



Huntington, WV • Winter 2002

## From the Director

Barbara Becker-Cottrill, Ed.D

It is a very busy season at the West Virginia Autism Training Center. Our work continues to expand to meet the education and training needs of our state. The Family Focus Positive Behavior Support model, developed with funding from the Centers for Disease Control and Prevention, continues to be a model that works for families and educators and so many other people that join together to make a better life for people with autism. It does take a community to embrace and support the unique differences and strengths that people with autism bring to that community. With the Family Focus Positive Behavior Support model, we see that teams of people in the community find their strengths together and collectively, make all the details of a comprehensive plan for an individual with autism work!

In the area of statewide teacher training, we have boldly gone into the world of the internet to make higher education autism coursework for teachers in West Virginia more accessible. These internet classes provide excellent information for all teachers, related personnel and parents. West Virginia will also announce shortly, a new teacher certification in autism. Those seeking final certification in autism will encounter a more rigorous course of study.

On new frontiers for the WV Autism Training Center are studies in the epidemiology of autism, specifically, the prevalence of autism in West Virginia. We were one of the first states to begin to conduct surveillance of autism activities and are now joined by seven states that are following a specific methodology

established by the Centers for Disease Control and Prevention. This work is a result of the Children's Health Act of 2000. We are proud to be a part of that. As a result of our surveillance of autism work, we are also proud to announce the beginning of the first national statewide autism registry. Our registry will track new cases of autism in West Virginia, year by year. If the numbers of people who are diagnosed with autism spectrum disorder are rising, which is indicated in the press, we will have some data to look at that question.

I hope you will enjoy this issue of our newsletter. There is a wonderful diversity in the articles, submitted by parents, siblings, community members and Autism Training Center staff. I really encourage you to consider submitting an article for the next edition!

## Expanding Horizons

Gloria Sage, Educational Specialist Senior

James Hatfield is a ten-year-old young man who lives in Fort Gay, WV and attends Fort Gay Elementary. He lives with his mother, Celestia, and his two younger siblings, Wade and Marly. James loves to draw and is a good artist. He and his family began the Family Focus Positive Behavior Support (FFPBS) program in January of 2002, and his PBS support team includes his mother, Celestia Presley, his teacher, Midge Jervis, his classroom aide, Linda Noe, his case manager, Carl Adkins, his educational specialist, Gloria Sage and his community partner, Linda Piccirillo.

At the start of PBS, James was spending most of his day in a special education classroom and his team felt that James could participate more in a regular education environment, with the proper

supports. The team also wanted James to participate in social and community activities with his typical peers.

James did not like to go on field trips or any activities that required a change in his schedule. His typical method of dealing with a change or outside- school activity was to stay home the day of the event. Team members decided this would no longer be an option for James. They began to plan for Special Olympics through the use of a social story. The story described what



James Hatfield

would happen at Special Olympics, the prizes that could be won, and the food and drinks that James could have. This story was read to James daily at school and at home for two weeks before the event. James' mother and educational specialist attended the event to watch and cheer him on. James won a medal for the 200- meter race and the day was a success. He even stated "This Special Olympics is pretty fun. I think I'll come back next year".

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**“The Key has been a strong support team that has worked together to create positive outcomes for James and his family.”**

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## Expanding Horizons

*(continued from page 1)*

Mrs. Presley enrolled James in the local 4-H Club and he started to attend monthly 4-H meetings. The team wanted James to attend a five-day 4-H camp in the summer and planning began between the camp director, Julie Ferry, Mrs. Presley, his case manager, Carl Adkins, and his educational specialist, Gloria Sage. The team decided a mentor should accompany James to camp, so they began a search for an appropriate person. James' mother, Celestia, contacted a family friend whose son had just graduated from high school and was available during the week of the camp. The educational specialist provided training on Asperger's Syndrome and specific strategies to assist James. Family Support Funds, through Autism Services Center, provided money to pay the mentor. The camping experience was a huge success. James had a wonderful time and everything went smoothly. The camp director told Mrs. Presley that James had done so well, he could attend camp next year without a mentor to accompany him. Mrs. Presley was extremely proud of James for handling himself so well. These experiences helped James to feel more self-

confident and he has begun to be willing to leave his “comfort zone” and try new things.

This September, James started in his third-grade classroom for almost 60% of his day. His special education teacher is working with him on reading, language and math skills. An autism-certified teacher was hired to provide consultative services to the regular education teacher and the special education teacher. This teacher will be adapting materials, providing supports and working closely with James' educational team. This support will help ensure James' success in the regular education environment and the team hopes to increase his amount of time in regular education.

James has made tremendous progress with social skills and his ability to handle changes. His world has expanded and James is ready to face new experiences. His mother is happy and proud that James is willing to try new things. The key has been a strong support team that has worked together to create positive outcomes for James and his family.

## Circle of Friends Preschool Fall 2002 Program Update

Cindy LeGrand, Preschool Coordinator

The Circle of Friends Preschool has started its third year this fall! We ended our second year on August 8<sup>th</sup> (extended school year) with our very first graduation. We had 6 students graduate from our program. It was an exciting day filled with pomp, circumstance, laughter and tears. The children all dressed for success and brought moms, dads, siblings and grandparents to witness the big event. They wowed us with songs, great food and their best manners. Although we celebrate the moving on of our students to the exciting world of Kindergarten we will miss each and every one of them dearly.

