behavioral intervention for parents who have a child recently diagnosed with an autism spectrum disorder. Dr. Fleming's goal is to produce brief, engaging modules that describe and demonstrate, through interactive video exercises, the most important aspects of behavioral intervention.\*

Parent input is needed to assist in the development of these online training modules.

A focus group will be held in late spring or early summer with 8-10 parents who have young children recently diagnosed with an autism spectrum disorder (within the last two years), and who have in that time taken steps to learn about and use behavioral intervention with their child. Behavioral intervention refers to discrete trial training, incidental teaching, pivotal response training, PECS, verbal behavior training, etc.

The focus group will meet one time for 2 ½ hours, and participants will receive a small stipend. The meeting will be held at the Education Connection, in Litchfield CT. Parents will be invited to share their own experiences in learning about behavioral intervention, (what worked and what didn't), and what they believe are the essential elements for parents to understand when learning about behavioral intervention.

If you are interested in sharing your experience and ideas in the parent focus group and would like to be contacted once the meeting is scheduled, please contact Nancy Luchene at Education Connection by telephone at 860-567-0863, ext. 117, or e - m a i l a t [luchene@educationconnection.org](mailto:luchene@educationconnection.org).

\* The development of the online behavioral training course for parents is funded by a grant from the National Institute of Mental Health ("Educating Parents: Behavioral Intervention in Autism," Grant # 1 R41 MH071130-01). .■

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## Parent Support Group at Northwestern Connecticut Community College



Northwestern Connecticut Community College (NCCC), in Winsted, CT, offers an evening support group for parents and care givers of children with autism. The group is facilitated by Sharon Cable (parent), Jeanne Torre (licensed social worker) and Dr. Robert Beck (NCCC faculty member and director of the Behavioral Studies program at the college).

The group began in January and meets on the second Thursday of every month at 6:30 p.m. **Participation is open to all persons who care for children with autism and is free.**

For more information, please contact Sharon Cable (860-693-9128), Jeanne Torre, LCSW (860-874-2168), or Robert Beck, Ph.D.(860-738-6386).■

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**Connecticut's First  
Recreation Fair**  
for Families and Persons with  
Developmental Disabilities



(John Hudson)

The interest and need for special recreation services was clearly confirmed on Saturday, March 19, 2005, when Connecticut's first Recreation Fair for Families and Persons with Developmental Disabilities drew families from throughout the state seeking information about recreational opportunities. The event, a delightful Saturday for all who attended, was co-sponsored by the Litchfield County Autism Spectrum Association, Inc. (LACASA) and the Education Connecticut of Litchfield.

The purpose of the Recreation Fair was to foster an interest among providers of recreational and art related therapies to offer services in Northwestern Connecticut - but of course the event was open for children and families from everywhere in need of after-school and recreational programming for their children.

Providers of special recreational and art therapy type services were on hand, as were retailers of toys and educational supplies for children with developmental and physical disabilities.

Perhaps the biggest hit of the day were two beautifully groomed golden retrievers on hand with staff from **East Coast Assistance Dogs** ([www.ecad1.org](http://www.ecad1.org)). The dogs and their handlers were well-worn by the end of the day, after having greeted and interacted with children and their families almost continuously throughout the day.



**EquiStrides Therapeutic Riding Center** ([www.equistrides.org](http://www.equistrides.org)) provided staff and videos demonstrating their expansive and very well supported program. EquiStrides offers a

year-round therapeutic riding program to people of all ages.

Other presenters at the Fair included: **The Talcott Center for Child Development** (of Farmington, CT), which offered information on various therapeutic programs available throughout the school year and specialized summer programs ([www.thetalcottcenter.com](http://www.thetalcottcenter.com)); **Kris' Camp, Connecticut**, Kris' Camp, Connecticut, a therapy-intensive respite camp for children with autism ages 4-12 ([wmoore.net/kconnecticut.htm](http://wmoore.net/kconnecticut.htm));

**Kangaroo's Korner Childcare**, of Water-town, a daycare that is willing and able to provide integrated services to special children (860-945-6628); **Trinity Episcopal Church Rhythms of Grace**, an informal play and non-denominational worship service for

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**All About  
Your Special Child**



Disability Awareness Pro-  
gramming on WTNH TV

(Denise Buckenheimer)

*All About Your Special Child*, with parent Julie Swanson, airs monthly as a guest segment of "Good Morning Connecticut Weekend" on WTNH-TV, an ABC affiliate out of New Haven, Connecticut - Channel 8 to many people.

One Saturday morning each month, at around 7:15 a.m, Julie addresses disability related issues affecting families of children with special needs. Past segment topics have included Assistive Technology for School-Age Children, Bullying and Children with Disabilities, Detecting Reading Disabilities, Holiday Gift Ideas for Differently-abled Kids and Assistive Technology for Daily Living.

Don't worry if you're not able to watch the

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show on Saturday mornings. Busy parents who want to keep tabs on the news from Julie can usually view the program anytime during the following week via the WTNH web site, [www.wtnh.com](http://www.wtnh.com). Click on "Good Morning Connecticut Weekend" and scroll to "Watch Our Stories."

From the WTNH site, you can travel directly to Julie's web site, [www.yourspecialchild.com](http://www.yourspecialchild.com), where past program notes and links to specific resources can be found.

Julie is a Connecticut parent of a child with autism who was a founding board member of CT FEAT. She's also an education advocate who travels throughout Connecticut helping parents secure special education services for their children with disabilities

Prior to starting a family, Julie worked as a television producer. After her son was diagnosed with autism, Julie found that she developed a very different perspective on television.

"My kids were toddlers and I was in the thick of it. A good day included squeezing in a shower and folding the laundry" she says. "I used to watch a lot of television when I folded the laundry and it was in those days when I realized that mainstream media no longer spoke to me - the new me, the mother of a child with a disability."

Julie became keenly aware that parent-directed television simply didn't include useful advice or information about parenting a child with autism. Nor about children who use a wheelchairs or who are visually impaired. So she did what came naturally and began planning television programming that would speak to people living with disabilities and to their care-givers.

"At the time, I was running a full-time ABA program for my youngest son, and there wasn't much time for anything else. But I kept writing all of my ideas down for the day when I would have time to act on them."

And act she has. Julie recently formed a media program development company, Diversity Media, which addresses program content geared

toward children and adults living with disabilities. At the heart of her work as a children's education advocate, and her efforts to make everyday media more meaningful to families with disabilities, is Julie's passion for empowering families to help their children.

*All About Your Special Child* focuses on a wide variety of issues that affect parents and caregivers of children with special needs. For more information, please see Julie's web site at [www.yourspecialchild.com](http://www.yourspecialchild.com).

*Julie Swanson Augeri will be the featured guest at the CT FEAT Parent Resource Meeting on May 12, 2005. See page 3 for*

### Social Skills Groups for Children and Adolescents at UConn



The Psychological Services Clinic at the University of Connecticut, Storrs, offers social skills groups for children and adolescents between the ages of 4 and 17 years old. Children eligible to participate must have a previous diagnosis of an Autism Spectrum Disorder.

Groups meet for eight sessions, each lasting for an hour and a half. For more information or to place your child on the waiting list please call Emma Esser at 860-486-2642

The Clinic also provides assessment and family support services for children on the ASD spectrum and other services. It is located on the Storrs campus of the University of Connecticut. To learn more about the Psychological Services Clinic at the University of Connecticut, you can call the clinic at (860) 486-2642 or visit their web site, [psychlops.psy.uconn.edu/PsychServClinic/](http://psychlops.psy.uconn.edu/PsychServClinic/). ■



NEW PROFESSIONAL DEVELOPMENT AT  
**UConn**  
**ABA CERTIFICATION COURSES**  
Online Program Begins This Summer

The University of Connecticut College of Continuing Studies is now offering coursework in applied behavior analysis (ABA) based on national Behavior Analyst Certification Board (BACB) standards.