We are excited to begin the new school year with some new staff and students. We welcome our new part-time lead teacher Alisha Bolton to our program. We also have a new full time teaching assistant, Jenny Signorini. We currently have enrolled one new student with autism and have one space open. (We serve 5 children with autism and 10 typically developing peers). We currently have 10 peers enrolled but several of them only attend 2-3 days per week so we still have a few



openings on the days they do not attend. Once again we are very fortunate to have a wonderful group of kids. They are all so exceptional.

Circle of Friends Preschool is still providing before and after school care to our families that need these services. Our grant funding for this service ended in June of this year and we are currently seeking other funding sources so we can continue this much needed service for our families.

# Autism Training Center Will House First Statewide Autism Spectrum Disorders Registry

Barbara Becker-Cottrill, Director and Cathy Jo Templeton, ASD Registry Coordinator

On January 1, 2003 The Autism Training Center will launch the first autism spectrum disorders registry in the nation. Autism spectrum disorder is a “reportable condition” in West Virginia (H.B. 4042 and Title 64, Legislative Rule, Division of Health, Department of Health and Human Resources, Series 7, Reportable Diseases, Events and Conditions). This means that doctors (neurologists, pediatricians, psychiatrists) and clinical psychologists must tell the state about any individual they have diagnosed with an autism spectrum disorder. The autism registry will be operated by and housed at the WV Autism Training Center. ASD registry project staff will provide training related to the registry process for reporting entities across the state. Initially, the establishment of the WV ASD Registry will further enable West Virginia to track prevalence rates. Eventually, however, once relevant health professionals are sufficiently familiar with screening, diagnosing, and reporting procedures, the tracking of incidence rates (the rate at which new events occur in a population) will be possible. Tracking incidence rates over time will shed light on the pressing question of whether or not the occurrence of ASD is increasing.

## Planning for Change

Dianna Grueser, Educational Specialist

Many children with autism have difficulty with change. Parents, teachers and others working with the child often find that behavior problems or anxiety exist during times of transition and change. This problem exists because children with autism often have difficulty with predicting what is going to come next and reacting to it appropriately. For example, if we see dark clouds in the morning we know it might rain. A child with autism may not be able to predict that rain may come and be very upset if they are caught in the rain without a hat. Although problems with change may create many challenges for individuals with autism, there are many things we can do to help.

We can assist a person who has difficulty predicting by preparing them for the change. With some individuals you may just need to tell them what is about to happen, but with others you may need to use a variety of visual tools. A visual schedule is often helpful for daily changes in the routine. Giving the child a visual representation of their day such as what they are doing now, what they are going to do next, and when they will be able to do an activity they enjoy can help reduce anxiety. Some other tools that are helpful are using video taping to preview an activity or situation, visiting a new location such as a school or doctor's office, or using social stories to give information about a new situation. The significance of the change and how your child typically reacts to change is going to guide you on how far in advance you need to plan for change and what tools you are going to use. You want to plan well in advance for a big change such as moving to a new house or school. For big changes you also want to start with slow introductions to the change and use a

For Current Training Opportunities  
in Autism in West Virginia  
Check our Web Site at  
[www.marshall.edu/coe/atc](http://www.marshall.edu/coe/atc)

wide variety of tools to assist in explaining the change. For example, if the child is going to a new school you might start with just a picture of the school, then drive by the location, then take a tour, then meet the teacher and then maybe participate in a fun activity at the new location.

Although adapting to change can be a challenge for a person with autism, proper planning can reduce anxiety and behavior problems and help make the transition a success.

## Circle of Friends Preschool Fall 2002 Program Update

*(continued from page 2)*

We are in the process of completing a video on Incidental Teaching to help us train and support other teachers in using this model of teaching. We still have lots of visitors and requests to make presentations about our program across the state. We look forward to sharing information with other counties in the state and replicating the Circle of Friends model in several counties.

The staff is very anxious to start a new year of services for these wonderful young children and their families. We've learned so much during the last few years that we feel this will be our most exciting year yet. The staff at Circle of Friends Preschool continues to work closely with our partner, Cabell County Schools, to make this an excellent program for young children with autism and their peers.

news and views

Winter 2002



**GOT A HEART  
FOR AUTISM?**

You can make a contribution that would help families who have children with autism. Your monetary donation will be used to purchase books and educational videotapes on autism for the Autism Training Center lending library. This is a free service for registered families throughout the state of West Virginia.

Donations can be made to the "Marshall University Foundation for the Autism Training Center" and mailed to:

Autism Training Center  
Marshall University  
One John Marshall Drive  
Huntington, WV  
25755



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## What The Walk For Autism Meant to Me

Anita Patnaik, Sister



A sunless, chilly day on April 6, 2002 marked a bright spot in the maturing voice of autism support. Despite the lackluster weather, over 250 faithful participants gathered to celebrate their unified hope that the compelling mysteries of this disorder will be understood one day. As the walk began, I clasped my brother Vijay's hand, exhilarated by the chance to share this special moment with him. As we trailed the flowing sea of humanity, I would catch glimpses of my brother smiling. The warmth he exuded demonstrated knowledge that the concentrated effort made for this project was not in vain. The small

steps we were taking on that day would lead the way to the accomplishments we all desire for this field. Knowledge is power and the knowledge that we were helping make a difference empowered us to enjoy an otherwise dismal day.

It appeared that the other participants also reveled in this knowledge. Rosy faces numbed by cold easily expressed joy for the success of the project. The event ended with food, laughter and conversation. Amidst all the energy and emotion, I topped off my day by hugging my brother. At the time, it just felt like an everyday display of affection. As I reflect on it now, I realize that it was both personally significant and generally symbolic: it displayed the fact that we all embraced the responsibility of supporting individuals with autism on that fateful day and, hopefully, throughout our lives.



## A Sibling's Perspective

Amy Porterfield, Sister

I learned to hate my brother in junior high. We went to the same junior high for two years, and I felt that he was ruining my whole life. My bitterness grew towards him during those two years, and I began to hate anything he did. My brother, P.T., is two years older, and severely mentally handicapped due to the genetic disorder Fragile X. I never had problems with him until then. I was a new girl, very nervous, and for the first time, in the same school as P.T. He was in the special education classes on the other side of the building, so I hardly ever saw him. We each had our own territories.

However, as the year progressed, my brother was having more and more panic attacks, and problems at school, ranging from not transitioning

to classes to throwing objects when he was upset. No one at the school knew how to handle him like I did, and the administration would get me from classes and lunch to help him. Day after day, I would be asked to help lure him onto the Special Education bus after school.

Since I can remember, my parents have told me that I was not responsible for him. Even though I had never felt that P.T. was my job to handle, I began to feel I was responsible for him at school. "I did not tell my parents that I was asked to help with P.T., because they would be upset. I didn't want them getting mad at the school and making it into a big deal. I was stuck in the middle. Even though I was feeling bribed with

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# Dance From Your Heart

Rose A. McDonough, RM Productions Dance Instructor

news and views

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Dance is a word that evokes many images and emotions for me. It isn't just movement, it is a look into the soul of another. It is a passion. It is a therapy. It is an escape. It is a release. It is an introduction from your heart to your body. It is more than getting the body to mold to a perfect form. It is about a transformation of thought and feeling from the mind, heart and soul through every fiber of your body. Every aspect of the human body has the capability of expressing.

It is from all of this talk of expression that I came to learn after dancing for 20 years. I began a teaching job, Creative Expressions, with a group of adults with developmental and physical disabilities with Shawnee Hills. Before that job, I knew the importance of stretching, rehearsing, pushing the body to perform better and better and challenging the mind to absorb more and more. I knew when I performed my heart felt good, but I didn't really understand the strong connection between dance and the expression of the soul and not to forget dance's wonderful medicinal qualities until I changed gears and looked at dance from a different perspective.



Working with students with disabilities has been the most educational and life enriching experience in my life. I found and still find that I am not just a teacher but a student myself. Witnessing how movement can truly touch someone in a way that nothing else can is positively amazing to me. Dance can offer a true education in music, physical form, rhythm, assertiveness, self-expression and respect for yourself as well as a beautiful art form.

Since moving on from Creative Expressions, I have felt a void in my teaching and from this has led me to begin teaching students with disabilities again through my dance studio in the community. I am currently working with children with disabilities which is a new venture for me and I am finding it to be wonderfully rewarding. Dance truly can bring together so many individuals all in the name of dance. Dance offers a way of expression that is non-threatening and fun along with teaching consistency and respect.

It is a dream within my reach to someday have a company of dancers of all abilities to come together and create art as I once took part of with Creative Expressions only on a different level. Everyone has something to offer and as a teacher I try to find that unique quality of each student and help them find a way in which to express it. Expression knows no barrier, the only barriers we have are the ones we place upon ourselves. My mission is to break past the barriers and help individuals unlock that special part of their soul and discover the world of dance.

There are so many wonderful possibilities that can come about when people come together and share their likes and differences and furthermore celebrate them. I am a strong advocate for the arts and all of the positive outcomes that are displayed from activities in the arts. Through dance, a student can learn how each part of the body can move, and how our emotions affect our bodies. Students also learn to develop concentration skills, follow directions, become less inhibited by our bodies and discover how wonderfully creative we all

are. The list could go on and on. From any angle, educational, physical or emotional, the benefits are positive. Students with disabilities are no exception. Although dance may be a non-traditional teaching technique, it is not new. It has just taken time to get the message out.

The main point I want to share is not about defining dance, but merely opening up the many possibilities that can grow from a dance experience. Everyone has a dancer inside and it is up to us to awaken those possibilities. In my eyes, no matter what ability level or age, dance is a wonderful positive option for those willing to take a look inside.

RM Productions offers classes from ages 3 to adult in ballet, tap and jazz in the Charleston area. Private lessons are available. If you are interested, please contact Rose McDonough at 304-766-8234 or via email: [tappinrose@aol.com](mailto:tappinrose@aol.com)



## *Second Annual Walk for Autism*

**MARK THE DATE !**

**APRIL 12, 2003  
Second Annual WALK  
FOR AUTISM  
An Autism Awareness  
and Fund Raising  
Activity at Ritter Park,  
Huntington, WV**

**For more information  
call 1-800/544-3115  
Get Involved!**



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**The Autism Society  
of America  
Conference is  
in Pittsburgh  
this coming year!  
"Bridges to the  
Future"**

**July 16-20, 2003**

**visit the ASA  
Website for more  
information at  
[www.autism-  
society.org](http://www.autism-society.org)**

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## "Thanks, Ms. Phares"

**Betty Holliday, Parent**

It is said good teachers are worth their weight in gold. A good special education autistic teacher has to be worth double their weight in gold. I'd like to commend an excellent autism teacher, Kathy Phares.

Ms. Phares exhibits motivation, a willing and understanding heart, and a knack for problem solving the many challenges of autism. Ms. Phares was named WV Elementary School Division Special Education Teacher of the Year 2002. She was presented the award March 22 at the Charleston Marriott during the annual spring conference of the Autism Society of West Virginia.