ABA courses may be taken as part of the Bachelor of General Studies (BGS) Focus in ABA curriculum, leading to a bachelor's degree, or they may be taken separately as a certification program by previously degreed individuals wishing to work toward national BACB certification as an **associate behavior analyst**. Students pursuing other undergraduate degrees in related areas (education, psychology, business management, etc.) may also take the newly offered BACB approved courses, available online beginning this summer. These courses may also be eligible for transfer into degree programs outside of the University of Connecticut.

The General Studies courses in applied behavior analysis are designed to meet the necessary academic training and experience requirements to become eligible to take the BACB examination for Board Certified Associate Behavior Analyst. (See [www.BACB.com](http://www.BACB.com) for details on national certification.)

UConn offers the necessary (3) courses as well as the supervised internship experience required, all in an on-line format.

Interested students, employers, or sites wishing to host an intern should contact Dr. Deirdre Fitzgerald, Program Director at [Deirdre.Fitzgerald@UConn.edu](mailto:Deirdre.Fitzgerald@UConn.edu). On-line course registration information can be found at

[www.continuingstudies.uconn.edu/](http://www.continuingstudies.uconn.edu/).

*Applied behavior analysis is a science that develops methods of changing behavior and provides services to meet diverse behavioral needs. Behavior analysis crosses the disciplines of education, psychology, social work, business, health and wellness, and other human services.*

*A behavior analyst focuses on improving the human condition, is well-trained in issues related to human behavior and qualified to help people attain personal goals, particularly as related to behavioral change.*

*Applications of behavior analysis include building the skills and achievements of children; enhancing the development, abilities, and choices of children and adults with various disabilities, including autism spectrum disorders; and augmenting the performance and satisfaction of employees in organizations.*

For further information, please contact the BGS office at the University of Connecticut campus of your choice:

Avery Point  
phone: 860-405-9190  
email: [BGSAPT@uconn.edu](mailto:BGSAPT@uconn.edu)  
Hartford  
phone: 860-570-9191  
email: [BGSHTFD@uconn.edu](mailto:BGSHTFD@uconn.edu)  
Stamford  
phone: 203-251-8550  
email: [BGSSTAM@uconn.edu](mailto:BGSSTAM@uconn.edu)  
Storrs  
phone: 860-486-4670  
email: [BGSSTORR@uconn.edu](mailto:BGSSTORR@uconn.edu)  
Torrington  
phone: 860-626-6801  
email: [BGSTORRI@uconn.edu](mailto:BGSTORRI@uconn.edu)  
Waterbury  
phone: 203-236-9932  
email: [BGSWTBY@uconn.edu](mailto:BGSWTBY@uconn.edu)

Toll Free: 888-BGS-5556 ■

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***Breaking New Ground in Connecticut***

CONNECTICUT ASSOCIATION FOR  
BEHAVIOR ANALYSTS  
First Annual Conference



The CT Association for Behavior Analysts (CT-ABA) will hold its first annual conference on Saturday, April 23, 2005, at Connecticut College in New London, CT.

Continuing Education Units will be available for Board Certified Behavior Analysts, Certified Associate Behavior Analysts, and certified teachers through the CT-ABA (\$5 per credit fee). Conference registration fee is \$20. Pre-registration is recommended. Walk-ins will be accepted as seating permits.

Topics and speakers include:

***Where Do Treatment Fads Come From?***

Presenter: Stuart Vyse, Ph.D. (Professor and Chair of the Psychology Department at Connecticut College)

The field of developmental disabilities treatment has become a breeding ground for unsubstantiated therapies. This presentation will examine the market forces that have led to the popularity of non-scientific approaches to disabilities treatment.

***Preference Assessment and Reinforcement Procedures: What We Know, What We Think We Know, and What We Still Need to Know***

Presenter: Richard B. Graff, M.S., BCBA (Program Director at The New England Center for Children)

Over the past 15 years, the topic of identifying reinforcers in individuals with special needs has received a great deal of attention. This presentation will begin by reviewing what we know about conducting stimulus preference assessments, and will focus on recent literature on the technology of assessing preferences and reinforcers, and how to increase the effectiveness of reinforcers in settings where reinforcement is used frequently throughout the day.

***Discrete Trial Instruction: Conceptual Considerations***

Presenter: Stein K. Lund (former Senior Clinician at the Autism Program at Rutgers University and

as Clinical Director of Bancroft NeuroHealth's Center for Autism Research and Educational Services).

Discrete trial instruction (DTI) is a widely used method in early intensive behavioral intervention (EIBI) for children with autism. Despite its prevalence and importance, DTI is surrounded by controversy and the details of implementation remain a matter of debate. This presentation discusses several conceptual issues of DTI as it relates to EIBI. It will be argued that discourse on this method is plagued with conceptual problems obscuring adequate understanding. Issues including prompting, errorless learning, contingencies versus content and the concept of "normalized intervention" will be discussed.

***The Business of Doing Science: Bringing Applied Behavior Analysis to Traditionally Non-behavioral Settings***

Presenter: John Molteni, Ph.D. (Senior Behavior Analyst for The Center for Children with Special Needs in Glastonbury, CT)

The utility of Applied Behavior Analysis for the effective treatment of children with Autism Spectrum Disorders is well documented. Bringing principles of learning into developing effective interventions for individuals with and without diagnoses in traditionally non-behavioral settings (e.g., educational, psychiatric) poses significant difficulties on several levels. Addressing systemic resistance to principles of learning across administrative, clinical and direct service personnel will be discussed. In addition, transdisciplinary communication as a crucial area in shaping systemic approaches to achieve targeted goals and objectives will be addressed.

***Panel Discussion: Bringing ABA Services Into Connecticut: Key Components to ABA Programs in Public Schools***

Chair: Suzanne Letso, M.A., BCBA (Co-founder and CEO of Connecticut Center for Child Development)

Panelists: Stuart Vyse, Ph.D., John Molteni, Ph.D., William Horn, Ph.D. (private consultant to public schools).

Registration fee \$20.

Preregistration is recommended; Walk-ins will be accepted as space allows.

CEUs available for certified behavior analysts and certified teachers at a cost of \$5 per credit.

For additional information, please contact Erica

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LEGISLATIVE UPDATE

**Important Developmental  
Disabilities Legislation  
Pending**

Parents and Others Urged to Contact  
Governor Rell In Support of Bills

(Maggie Casciato)

Connecticut is one of only 3 states that do not offer services to adults with developmental disabilities who do not also have a diagnosis of mental retardation. Services such as social skills and independent living training, and housing are already in place for other vulnerable populations, but to date remain out of reach for adults challenged with developmental disabilities.

You can help to change this inequity in Connecticut's public policy by giving just a few minutes of your time as soon as possible. There are two bills now in the Connecticut legislative process that are very important to people with developmental disabilities and their families, and which can greatly impact our children's future. Please express your support for these important bills by contacting Governor Rell by fax at 860-524-7395, or by calling her office at 860-566-4840. They are:

***HB 6118, An Act Concerning a Home and Community-Based Waiver for Individuals with Developmental Disabilities.***

"To obtain a waiver from federal law that will permit children and adults who have developmental disabilities, but do not qualify for specialized services because they do not have mental retardation, increased access to individualized supports and self-directed services in their homes and community".