My daughter, Amy, has made steady progress under Ms. Phares over the last four years we've been privileged to have her. Ms. Phares has a total of five students she integrates into regular education as appropriate. Amy has kept up with her third grade class and will now enter fourth grade.

We're looking forward to one more year at Oak Hill Elementary School with Ms. Phares and Mrs. Wilson. OHES has been a very "parent friendly" school. Amy has had some excellent homeroom teachers: Harfer-third grade; Burns-second grade; Maddy-first grade; Humphries/Clay-kindergarten; and Garrett/Bragg-preschool. Greg Hansen has been a wonderful occupational therapist and Mr. Andy & Mrs. Epperly have been good speech therapists. Thanks also to aides Mrs. Gibson and Mr. Cooper for their help too." We are also appreciative of the support of Mr. David Cavalier, Principal.

**Vicki Kiser, Parent**

My son, Drew Kiser, has come a long way. He was in a school where he was being suspended for behavioral problems. He had a teacher who was always telling me that she could not teach like that.

Drew is at OHES now where he regularly makes the outstanding honor roll. I know this would not be possible if it weren't for his wonderful teacher, Kathy Phares. She has a great attitude and an amazing sense of knowing what each child specifically needs. We all know autism affects each child differently.

Ms. Phares also has a wonderful sense of humor which I think is extremely important when dealing with our kids, or any kids for that matter. This is why I nominated her for special

education teacher of the year. I am so very pleased that she won because her job is by no means easy. Ms. Phares deserved this honor.

We look forward with high expectations and hope for our children's future. We realize the importance of consistent, motivating, and appropriate teaching. We cannot say enough thanks for help already received and expected in the coming year. Middle School looms ahead with many changes and challenges. Our goal is to move Amy and Drew ahead with Ms. Phares to keep a good thing going. Planning this middle school transition without Ms. Phares would prove problematic in our goal of personal growth and maximum integration.



*Ms. Kathy Phares, Drew Kiser, & Amy Holliday at OHES field day 2002*

## Our Journey with Cody: Managing Medication Issues

**Jerri Elliott, Parent**

Our journey began on June 19, 2000. That was the day a doctor diagnosed our son, Cody, with autism. Cody is five years old and so incredibly bright, but he is trapped in a body that doesn't want to cooperate. This lack of cooperation results in it being difficult for him to concentrate on tasks. Sometimes he is so intent on some tasks that he can't seem to stop. With close supervision from our doctor, we have found that medication helps him so he can focus on needed tasks;

however, it has been a rollercoaster ride as we continue to try to find a medication or combination of meds that can have a positive long-term effect for him.

Cody also has a diagnosis of ADHD, characteristics of OCD and some serious anxieties. We started with management of the anxieties. This medication had no side effects for him and it worked wonderfully for about nine months. At that time the OCD problems started. He couldn't stop

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picking skin, nails, apples, cherries, flowers, and leaves off trees. We then discontinued that med and started with an OCD medication. It has been a year since we began that one and its effectiveness is starting to subside. These days he picks his eyebrows, arm and leg hair and moles.

The management of the ADHD has been a major rollercoaster. In the winter of 2000, we began with stimulants. The first two we tried absolutely just put him to sleep. I then agreed to give him a more common stimulant and that worked for four months. It didn't put him to sleep, but it eventually overstimulated him and that is when the picking got out of control. We thought at first the picking was sensory, but for the most part it was OCD. Later on we found it didn't just happen with a stimulant. It was happening when he hadn't had a stimulant for weeks. During the summer of 2001, we started a time released stimulant and along with the OCD med and a medication for aggression (which was getting pretty worrisome). This combination was wonderful for Cody and for our family. In August of that year we started him on a Gluten Free/Casein Free, yeast free, no refined sugar diet. All of these showed up as sensitivities in testing. The combination of the meds and the diet gave us a wonderful start to his preschool year.

On September 17, we began a discrete trial training program at school and at home. We have wonderful support at school. We have team meetings every two weeks and the communication is great. Of course, Mom is the team leader. Cody was progressing so well in his trials and hyperactivity was at a minimum until November 25th. Cody started by having trouble keeping his tongue in his mouth. He is always doing sensory things with his mouth so I was just prompting him to put his tongue back in. After a few times I noticed he couldn't. It wasn't that he wouldn't. Then he couldn't close his mouth or swallow. We didn't know what was going on. We took him to the emergency room and later learned it was a reaction to the medication for aggression. His neurologist sent him for an EEG later that week to look for seizures. The test was negative. The doctor that prescribes his meds told us it was a reaction to that medication. Three days later Cody was in an acute manic state! He was running around the house non-stop. He was clustering furniture together and would panic if we moved it back. He put on four layers of clothes and would not take them off. He was also talking to himself constantly. Cody had rarely done this before at all. He also was getting dehydrated fast.

We went for two months with no stimulant. Wow, what a challenge for us at home and for the people at school who had seen what he was capable of. In the spring we tried a fairly new stimulant and it overstimulated him. He didn't take it very long. We then tried a new time released version of one that he had tried a year and a half earlier. It made him sleepy. Cody is currently taking a stimulant. It will probably be increased soon for concentration purposes. Just recently we started giving him a couple of supplements to deal with and heal some of his issues. SSSHHHH! The hyperactivity is VERY quiet these days, for about three weeks now, even with several days without the stimulant.

After the episode with the med for the aggression, we started with a seizure medication to be used as a mood stabilizer. That worked but after a few months it was giving him tremors and he was very, very shaky if I had to wake him up. I asked to take him off and we weaned him. No more shakes. Plus, recently we took him to see a wonderful doctor. She checked his thyroid and his T4 cell count was very low. When checking into it, the wonderful nurse who works with the doctor that prescribes his meds found with some patients this medication will lower the T4 cell count. I'm so glad we got him off that when we did. More recently Cody has needed something to get him to sleep and sleep through the night. That all came to a head in February of this year. Our daughter woke up at 2:30am, which she never does, and noticed the tv and lights on and the back door open! She woke us up and that was the most undecipherable feeling. Cody was found wrapped up at the bottom of our steps. He did not answer us. He seemed surprised that he was in trouble.

We finally got him to say something and he said "I was just sleeping on the steps." He started taking a medication to sleep within a week of that incident. We also installed a new key lock on that door that stays locked at all times. He will just leave out the door anytime of day. All of our other entries were locked before this incident.

As you can see, this adventure with Cody is a major rollercoaster. It puts stress on every aspect of our lives. Cody has a wonderful, understanding and patient sister named Caitlin. She has taken a lot of grief from him. It's so tough on the siblings of these children. They sacrifice more than anyone realizes. Our family has made adjustments for the way we have to live our lives. It seems to come natural for parents of children. I'm sure that is the reason God has given these children to the parents who have them.

## FIRST INTERNATIONAL CONFERENCE ON POSITIVE BEHAVIOR SUPPORT

On March 27-29, 2003 in Orlando Florida, the Rehabilitation Research and Training Center on Positive Behavior Support at the University of South Florida will be hosting the First International Conference on Positive Behavior Support. For more information you can visit the RRTC website, [www.rrtcpbs.org](http://www.rrtcpbs.org), e-mail: [rrtcpbs@fmhi.usf.edu](mailto:rrtcpbs@fmhi.usf.edu) or call 813/947-8295.



# The Ultimate Juggling Act

Kent Moreno, Educational Specialist Senior

Raising a child with a disability requires a significant amount of time and effort not to mention worry. So much so that sometimes certain needs experienced by the non-disabled or “typical” brother(s) and/or sister(s) get overlooked. We face the ultimate juggling act! Given the demands of raising a child with a disability, how do we raise typical children who don’t feel “short-changed” and who see their brother or sister who has a disability as a positive occurrence in their lives?

I need to begin with a confession. With regard to parenting my daughter, Megan, who is 11 going on 25. I think I’m doing a good job as a father but I’m never quite sure. I think much of my uncertainty comes from having a daughter who’s sure she knows more than I do and who would be an incredible asset to any corporation wanting to negotiate a multi-billion dollar deal. As such, I frequently experience Megan’s expertise in the art of negotiation. A “no” never means “no” to Megan. It just means the current details are unacceptable and she revises her request accordingly.

On the other hand I have no hesitation in telling you that my wife, Mollie, is doing a fantastic job! I’d like to think Mollie experiences the same uncertainty I do but I’ve never actually asked her (I’m somewhat afraid she’ll say that she doesn’t experience the same uncertainty). In truth, a bit of uncertainty is probably a good thing because it causes me to constantly evaluate the kind of job I’m doing and see if I can do anything better.

Despite my uncertainty, every once in a while Megan does something which lets me know I’m doing more things right than I would have ever suspected. One area where Megan lets me know I’m doing a good job as a father is with regard to her brother, Ben, who is dually diagnosed with Down Syndrome and Autism. I say this because I see Megan seeking Ben out. I see Megan including Ben in activities when her friends are visiting the house. Most of all, I see the joy Megan derives from having Ben as a brother.

While having a typical child who gets significant joy from a sibling who has a disability is not uncommon, it’s also not as common as I initially thought. I frequently hear stories of typical children who are jealous of or who resent their brother or sister who has a disability.

What can we, as parents do to prevent that? Here’s what I think Mollie and I did, or are doing, right:

## **Open and honest communication:**

Having a sibling who has a developmental disability brings about some interesting challenges. One of these is how you talk with the typical child about their sibling who has a disability? Megan was almost 3 years old when Ben was born. Within a year of Ben’s birth, we began talking with Megan about Ben having Down Syndrome. We did this very informally. If there was a character on tv with Down Syndrome we’d say “Oh look there’s someone who has Down Syndrome just like Ben”. We purchased children’s story books which had as characters children with Down Syndrome. When the individual from Early Intervention would come to work with Ben, we explained to Megan that because Ben has Down Syndrome he’s going to have a harder time learning than other boys and girls. We further explained that “Debbie is a teacher who is going to help Ben learn.” As Megan has gotten older, our explanations, while remaining informal, have gotten more complex. Megan now knows that Down Syndrome is a genetic disorder. She also knows Ben has autism and autism is a problem which occurs in the brain.

Actually just how much Megan knows really surprises me sometimes. I host a three day “get together” every summer for individuals with Down Syndrome and their families. This year I asked a local retailer if they would donate a cake for the event. When an employee from the retailer called to let me know they would donate the cake, Megan took the call. When Megan told me about the call, she chuckled and shook her head in dismay as she recanted how the employee on the phone referred to me as the guy who has the picnic for “those disabled kids.” Megan, at age 11, understood, however well intentioned the employee was, her statement reflected a certain lack of awareness about individuals with disabilities.