This bill would allow the state to provide services and supports to our children who do not now qualify for assistance. A Medicaid waiver such as this one, is paid 50/50 by the Federal and State governments. It is

for a specified amount of time (usually 2 or 3 years) and is renewable. It covers a specified number of people (we don't know how many yet) but might be expanded. This would be a good start towards our goal of offering services to all our children/adults with unmet needs, as recommended by the July 2002 final report from Advisory Commission on Services and Supports for Persons with Developmental Disabilities who do not have Mental Retardation.

***SB1209, An Act Concerning a Pilot Program to Provide Services to Developmentally Disabled Persons without Mental Retardation.***

"To direct the Commissioner of Mental Retardation to implement a pilot program to coordinate supports and services for persons with developmental disabilities who do not qualify for services from the Department of Mental Retardation".

This bill would set up a two-year pilot program for 150 people, and give them the individualized services and supports they need. Our hope is that at the end of this pilot, we would have proven the necessity and the efficacy of such a program, and that it would be expanded at that point. This program would further fulfill the recommendations of the Advisory Commission.

Both of the Bills had public hearings in Hartford, at which many of our fellow parents and advocates showed up to support the proposed legislation. Both were voted on and passed by their respective committees (Human Services for 6118; Public Health for 1209), and are now sitting in the Appropriations Committee of the General Assembly.

Please add your support to the generous work of other families and professionals by calling (860-566-4840) or faxing (860-524-7395) Governor Rell's office as soon as possible. Mention that you support Bills HB 6118 and SB 1209. Thank you. ■

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## CONFERENCES, WORKSHOPS AND LECTURES

This conference listing focuses on effective autism treatment practices primarily in and around Connecticut. The information also appears at the CT FEAT web site ([www.ctfeat.org](http://www.ctfeat.org)). It is periodically updated and circulated on the "parents only" CT FEAT listserv. Details about joining the listserv are available at the CT FEAT web site or by calling the CT FEAT Information Hotline at 860-571-3888..

Other presentations of interest and fundraising events are listed separately.

*Please verify registration deadlines with event sponsors.*

April 23, 2005

New London, CT

Connecticut College

### **BREAKING NEW GROUND IN CONNECTICUT**

CT Association for Behavior Analysts (CT-ABA) First Annual Conference

(Please see page 13 of this issue of the CT FEAT Newsletter for topic descriptions and additional information.)

Topics and speakers include:

Stuart Vyse, Ph.D. *Where Do Treatment Fads Come From?*

Richard B. Graff, M.S., BCBA *Preference Assessment and Reinforcement Procedures: What We Know, What We Think We Know, and What We Still Need to Know*

Stein K. Lund *Discrete Trial Instruction: Conceptual Considerations*

John Molteni, Ph.D. *The Business of Doing Science: Bringing Applied Behavior Analysis to Traditionally Non-behavioral Settings*

Panel Discussion: *Bringing ABA Services Into Connecticut: Key Components to ABA Programs in Public Schools*

Suzanne Letso, M.A., BCBA, Stuart Vyse, Ph.D., John Molteni, Ph.D., William Horn, Ph.D.

Registration fee \$20.

Advance registration is recommended; Walk-ins will be accepted as space allows.

CEUs available for certified behavior analysts and certified teachers at a cost of \$5 per credit.

For additional information, please contact Erica Smith @ [ericquinn@aol.com](mailto:ericquinn@aol.com), or Holly Sickles at the Connecticut Center for Child Development, 203-882-8810.

April 27 & 28, 2005

New York, NY

### **2-DAY PICTURE EXCHANGE COMMUNICATION (PECS) TRAINING WORKSHOP**

Anthony Castroigiovanni, Ph.D. & Jo-Anne Matteo, M.S., CCC/SLP

The Picture Exchange Communication System (PECS) is a dynamic alternative/augmentative system that fo-

cuses on initiation of communication rather than teacher controlled responses. The PECS Training Manual, written by Ms. Frost and Dr. Bondy, has helped thousands implement this widely acclaimed system. Workshop description, brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Johanny Fernandez at 212-787-9700 or [training@losninosservices.com](mailto:training@losninosservices.com)

April 30, 2005

North Haven, CT

Gateway Community College

### **SOLVING THE SOCIAL EQUATION IN AUTISM SPECTRUM DISORDERS: FROM SOCIAL STORIES TO REAL-LIFE STRATEGIES FOR HOME AND SCHOOL**

*15th Annual Conference - Autism Society of Connecticut*  
Carol Gray (creator of "Social Stories").

A full day workshop for parents and professionals working on behalf of children with autism spectrum disorders of all ages, with applicability to adolescents and adults with ASD. This fun and practical workshop uses lecture, demonstration, and activities to explore instructional strategies that directly address the core deficits in ASD through utilization of *everyone's* strengths. This includes a research based rationale and social learning strategies that systematically model and teach friendship concepts and skills. Further details about this workshop may be found on The Gray Center web site, [http://www.thegraycenter.org/final\\_workshops.PDF](http://www.thegraycenter.org/final_workshops.PDF)

ASCONN conference registration and directions may be obtained at the ASCONN web site,

[www.autismsocietyofct.org](http://www.autismsocietyofct.org), or by calling ASCONN at (203) 235-7629. **Registration deadline is April 21, 2005**

FEE: \$50.00 ASCONN members/ \$65.00 non-members

*(Continued on page 16)*

May 2 & 3, 2005

Boston, MA

**2-DAY PICTURE EXCHANGE COMMUNICATION (PECS) TRAINING WORKSHOP**

Presenters: Christine Cavarretta, BCBA & Anthony Castrogiovanni, Ph.D.

Workshop description, brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs Offered

May 3 & May 4, 2005

Warwick, RI

**AUTISM-SHARING THE KNOWLEDGE**

***Families for Effective Autism Intervention, Rhode Island (FEAT RI)***

Speakers & breakout sessions include:

Bobby Newman, PhD, BCBA

*Autism Treatment & Scientific Reasoning: How do we know what we know?*

Peter F Gerhard, EdD

*Adolescence & Transition*

Christina Burk, MA

*Introduction to Teaching Verbal Behavior Through Applied Behavior Analysis*

Jean Estes, Esq.

*IDEA & IEPs*

Jane I Carlson, PhD, BCBA

*What's New in Autism Research?*

Craig Parlo, MS

*Behavior Analysis in the Public School*

Larry M Hirschberg PhD

*Wanting to Connect*

Patricia Meinhold, PhD, BCBA

*Beyond Early Autism Intervention: Behavioral treatment benefits youth of all ages*

Kelley Harrison Pistacchio, PhD

*Social Skills in Asperger's Syndrome and High Functioning Autism*

Margaret Klitzke, DO

*To Medicate or Not To Medicate*

MA and RI DOE, and BACB CEU's/PDP's available.

For registration materials, conference brochure or more information call (401) 886-5015 or go to [www.featri.org](http://www.featri.org)

June 10, 2005

Newburgh, NY

**PYRAMID APPROACH TO BEHAVIOR INTERVENTION**

*Anthony Castrogiovanni, Ph.D.*

The Pyramid Approach to Behavior Intervention training involves the introduction of broad-spectrum behavior analysis in the form of the Pyramid Approach to Education. Workshop will explore why the creation of effective learning environments is a key element in effective behav-

ior management intervention. The model stresses that functional activities and functional communication skills backed by powerful reinforcement systems are critical elements to designing effective interventions. The importance of understanding the function of the behavior target in order to effectively identify functionally equivalent alternative behaviors will also be addressed, as will data collection strategies and ethical obligations associated with implementing any intervention plan. Workshop brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs offered.