With regard to Ben’s disability, probably what hit Megan the hardest occurred about 2 years ago when Ben was six and Megan was nine. Megan asked when Ben was going to learn to talk. I told her the truth, that Ben would probably never learn to talk but there were other ways we could help Ben to tell us what he wanted or needed. Hearing that Ben would probably never talk was extremely upsetting to Megan. I was really quite surprised at how hard Megan took the news. Later, when she had calmed down, Megan explained that she really wanted Ben to be able to talk to her.

As important as it is to be open with a typical child about their sibling’s disability, it’s impossible

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**“I see Megan including Ben in activities when her friends are visiting the house. Most of all, I see the joy Megan derives from having Ben as a brother.”**

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# Computer Corner: Applying the Elements of Instructional Design to Educational/Edutainment Software

news and views  
Winter 2002

by Kent Moreno, Educational Specialist Senior

In my last Computer Corner column, I discussed educational software in more general terms. In this edition, I want to get down to the nuts and bolts of the issue. Specifically, I'm talking about applying the elements of good instructional design to evaluate whether an item of educational software is well designed and worth your investment.

Before we begin, a quick review from my last column. There are two types of software designed to teach academic skills, "educational" and "edutainment." Educational software is specifically designed to teach skills and, as such, its main focus is on the presentation of academic material, rather than on sights and sounds or games. Examples of educational software are the Jostens and Laureate programs used in many schools as well as many shareware/freeware programs such as Creepin' Critter Math and Math Stars. Edutainment software is the "Sesame Street" of software. It's designed to be a fun, enriching environment with a diversity of entertaining sights and sounds present throughout the experience. With edutainment software, instruction mainly occurs through playing games. Examples of edutainment software are the "Jump Start" series and the "Math Blaster" series.

And now, onward.

## Interface

The interface is the set of on-screen controls which allow the user to navigate to the different content areas in a software program. An interface should be simple, clear and concise. A good example of a well designed interface can be found in the program "Beginning Reading." The on-screen controls are well spaced and the function accomplished by clicking on any one of the on-screen controls is fairly intuitive. An example of a poorly designed interface is the "Jump Start" series. The interface is cluttered, you rarely have an idea what will happen when you click on one of the on-screen controls and there are many sub-menus. One time while exploring "Jump Start 2nd Grade" I found something kind of nifty. Due to the poorly designed interface, I was never able to find that "nifty" thing again. Navigating Jump Start 2nd Grade is very much like being lost in a maze and that is simply not a good thing.

## Adjustability

Good software should allow the level of difficulty to be changed. Initially the level of difficulty should reflect a learner's entry level skills. This is important because being successful (contacting reinforcement) is a critical factor in an individual's motivation to learn. The program should then allow the level of difficulty to increase so the student may continue to acquire new skills. Increasing the level of difficulty also keeps the learner challenged and reduces the likelihood of boredom. Adjustability can occur in three ways: 1) the level of difficulty can be made easier or more difficult, 2) the amount of time a learner has to respond can be increased or decreased and, 3) a combination of changing both the level of difficulty and the amount of time a learner has to respond. It is highly recommended that some of the software selected for a learner have, as the means of adjusting difficulty, a change in the amount of time permitted to make a response. This is a good way to build fluency (think languages) in emerging skills. To be fluent in a skill indicates one can perform that skill quickly, with a high level of accuracy and with minimal thought given to the actual process.

## Transition Times

Transition time is the amount of time it takes to go from the end of one activity or problem to the beginning of the next. The shorter the transition time, the better. With educational software, transition times are usually quite brief. With edutainment software, the transition times can be extremely lengthy. In one Jump Start program the activity is teaching addition through the use of football. Using football is a fantastic way to teach addition! The difficulty is or the time the learner answers the math problem to the appearance of the next problem is approximately 30 seconds. This is highly problematic when your target audience are young learners with short attention spans. Even if the learner has an excellent attention span, such long transitions inhibit the opportunity for lots of practice.

## Reinforcement

It is important that the student is given a clear and concise response from the computer when he/she gives a correct answer. It is equally important





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Some sites worthy of investigation include:

[www.shareware.com](http://www.shareware.com)

[www.tucows.com](http://www.tucows.com)

[www.crayons.com/links.html](http://www.crayons.com/links.html)

[www.winsite.com](http://www.winsite.com)

[www.shareware.miningco.com](http://www.shareware.miningco.com)

[www.nickjr.com](http://www.nickjr.com)

[www.trollbridge.com](http://www.trollbridge.com)

[www.download.com](http://www.download.com)

[www.macshare.com/sftwre.html](http://www.macshare.com/sftwre.html)

In our next newsletter, I will provide information on how to select educational/edutainment software based on its instructional design.

that the method of reinforcement chosen is pleasant to the senses, yet does not last for more than a second or two. If it lasts any longer, the individual will soon tire of the reinforcer and his/her motivation to learn will be reduced. As mentioned previously, reinforcement should occur immediately after a correct answer in order to increase the likelihood of learning.

#### Error Correction

Good software gives the learner immediate feedback when they make an error. This is important because immediate feedback is essential to minimizing learner errors and ensuring the learner acquires the new skills as quickly as possible. In addition to letting a learner know when a mistake has been made, good software should require the learner to go back and correct his/her response.

#### Content Validity

Content validity is somewhat difficult to explain. Essentially, software should be designed in such a way that clues are not present which would allow the learner to give the correct response without completing the exercise or activity as intended. A quick example to illustrate this point, using my daughter, Megan: Megan was using the program, Beginning Reading, which is one of the better designed programs for teaching reading skills. In one part of the program, a paragraph is shown on the screen and is read aloud by the computer. In the paragraph are three spaces where words are missing. At the bottom of the screen are three words. The object of the exercise is for the learner to place the correct word in the appropriate space. At the time this occurred, Megan was about four and a half years old and could not read. In spite of not being able to read, Megan was getting the correct answer 100% of the time. While the proud parent in me would like to attribute Megan's performance to her being some sort of super-genius, in this case, at least, it was not so. Rather, there were serious flaws in the design of the software which allowed Megan to figure out the correct answer. The first design flaw involved putting the words on the word list located at the bottom of the screen in the same order as the blanks for which each word is the correct answer. Thus, the first word in the list was always the correct answer for the first blank. The second design flaw was the blanks in the paragraph were the same length as the correct word. Thus the blank for "day" looked like "\_\_\_" and the blank for "computer" looked like "\_\_\_\_\_." While this example is somewhat amusing, the fact that Megan was able to obtain the correct answer without doing the program as designed essentially destroyed the educational value of that particular activity.

#### Final Tips

Don't make yourself crazy searching for the perfect software program. It doesn't exist.

Everyone is an individual and even if a piece of educational software is well designed, it may not be the right piece of software for a particular learner. Know your learner.

Modifications may need to be made. If a child becomes over-stimulated by the multi-media aspects of a piece of software, turn off the sound and have the individual sitting with the learner provide the reinforcement and error correction.

To make the most of educational/edutainment software, treat it as an educational tool not as a game or toy.

## A Sibling's Perspective

*(continued from page 4)*

coke and passes to events at school, and constantly being told that I was a good sister, I could not find the words to tell them.

After two years of helping out with P.T. and his panic attacks nearly every day at home and school, I became overwhelmed. Due to P.T. we couldn't have many people come to the house, and he couldn't be left alone. Whenever I would have to go anywhere, P.T. would have to come with us, since he couldn't be left alone. I was late to soccer practices due to him, and I got sick of it. Between school and things at home, I couldn't stop getting annoyed and angry with P.T.

In ninth grade, I went away to boarding school while P.T. stayed at home. Even though I was still sick of P.T. when I left home, I missed him. My time away from him made me understand that his actions were unintentional. I had focused on everything annoying about him that I had missed the big picture, he was my brother, and I loved him. I still get annoyed with him, but I have never had the same deep hostile feelings. If I kept my feelings of hatred, I would have shut him out. Now that I have been out of the house for three years, I have a better understanding of our roles in the family. I am there to support him, and love him, and not to take care of him every second. He is now in a group home, enjoying it, and having fewer and fewer panic attacks.

When my parents were changing their wills, I asked them to name me as his guardian. My parents looked at me quizzically, but I said "Who else knows what P.T. needs better, his sister or someone who doesn't know him?" I realize it will be a big responsibility, but I will be prepared for it this time, because despite everything, I love him all the more.

# The Ultimate Juggling Act

(continued from page 8)

to anticipate everything the typical sibling needs to know or wants to know. Additionally, the typical child will most likely experience situations which, due to having a sibling with a disability, are particularly hurtful. Two examples of situations which are hurtful to Megan are when she notices people staring at Ben or when she hears a person calling someone a “retard.” More than once, Mollie or I have sat down with Megan after she has been present during such situations to discuss her feelings and possible solutions. For these reasons and many more, if we are to adequately support our children, the lines of communication have to remain open at all times. Our children need to know if they have a question or something they need to talk about, they can come to us and we will be there for them.

## Reserving time for the typical child:

Parenting a child with a disability takes a lot of time, much more time than is required with a typical child. Ben has such significant delays that even when we’re not directly involved with him, he requires constant monitoring. I strongly suspect when a typical child resents a brother or sister who has a disability, one factor may be the typical child feels neglected or ignored.

We regularly participate as an entire family in games, outings and activities. Having Ben as a participant, while leading to some interesting challenges, can significantly enhance the fun we derive from an event. In addition to family activities, we have always tried to set aside one-on-one time with Megan where she has our undivided attention. When Megan was younger, Mollie and I took turns reading aloud to Megan just before bedtime. During my turns at reading to Megan we read pretty much every book written by Roald Dahl and we took 2 years and read the Hobbit and the Lord of the Rings trilogy. We also make time to play games and do special activities at home. Playing cards, chess, trivia games and “Friday night movies” are all regular occurrences in our home. We also go on outings without Ben. Either, one of us stays home with Ben or we get a sitter and all three of us go out together. Movies, concerts, excursions to the mall... happen almost monthly in our family.

In addition to our spending one-on-one time with Megan, we’re fortunate enough that Megan and Ben are the only grandchildren on my side of

the family (there are 36 on Mollie’s side of the family!). Megan has experienced many adventures with my Mom and her husband and I’m very grateful she has these additional opportunities for high quality time where she is the center of attention.

## Letting a child be a child:

As a result of all the work that comes with raising a child with a disability, many times parents look to their typical children to help share the weight of the increased demands. For a typical child to be responsible for a sibling who has a disability is a heavy weight for that child to bear. I know a few adults who have brothers or sisters with disabilities who have expressed resentment over being made to feel they had to be responsible for their brother or sister.