June 15, 2005

**Incorporating PECS Across the Day**

Hartford, CT

*Jo-Anne B. Matteo, M.S., CCC/SLP*

The Picture Exchange Communication System (PECS) is a widely used AAC strategy for children and adults with limited spoken language. While it initially can be implemented within a structured setting, the successful use of PECS is dependent on the student's being expected to and being able to communicate across the entire day within both structured and incidental formats. This presentation will describe strategies for incorporating PECS across an entire day within functional contexts with expectations for the student to use language beyond single picture requests. Specifically, "Advanced" PECS lessons that teach a variety of linguistic concepts and syntactical structures will be described. Selection of appropriate targets, creation of functional lessons, and strategies for incorporating PECS within **all** activities will be discussed.

Workshop brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs offered.

July 18 & 19, 2005

New York, NY

**2-DAY PICTURE EXCHANGE COMMUNICATION (PECS) TRAINING WORKSHOP**

*Anthony Castrogiovanni, Ph.D. & Jo-Anne B. Matteo, M.S., CCC/SLP*

Workshop description, brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".) ASHA CEUs offered.

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com).

July 20, 2005

New York, NY

**USING VERBAL BEHAVIOR TO ANALYZE LANGUAGE AND PECS AND TO ACHIEVE A BETTER UNDERSTANDING OF AUTISM**

*Anthony Castrogiovanni, Ph.D.*

Participants will learn about B. F. Skinner's book Verbal Behavior (VB) and how it can help them improve their communication training programs for children and adults with various learning and developmental disabilities. The workshop will describe Skinner's core language functions, each defined in terms of its functional relevance. The protocol for PECS (Frost and Bondy, 2002) will be used as an example of a training sequence that can be analyzed using VB. Issues related to the difficulty of teaching communicating about emotions and feelings, as well as some of the central issues related to autism will be described. Workshop brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".) Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs Offered.

August 8, 2005  
Boston, MA

### **PECS REVIEW, PRACTICE & PROBLEM SOLVING WORKSHOP**

*Anthony Castrogiovanni, Ph.D.*

Advanced PECS training for people who have taken the introductory Picture Exchange Communication training workshop. This follow up to the PECS Training workshop focuses suggestions for effectively implementing PECS at all phases. The focus is a thorough review of how to implement PECS, including reviewing the most common implementation problems as well as discrimination difficulties and strategies. Participants will have opportunities to practice their PECS skills under the guidance of a Pyramid consultant, troubleshoot any implementation problems they may be having as well as opportunities to watch video examples of PECS lessons in action. Participants are encouraged to share their successful and difficult cases. Problem solving strategies will be explored. Participants implementing PECS may bring videotapes of their PECS programs. Please contact PECS in advance if you would like to have your video reviewed at the training session. Workshop brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs Offered.

August 9, 2005  
Boston, MA

### **PYRAMID APPROACH TO BEHAVIOR INTERVENTION**

The Pyramid Approach to Behavior Intervention training involves the introduction of broad-spectrum behavior analysis in the form of the Pyramid Approach to Education. The creation of effective learning environments as a key element in effective behavior man-

agement intervention will be addressed. The model stresses that functional activities and functional communication skills backed by powerful reinforcement systems are critical elements to designing effective interventions. Participants will review the importance of understanding the function of the behavior target in order to effectively identify functionally equivalent alternative behaviors, and data collection strategies, as well as ethical obligations associated with implementing any intervention plan. Workshop brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".) Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com). ASHA CEUs offered.

August 22 & 23, 2005  
Albany, NY

### **2-DAY PICTURE EXCHANGE COMMUNICATION (PECS) TRAINING WORKSHOP**

*Anthony Castrogiovanni, Ph.D. & Diane Black, M.Ed.*

Workshop description, brochure and registration form available at [www.pecs.com](http://www.pecs.com) (See "Workshops and Lectures".)

Contact: Pyramid Educational Consultants, Inc. (888) 732-7462 or [pyramid@pecs.com](mailto:pyramid@pecs.com) □

### **OTHER PRESENTATIONS OF INTEREST**

May 6, 2005  
Waltham, MA

#### **AUTISM UPDATE**

*Sponsored by the Dug Flutie Jr. Foundation for Autism and Children Making Strides*

Eustacia Cutler *Temple Grandin's Mother Tells the Family Story*

Sue Constable, MA *Inclusion: Making it Work for All Children on the Autism Spectrum*

Lynne Mitchell, MSW *Parenting the Child with Asperger Syndrome*

Lauren Krueger Weeks, PsyD *Teaching the Head and the Heart: Relationship Development Intervention (RDI)*

MA Advocate for Children *Special Education Law: A Primer for Parents*

Presentation of the Doug Flutie Jr Award to Dr. Margaret Bauman, MD.

Registration is by mail only. Parents \$60; professionals \$75. For more information, please call 508-563-5767.

June 3, 2005  
Princeton, NJ

#### **AFFECTING THE RESEARCH AND SERVICE AGENDA**

*The Eleventh Annual Eden Institute Princeton Lecture Series on Autism*

Featured speakers include:

*(Continued on page 18)*

Barry Prizant, Ph.D., CCC-SLP

Dr. Prizant has more than 30 years experience as a clinical scholar, researcher and consultant to children with social communication disabilities including ASD, and their families. He is the Director of Childhood Communication Services, a private practice, an Adjunct Professor in the Center for the Study of Human Development at Brown University, and a Fellow of the American Speech-Language Hearing Association.

Cathy L. Pratt, Ph.D.

Dr. Pratt is the Director of the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community located at Indiana University.

Nancy Minshew, MD

Dr. Minshew is a professor of Psychiatry and Neurology at the University of Pittsburgh School of Medicine. She is Director of one of the nine NICHD Collaborative Program of Excellence in Autism investigating the neurobiologic and genetic basis of behavior in autism.

The cost is \$130 for this day long event. For more information contact Eden at (609) 987-0099 and ask for Joni.

□

## Internet Learning Opportunities

Research-Based Autism Treatment



### **The Mariposa School for Children with Autism Training Manual**

A collection of comprehensive notes from a series of verbal behavior training seminars, including: Beginning a Verbal Behavior Program, Rules of Reinforcement, Evaluating the Child's Response to the Environment, Teaching the Child To Play (beginning, intermediate and advanced play skills)

[www.mariposaschool.org/programs/TrainingManual.pdf](http://www.mariposaschool.org/programs/TrainingManual.pdf)

### **Cambridge Center for Behavioral Studies Online Tutorials**

A collection of introductory tutorials on behavior analysis. **Also available in Spanish.**

[www.behavior.org](http://www.behavior.org).

### **An Interview with Dr. Ivar Lovaas**

Parents and educators interested in learning more about Lovaas' groundbreaking model of effective autism intervention, without the common misconceptions, will find this article from the Autism Society of America,

**Intensive Behavioral Intervention**, helpful. The interview with Dr. Lovaas begins on page 9.

[www.asotoronto.org/PDF/IBI\\_Lovas\\_interview.pdf](http://www.asotoronto.org/PDF/IBI_Lovas_interview.pdf)

□

## AREA HAPPENINGS

April 21, 2005

New Canaan, CT

### **SPECIAL SIBLINGS with Mary McHugh**

Sponsored by SPED\*NET New Canaan.

A talk and book signing at DandyTales Bookstore, 13 South Avenue in New Canaan. Thursday, 10 AM to noon. Mary McHugh is the author of seven books, the most recent of which is "Special Siblings: Growing Up With Someone With a Disability," a memoir about growing up with her brother Jack who has cerebral palsy and mental retardation.

April 27, 2005

Trumbull, CT

### **OUR PLACE: THE PLACE TO BE FOR YOUNG ADULTS.**

The Kennedy Center offers this social group for young adults ages 17-21 with special needs. Music, dancing, games, art, cooking, snacks and more. Wednesday evenings from 7:00-9:00 p.m. There is a fee of \$10 per session, and registration is required. Opportunities Unlimited (203) 332-4535 ext. 223 or email [oppunlimited@kennedyctr.org](mailto:oppunlimited@kennedyctr.org).

May 1, 2005

Brooksvale Park, Hamden CT

### **THE CONNECTICUT AUTISM SPECTRUM RESOURCE CENTER 7TH ANNUAL WALK FOR AUTISM**



Fundraiser

3 Mile Family Walk on Linear Trail

Music by *Fender Bender*, Raffle, Jazzercise Warm-up,

Conny Deming Singing Butterflies

Barbecue Picnic - Following Walk

Includes : Raffle, Walk of Art, Music, Sensory Fun, Magic, Caricatures, Face Painting, More.

Call CT-ASRC at 203-248-5222 for more info or visit their web site at [www.ct-asrc.org](http://www.ct-asrc.org).

May 1, 2005

Torrington, CT

### **Rhythms of Grace**

Play-based worship service for all families. (See article on page 8 of this issue of the CT FEAT Newsletter.)

Trinity Episcopal Church (860-482-6027)

[www.trinitytorrington.org](http://www.trinitytorrington.org).

May 12, 2005

University of CT, Waterbury, CT

### **CT FEAT PARENT RESOURCE MEETING**

Open meeting for parents of children with autism.

Please see page 3 for details about this parent-only meeting. For more information, e-mail Roberta Daversa at [RoDaversa@aol.com](mailto:RoDaversa@aol.com), or call the CT FEAT Parent Hotline at 860-571-3888. □

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## **RESEARCH OPPORTUNITIES**

### **University of Connecticut**

UConn Researchers Focus on  
Autism Spectrum Disorders;  
Participants Sought for Several Studies

#### **Language Functioning in Children with a History of Autism (Ages 7 – 15)**

This study is examining higher level language functions (for example, ability to tell a story) in three groups of children: (a) children who are on the autistic spectrum (ASD) and are considered “high functioning”, (b) children who have a history of ASD but no longer meet criteria for ASD, and are mainstreamed successfully, and (c) typically developing controls. Testing can take place in your home, over two sessions, by a graduate student. You will get a brief report of results (how your child did on each specific test), and your child will get \$10.00 for participating. Optional MRI session at Yale may be available, in which the child will do some language tasks while we look at brain activation. The family will get \$100.00 for this part of the study, and if traveling from a distance, can stay in New Haven for a night free of charge. In addition to the money, the child gets to see his/her brain, and a radiologist reads each of the scans. We are hoping to shed light on subtle residual language difficulties that may benefit from remediation in children with a history of ASD who either are still on the spectrum, or who are not. For further information, please contact Dr. Deborah Fein (see below) or Beth Kelley at [Elizabeth.kelley@uconn.edu](mailto:Elizabeth.kelley@uconn.edu).

#### **Early Detection of ASD (Ages 16-30 months)**

Screening of toddlers in three groups: (a) well baby pediatric offices, (b) early intervention offices for children not yet diagnosed, and (c) younger siblings of children on the ASD spectrum. If you have one ASD child, and a younger child not yet 30 months and would like to have the child screened either now or when the child reaches 16-18 months, please contact [juhi.pandey@uconn.edu](mailto:juhi.pandey@uconn.edu) (860-486-5767).

The research team is also interested in contacting pediatric offices not currently participating in early detection screening for autism spectrum disorders. Please call the Early Detection office at 860-486-5767.

Please call Deborah Fein, Ph.D. at 860-486-3518 or e-mail at [deborah.fein@uconn.edu](mailto:deborah.fein@uconn.edu), with any questions or to express interest in either of the above studies.

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#### **Joint Attention in Autism Spectrum Disorders (Ages 6-18)**

This study uses computer-based games in combination with non-invasive brain imaging (MRI) to examine

attention skills in ASD. Children complete several standardized assessments, including a diagnostic workup; they also participate in some simple, fun, child-friendly computer games. We write a brief report about the findings. This session lasts 2 hours with breaks. This will take place at U-Conn. If appropriate, children participate in an optional MRI brain imaging session at Yale. Participants are compensated with a total of \$75. \*

#### **Language and Learning Skills in Autism Spectrum Disorders (Ages 4-12)**

The goal of this study is to understand some of the basic mechanisms that seem to lead to difficulties in developing language and social difficulties in autism, so that we can develop interventions, or treatments, based on this knowledge. Children participate in computer games and standardized assessments. The session lasts 90 minutes. Participants are compensated with \$25. \*

#### **Syntactic Development in Autism Spectrum Disorders (Ages 2-6)**

One of the most powerful influences on children’s development is their parents. We are interested in the strategies that parents use to communicate with their children, particularly when those children have trouble talking and communicating – we can learn a lot from parents that might be helpful in developing therapeutic strategies. Parents bring their child in for one session of approximately 2 hours, for which they are compensated \$25. If interested, we will ask parents to return again in 6 months and then in one year, so that we may track the child’s language over time. In total, you may participate in three sessions of from one to two hours each. Sessions include a thorough language evaluation and standard assessments of general thinking skills, as well as a free play session. We will write a report about the child’s performance on standardized measure.\*

\*For further information, please contact Professor Inge-Marie Eigsti by e-mail at [inge-marie.eigsti@uconn.edu](mailto:inge-marie.eigsti@uconn.edu) or by telephone at (860) 486-6021. You can learn more about Prof. Eigsti’s research at her new website: [eigsti.psy.uconn.edu/DCNLab/](http://eigsti.psy.uconn.edu/DCNLab/).

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### **Yale Developmental Disabilities Clinic**

The Yale Developmental Disabilities Clinic is headed by Fred Volkmar, M.D., and Ami Klin, Ph.D.. The clinic is accepting research participants for several studies involving people with Asperger Syndrome and autism. Information about each can be found at [info.med.yale.edu/chldstdy/autism/research.html](http://info.med.yale.edu/chldstdy/autism/research.html) or by contacting the clinic by fax at (203) 737-4197. Yale is also conducting an Asperger’s Syndrome Internet Survey, available at [info.med.yale.edu/chldstdy/autism/assurvey.html](http://info.med.yale.edu/chldstdy/autism/assurvey.html). ☐

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(Continued from page 10)  
**RECREATION FAIR**

special children and their families ([www.trinitytorrington.org/worship.html](http://www.trinitytorrington.org/worship.html)); **Drumming About You**, featuring Mike Bloom, a nationally known drum specialist and member of the Connecticut Council for the Arts ([www.drumming-about-you.com](http://www.drumming-about-you.com)); Tom Hammond of **Music Together**, music and movement workshops for children ([www.musictogether.com](http://www.musictogether.com)) ; **Simsbury Soccer Club TOP Soccer**, outreach soccer program for children with special needs, ages 6 to 19 ([www.simsburysoccerclub.org](http://www.simsburysoccerclub.org)); **Creative Memories Scrapbooking** ([www.creativememories.com](http://www.creativememories.com)); **Camp LARC of Torrington**, day camp program for children with disabilities (860-482-9364); **Discovery Toys** ([www.discoverytoys.com](http://www.discoverytoys.com)); and **Camp Harkness, United Cerebral Palsey** (860- 236-6201).

The **CT FEAT** resource table was especially laden with books and materials for parents to browse, and board member Roberta Daversa bestowed advice that kept parents lingering around her table after the Fair had officially ended. The Reverend Audrey Scanlon of Trinity Episcopal Church assisted with the **CT FEAT book drawing** at the close of the fair and awarded first prize, *Peer Play and the Autism Spectrum* by Pamela Wolfberg, to parent Linda Ladden. Runners up received copies of a handy “go anywhere guide”, *The Child with Autism Goes to Town* by Kathy Labosh.

John Mongeau, Vina McDermott and Orié Marrero of the Education Connection, hosted the event in the usual friendly and professional style of the Education Connection, and ensured that guests and vendors alike enjoyed the experience. They counted about 100 parents and 50 children attendees, and are already thinking about a repeat performance of the Recreation Fair for Families and Persons with Developmental Disabilities for next year! ▣

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(Continued from page 1)  
**CT FEAT BOOK DONATION TO LIBRARIES**

The collection includes all the books in our *ABA RESOURCE GUIDE, VOLUME I: An Annotated List of Parent-Recommended BOOKS, VIDEOS and ARTICLES on Effective Treatment and Teaching Programs Utilizing Applied Behavior Analysis for Children With Autism Spectrum Disorders*.

The collection represents books carefully chosen and reviewed by our board as practical, informative, research-based guides to treating autism. We’ve published reviews of these books in our newsletters, and often refer parents to them through our hotline and informational meetings. The Guide was published as our Spring 2004 newsletter and is available (free) by contacting CT FEAT. An electronic version of the Guide is available on the CT FEAT web site, [www.ctfeat.org](http://www.ctfeat.org).

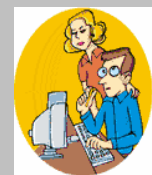
This project is made possible through your donations and support. We hope you will avail yourselves of this wonderful resource when it becomes accessible in your area, or through the inter-library loan service of the Connecticut library system.

The books will also be donated to several college and university libraries in order to be available to students and faculty. (Parents and the general public may also borrow books from academic libraries.)

A list of the libraries that will carry these books will be made available through the CT FEAT web site and newsletter when the process is complete. Stay tuned! ▣

*Visit Us on the Web*

[www.ctfeat.org](http://www.ctfeat.org)



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**BOOK REVIEW: THE SOCIAL SKILLS PICTURE**  
**BOOK by Jed Baker**

Part one of the book, which is only 25 pages long, provides some quick background information about autism, teaching social skills, and using social skills picture stories.

Part two of the book provides 26 different picture stories, ready to go. Some are about communication skills, like how close to stand to others, how to greet others, how to introduce yourself, how to interrupt a conversation, how to start & maintain a conversation, and how to end a conversation.

Some stories are about play skills, like asking to play, joining in, sharing, turn taking, game playing, and dealing with losing.

And some stories are about managing emotions: keeping calm, dealing with mistakes or teasing, trying new things or hard things, and showing understanding for other people's feelings.

This book is geared toward all students with autism spectrum disorders, not simply those with autism, as the title might imply. Students with Asperger's syndrome and PDD-NOS will also find it helpful.

The photographs in the book are primarily of elementary school children. Therefore, parents and teachers of older students may prefer to take their own photographs and make their own picture stories.

New picture stories may also be needed, no matter what the student's age, in order to teach other skills that are not covered in this book. Fortunately, Jed Baker gives clear instructions about how to create picture stories. He uses a digital camera, and then imports the photographs into Microsoft Power Point to add word bubbles and text. But other software can be used, or pictures can simply be pasted onto paper, with handwritten word bubbles and text.

Students can do more than pose for the pictures. They may enjoy assembling the stories, perhaps sequencing the pictures themselves.

One drawback of the book is that it often depicts the "right way" and the "wrong way" to do something on the same page. Baker acknowledges that some students are so entertained by inappropriate behavior that they may continue to do it for their own or others' amusement. If this is the case, he suggests covering up the picture of the wrong way. However, using this strategy means that these students can never refer to the story on their own. Parents and teachers may need to find more dramatic ways to delete those pictures. Perhaps a future edition of this book could separate the "right way stories" and "wrong way stories" onto different pages.

Another helpful addition would be a sample data sheet. Baker explains the steps to take in using picture stories: reviewing the story, role-playing the skill, providing corrective feedback, and generalizing the skill. A sample data sheet could help parents and teachers track the student's progress, by documenting the date, time, and place of each step—especially the student's success in enacting the skill outside of formal teaching sessions.

However, these are minor criticisms of the book.

Students will love looking at the pictures. Time-strapped parents and teachers will be delighted by how "user friendly" the book is—and by how quickly it helps the students to pick up new social skills. Buy this book!

The book is hardcover, 216 pages. The list price is \$39.95. It is available through *Different Roads to Learning* ([www.difflearn.com](http://www.difflearn.com)) and other book dealers. ISBN number 1-885477-91-0. ■

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(Continued from page 5)

APPLIED BEHAVIOR ANALYSIS FOR AUTISM

reducing problem behavior in individuals with autism and related disorders of all ages. Today, *bona fide* ABA programming for learners with autism often combines many research-validated methods into a comprehensive but highly individualized package. For each learner, skills to be increased and problem behaviors to be decreased are clearly defined in observable terms and measured carefully by direct observation, with independent verification by secondary observers. An initial assessment is done to determine skills that the learner does and does not have. Selection of treatment goals for each individual is guided by data from that initial assessment, and a curriculum scope and sequence that lists skills in all domains (learning to learn, communication, social, academic, self-care, motor, play and leisure, etc.), broken into smaller component skills and sequenced developmentally, or from simple to complex. The overall goal is to help each learner develop skills that will enable him or her to be as independent and successful as possible in the long run.

A variety of behavior analytic procedures are used to strengthen existing skills and build those that have not yet developed. That involves explicitly arranging for the learner to have multiple, repeated opportunities to learn and practice skills throughout every day, with abundant positive reinforcement. One way to arrange learning opportunities is for an adult to present a series of trials to the learner, each consisting of a specific cue or instruction from the adult, an opportunity for the learner to respond, and a consequence delivered by the adult depending on the learner's response. Such arrangements are called discrete trials, and they are essential for building many important skills in learners with autism. But programming that relies exclusively on discrete trial procedures – often referred to as "discrete trial training" or "DTT" – is not state-of-the-art ABA, particularly when

"drills" are used in a cookbook fashion that is not individualized to each learner. Research has shown that overusing discrete-trial procedures tends to produce skills that do not carry over (generalize) from the training situation to other everyday situations. For that reason, effective ABA programming blends discrete-trial procedures with a variety of other ABA methods, including child-initiated instructional sequences (known as incidental teaching procedures), task analysis and chaining to teach skills involving sequences of actions or steps, instructional trials embedded in ongoing activities, and others. There is a heavy emphasis on making learning enjoyable, and on engaging the learner in positive social interactions.

In a quality ABA program, behavior change procedures are specified clearly. The instructions and prompts, reinforcers ("rewards"), materials, and so on that are used to develop each skill are tailored to the individual learner. There is a written program or set of instructions for teaching each skill; the behavior analyst in charge of the programming trains everyone who works with the learner to implement those programs consistently. It is particularly important for parents to be trained to implement the procedures outside of formal treatment sessions, in a variety of settings (home, playground, community); research has shown that otherwise, the learner's skills are not likely to generalize. Maladaptive behaviors (such as stereotypic behavior, self injury, aggressive and disruptive behavior) are explicitly not reinforced; appropriate alternative behaviors are taught and reinforced instead. Learner progress is measured frequently, using the direct observational measurement methods mentioned earlier. Data are graphed to provide visual pictures of what is happening with each skill and each maladaptive behavior targeted for treatment. The data are reviewed regularly by the behavior analyst directing the programming so that learning errors can be caught early and intervention

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(Continued from page 22)

APPLIED BEHAVIOR ANALYSIS FOR AUTISM

methods adjusted promptly if progress is not satisfactory. The behavior analyst also observes treatment and provides feedback to interventionists on an ongoing basis.

Last but certainly not least, a defining feature of ABA programs is that they are directed by professionals with advanced formal training in behavior analysis – at least a master's degree – as well as supervised experience in designing and implementing ABA programming for learners with autism and related disorders. These professionals have either met the educational, experiential, and examination performance standards of the Behavior Analyst Certification Board and are Board Certified Behavior Analysts, or can document that they have at least the equivalent training and experience. They adhere to the BACB's Guidelines for Responsible Conduct, and base treatment on the best available scientific evidence. For further information about the training and skills required to direct ABA programming for learners with autism, see the guidelines for consumers developed by the Autism Special Interest Group of the Association for Behavior Analysis in this section of [behavior.org](http://behavior.org).

*Gina Green's article is reprinted here with permission from the Cambridge Center for Behavioral Studies, Concord MA. The article can be found online at the Center's web site, [www.behavior.org](http://www.behavior.org) (see "Autism"), along with numerous articles about effective autism intervention and other social applications of behavior science. Dr. Green serves on the Board of Trustees of the Cambridge Center. She is a past President of the Association for Behavior Analysis International (ABA), and President Elect of the California Association for Behavior Analysis (CalABA). - Editor*

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OAR EDUCATOR'S GUIDE TO AUTISM

The heart of the *Educator's Guide* is a **six-step approach for a teacher preparing to teach a child with autism in his or her classroom**. The steps include: (1) educate yourself (2) reach out to parents (3) prepare the classroom (4) educate peers and set social goals (5) collaborate on the implementation of an educational program and (6) manage behavioral challenges. The discussion of each step includes practical tips on what a teacher should look for and how to navigate the challenges that may arise. Following these steps offers the teacher the potential to create the most favorable educational environment for all learners in the classroom, including the student with autism.

Since the publication of *An Educator's Guide* in October, 2004, OAR has already received requests and distributed more than 500 copies of the guidebooks to educators, parents and autism professionals across the country. *The Educator's Guide* is the second in OAR's *Life Journey Through Autism* series. In December 2003, OAR published *A Parent's Guide to Research*, which provides parents and families with the basics of autism research in a concise and user-friendly way. *A Parent's Guide to Research* lays a strong foundation for those who are new to the complex process of finding and evaluating autism information. In addition, OAR is currently producing *An Educator's Guide to Asperger Syndrome*, slated for publication in June, 2005

To request a hardcopy of ***An Educator's Guide*** or ***A Parent's Guide to Research***, email [OAR@researchautism.org](mailto:OAR@researchautism.org) and include your name and mailing address, or call 703-351-5031. *The Guide* can also be viewed online by visiting OAR's website, [www.researchautism.org](http://www.researchautism.org) and clicking on the *Educator's Guide* icon in the right hand navigational bar.■

### ***The Start***

The first problem is finding a lawyer who specializes in estate planning for persons with special needs. Most lawyers write Wills. Very few of these lawyers have expertise in public benefits and disability law. Through *Exceptional Parent Magazine* Harry and Sally learn about the *Special Needs Alliance*. This is an organization of leading elder law and disability law attorneys located throughout the country. These lawyers specialize in planning for persons with special needs. At [www.specialneedsalliance.com](http://www.specialneedsalliance.com) Harry finds a lawyer in his state. Harry and Sally visit with the lawyer and learn about the importance of a special needs trust.

#### **The Special Needs Trust**

Special needs trusts are discretionary, spendthrift trusts created for the elderly or persons with disabilities which are intended to supplement, but not replace, any public benefits that the trust beneficiary receives. They learn that a special needs trust is designed for persons with disabilities receiving public benefits, such as SSI, Medicaid, Section 8 Housing and other programs. Harry and Sally's special needs trust will maintain Bill's SSI, Medicaid and potential eligibility for a group home in the future. At the same time, the trust will enable Bill to take advantage of the future inheritance that Harry and Sally will leave for his benefit. The trust fund can be used to supplement the government benefits by paying for services and equipment that Medicaid would not cover. The special needs trust could purchase a home, special wheelchairs, handicap-accessible vans, mechanical beds, as well as pay for vacations, a personal attendant, and recreational and cultural experiences. This trust will be specifically tailored to enrich Bill's life.

The Special Needs Alliance attorney explains to Harry and Sally that SSI is designed to provide Bill with food, clothing

and shelter. Medicaid pays Bill's medical bills. The trust funds can be used for Bill's other needs that are specifically defined in the trust document. The trust funds can be used to supplement SSI in paying for food, clothing and shelter for Bill, but this would result in a reduction of Bill's SSI benefit by approximately one-third. Bill would maintain his Medicaid. Since SSI is rarely sufficient to pay for food, clothing and shelter, most likely the trust will be needed to pay for some of these expenses.

There are two keys to establishing a special needs trust. First, the trustee must be given absolute discretion over the distribution of the funds. If Bill can compel a distribution from the trust, the assets in the trust would be considered available to him for SSI purposes and he would lose his SSI and Medicaid. Support trusts for minor children traditionally authorize the trustee to make distributions for the health, maintenance and support of the beneficiaries. If the trust directs the trustee to provide for a child's health, maintenance and support, the government will determine that the trust is available to the individual. This will cause the individual to be ineligible for public assistance. The trustee shall be forced to spend the trust funds on medical expenses normally covered by Medicaid. Second, Bill cannot have the authority to revoke the trust. Therefore, the trust must be carefully drafted.

#### **Funding the Trust**

Harry and Sally must decide how much money to put in the special needs trust. Parents often divide their estates equally among their children. If all of the children are healthy, this makes sense. If one child has special needs, that child may need more or less than an equal share. The best way to make that determination might be to have a life care plan designed for Bill. Harry and Sally would define the lifestyle that they want for Bill and the life care planner would estimate the cost of Bill's care over his lifetime. Harry and Sally could determine how much of their estate to leave to Bill's special needs trust. Once the life plan

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*(Continued from page 24)*

**ESTATE PLANNING FOR PARENTS OF CHILDREN WITH DISABILITIES**

is analyzed, it may reveal that the assets in Harry and Sally's estate are insufficient to provide for Bill and his sister, Joan. In that case, Harry and Sally may consider buying a second-to-die life insurance policy. On the death of the survivor of Harry and Sally the insurance proceeds would be paid in to Bill's special needs trust. Joan may then receive a larger share of the other assets.

**Selecting the Trustee**

A critical part of the special needs trust process is the selection of an appropriate trustee. The role of the special needs trustee requires a long term commitment, a keen sensitivity to the individual's disabilities, involvement in monitoring the individual's services, advocating for medical and financial entitlements, and prudently investing and distributing the trust funds. The trustee also has to comply with a number of very complicated laws, including the Prudent Investor Act, the Principal and Income Act, the Social Security Administration requirements concerning distributions from the trust, and the general laws pertaining to serving as trustee.

After the Special Needs Alliance attorney explains these responsibilities to Harry and Sally, they are concerned that Joan does not have the required expertise to serve as trustee. The attorney suggests that Joan be a co-trustee with a professional trustee. The professional could be a bank or an attorney experienced in serving as trustee of a special needs trust. If a bank is selected, it should be a bank with a trust department with a good track record for managing money. If an attorney is selected, he/she should either have a good track record for investing money or agree to employ a professional money manager to manage the investments. If the investments do well, Bill's lifestyle will be enriched. If the investments do poorly, Bill's standard of living will be adversely affected.

Harry and Sally hesitate at appointing a professional trustee because of the fees

involved. Trustee's fees typically run 1-1.5% of trust assets on an annual basis. The difference between money management by a professional and money management by a family member is usually far greater than the trustee's fee. The Special Needs Alliance attorney explains that the trustee's fee should be considered an investment rather than a cost. The trustee should be someone who (a) is responsible for managing finances, (b) understands Bill's special needs, (c) understands the rules governing Bill's public benefits programs, and (d) is someone who will be an ardent advocate for Bill's best interests.

**Accountings**

The Social Security Administration requires annual accountings, which report as to the expenditure of funds. If the trust has other beneficiaries, they too are entitled to accountings. Accountings must be done in accordance with the Principal and Income Act, which is fairly technical. The accountings ensure that no funds were mishandled. This protects Bill and any beneficiaries who will inherit upon Bill's death.

**SSI**

The Supplemental Security Income (SSI) program of the Social Security Act is minimum monthly cash payment for "categorically" aged, blind and disabled individuals. Aged persons must be over age 65, and although the disabled and blind can be any age (including children), the individual must meet the Social Security definitions of disability or blindness. SSI eligibility is based upon limitations of income and assets. SSI should not be confused with other Social Security retirement, survivor, dependent or disability insurance benefits.

An extremely important duty of a trustee of a special needs trust is to make distributions in accordance with the requirements of the SSI program. If distributions are made directly to Bill, this will reduce or eliminate his SSI. Any cash received by Bill reduces his benefit dollar-for-dollar. If he loses his SSI, he loses his Medicaid. The

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**ESTATE PLANNING FOR PARENTS OF CHILDREN WITH DISABILITIES**

Special Needs Alliance attorney explains that the trustee arranges to pay Bill's expenses directly to third parties. Payments for goods and services other than food, clothing and shelter there have no effect on Bill's SSI payment. These payments are called "in-kind support and maintenance" (ISM).

The trustee for Bill's special needs trust must understand the SSI rules and Medicaid laws to prevent an overpayment of public benefits or a disqualification for Medicaid eligibility. Either of these events could reduce the value of the assets in the trust and ultimately the money available for Bill's lifetime.

**Care Manager**

Harry and Sally explain to the Special Needs Alliance attorney that they spend a considerable amount of their time caring for Bill. They are hopeful that Joan will care for Bill. The attorney explains to Harry and Sally that the trust can direct the trustee to hire a care manager. A care manager specializes in making the necessary arrangements for providing the appropriate level of care that Bill needs. The care manager would monitor Bill's progress and ensure that his needs are being met. The care manager would coordinate nutritional and cleanliness programs, exercise and physical therapy, socialization, psychological counseling, and ensure that Bill has adequate assistive devices and emergency response systems. Making arrangements for all of the necessary services for the beneficiary can be a daunting task for a trustee who does not have a background in social work and is not aware of the different services that could be made available for the beneficiary. An experienced care manager can relieve the trustee of this considerable burden, thus allowing the trustee to devote time to other trust-related tasks.

**Letter of Intent**

Finally, the attorney discusses the need for a Letter of Intent. This letter provides Harry

and Sally with an opportunity to speak to the successor trustee about making difficult decisions for Bill long after they have died. The letter can be addressed to the successor trustee and the care manager. Harry and Sally want to tell Bill's story in their letter. This letter contains his medical history and background; special education; treatments and therapies; his daily care needs; his favorite foods and clothing; important people in his life; his favorite recreation and sports activities; vacations he has taken and places he wants to visit. The letter of intent paints a picture of Bill and his unique characteristics and traits so that the trustee can see him as a human being and not a "faceless" person named in a legal document. This useful tool helps the trustee understand Harry and Sally's specific wishes and expectations as they relate to decisions about Bill's future.

**Mission Accomplished**

Executing their special needs trust eliminated the anxiety that had bothered Harry and Sally for years. They were prepared for their future and Bill's.

Harry and Sally thereafter discovered that the special needs trust was a thoughtful methodical process, not a simplistic form. This process was a journey that required them to learn. They learned about the special needs trust protections, SSI, Medicaid and how to select the best trustee for Bill. They wrote a detailed colorful picture of Bill's unique personality and character in their Letter of Intent. Their trust was special, because they tailored it to fit Bill and protect him for his lifetime.

*Thomas D. Begley, Jr., of Moorestown, New Jersey, and John F. Kearns III, of West Hartford, Connecticut ([www.ctelderlaw.com](http://www.ctelderlaw.com)), are founding members of the Special Needs Alliance, a national network of attorneys serving the special needs community. For more information, visit [www.specialneedsalliance.com](http://www.specialneedsalliance.com) or call 877- 572-8472.□*

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## ABOUT CT FEAT

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

### GOALS:

- To provide information and resources that enable families to evaluate and compare the effectiveness of current treatment approaches;
- To support families seeking or implementing behavioral intervention programs;
- To expand the availability of high quality professional services by supporting education and training opportunities in applied behavior analysis (ABA);
- To increase public awareness regarding the high incidence of Autism Spectrum Disorders and the availability of effective, scientifically validated treatments.

### RESOURCES:

- An **"Information Hotline"** by which **Connecticut** families can learn about CT FEAT's activities and request an information packet. Parents also can request to speak in confidence with another parent about issues related to ABA-based treatment. Call (860) 571-3888.
- **Parent Support Group meetings**, which take place in Rocky Hill, CT. The only requirement for participation in the meetings is that parents agree to respect each other's privacy and confidentiality. Please call the Parent Hotline (860-571-3888) or visit the CT FEAT web site, [www.ctfeat.org](http://www.ctfeat.org), for information about future meetings.
- An **Unmoderated "Parents Only" Internet Mailing List** that provides **Connecticut parents** of ASD children with a forum to discuss issues of concern. **To subscribe to the list**, send an E-mail message to [ctfeat@ctfeat.org](mailto:ctfeat@ctfeat.org), providing your name, e-mail address, and mailing address. Also please state why you want to join the list, **and** your explicit agreement to honor the confidentiality requirement.
- The **CT FEAT Newsletter** which contains news of interest (e.g. book reviews, conference announcements, etc.). To subscribe (free), please contact send an e-mail to [ctfeat@ctfeat.org](mailto:ctfeat@ctfeat.org) or call the Information Hotline (860-571-3888).
- The CT FEAT web site, [www.ctfeat.org](http://www.ctfeat.org), provides extensive information resources including book and video reviews, conference listings, an 'ABA Job Connections' employment section where prospective employees and employers can find each other, Spanish language resources, research articles, and back issues of the information-packed CT FEAT newsletter.
- **Advocacy and resources** to expand the availability of high quality professional services for children and families.

CT FEAT Bylaws provide that all members of the Board of Directors shall be parents or family members of children with Autism Spectrum Disorders. There is Board representation from throughout the state.

Connecticut Families for Effective Autism Treatment (CT FEAT) is a non-profit organization staffed by **volunteers** and funded through the generosity of caring supporters.

If you are a **Connecticut parent or professional** and would like to be a volunteer for CT FEAT activities, you can call (860) 571-3888, write to P.O. Box 370352, West Hartford, CT 06137, or e-mail [ctfeat@ctfeat.org](mailto:ctfeat@ctfeat.org). We'd like to hear from you! ☺



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**CT FEAT**  
**Parent Resource Meeting**  
**May 12, 2005**  
**UConn Waterbury**  
*See page 3 for details.*

*Helping Children Reach Their Full Potential*