I have to admit not making Ben’s care a responsibility for Megan is not always such an easy thing and, as Ben grows older, I expect it will become even more difficult. Due to the

significance of Ben’s delays, he will most likely always need a high level of care. It is very important to Mollie and I that the individuals who provide care for Ben love him and cherish him as much as we do. I’ve spent a good amount of time worrying about this. There have been so many times when I’ve wanted to beg

Megan to promise me when Mollie and I are older and can no longer care for Ben, that she will take over. As much as I want to ask Megan to do so, I can’t. Not just because of Megan’s age but because to do so would deny Megan her chance to dream and to find her place in the world and then I would be deficient in my responsibilities as a parent to Megan.

Not making Ben’s care one of Megan’s responsibilities is not to say we don’t have Megan help out. We do. If we need to do some work outside or in the basement, we have Megan keep an eye on Ben and frequently Megan acts as the “gofer.” When Megan is keeping an eye on Ben, she knows he is still our responsibility and she will call us if something needs attended to. As Megan gets older, I’m sure we will increase the demands we place on her with regard to Ben. What we will try to do is, as much as possible, keep those demands in line with what we would expect from her if Ben did not have a disability.



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The WV ATC Training Calendar is now available on the web.

Keep up to date with statewide training opportunities related to autism and education. Visit us at [www.marshall.edu/coe/atc](http://www.marshall.edu/coe/atc)

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*(continued from page 11)*

**Acknowledging the typical child's efforts:**

During the hustle and bustle of life it's easy to forget to acknowledge the good things our typical children do in relation to their sibling who has a disability. While being a parent is many times a thankless job being the sibling of a child with a disability should not be. When Megan helps out with Ben, we always try to thank her for doing so. When we see Megan seeking Ben out, including Ben in activities with her friends, making toys for Ben she thinks he will like (Ben loves things which make noise), we make sure we let Megan know how lucky Ben is to have a sister like her. The result is that Megan rarely, if ever, complains when we ask her to help out with Ben and, many times, she will independently do things for Ben without having to be asked. (Now, if we could just get her to do that with cleaning her bedroom!)

**Including the typical child in disability-related events:**

As I mentioned previously, every summer we have what has evolved into a three day event for individuals with Down Syndrome and their families called the East Coast Suaree. Also, Camp Gizmo, a week long assistive technology camp, which I help run, is in the summer. Two of the highlights of Megan's summer are the East Coast Suaree' and going to Camp Gizmo with Ben and I. Megan has a great deal of fun at both of these events and is able to participate in them in part due to having a brother with a disability. Additionally, Megan has the opportunity to be

around other individuals with disabilities and more importantly around other brothers and sisters who are in situations similar to her own.

**In conclusion:**

How do we raise typical children who don't feel "short-changed" and who see their brother or sister with a disability as a positive occurrence in their lives? Ultimately, there is no "magic formula" for success. I would suggest there are three key ingredients. The first is communication. Communication is multi-faceted. It begins with communication between parents as to how the issue of disability will be approached with the typical child. Communication with the typical child should be age appropriate and reflect what they need to know for their given age. Communication goes two ways. The typical child should be encouraged to let a parent know when they feel overwhelmed or have questions. Should the typical child have a question or concern, we as parents need to listen. The second key ingredient for success is creating frequent opportunities for each child to feel special and loved. This can be accomplished by being aware of what's going on in our children's lives, by acknowledging their successes and by making sure time is set aside when the typical child gets our undivided attention and fun things occur. And third when our typical children help out or do good things with their sibling who has a disability, acknowledge (reinforce) those good acts and not only will the typical child feel good about helping out, but those good acts will continue to occur in the future.

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**"We make sure we let Megan know how Lucky Ben is to have a sister like her."**

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## **April is Autism Awareness Month!**

**Let's make Autism Awareness Month 2003  
the most successful ever!!**

April is the official Autism Awareness month,  
but every month is actually Autism Awareness Month.

Help teach others  
about autism. Call the West Virginia Autism Training Center  
(1-800-344-5115) and request autism awareness brochures.  
Give them to everyone you know!

# DON'T MISS IT!

**Autism Society of West Virginia  
Announces the date for the next Annual Spring Conference**

**April 4-5, 2003**

**Mountaineer Race Track and Gaming Resort  
Chester, West Virginia**

**Keynote Speakers:**

**Phyllis Hunter:** *"Reading is the New Civil Right"*

**Gail Richard:** *"Methodology Issues and Decisions"*

**Bart Stevens:** *"Future and Special needs Planning"*

Additional speakers include: **Ruth C. Sullivan, Jeanne Lyons,  
Lynne Shroads and Pat Haberbosch**

**DON'T MISS THIS OPPORTUNITY!!!  
Call (800) 344-5115 for more information.**

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Share your tips with our  
News and Views  
readers.

Submit your articles to  
NEWS AND VIEWS  
WV Autism  
Training Center  
Marshall University  
One John Marshall Drive  
Huntington, WV 25755

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## Safety Tip - Screen Doors

Kent Moreno, Educational Specialist Senior

Although we live in a rural area, the road, which runs in front of our house, can be fairly busy at times. During times of cold or significant heat, we keep our doors closed which Ben, our son, is unable to open. On the days and evenings when the weather is pleasant, we faced a real dilemma. We wanted to open our doors to allow the pleasant weather in and rely on the screen doors to keep out the unwelcome elements. The problem, how do we keep Ben safe at the same time? The locks on screen doors are not particularly stout and Ben found if he hit the door handle hard enough, sometimes it would give way and he was able to exit our home. Additionally, if we needed to go outside, to do so required us to unlock the screen door and it could not be re-locked until we had returned or we had someone lock it behind us. After pondering this for some

time, I came up with a solution. I went to our local hardware store and purchased an extra handle and locking mechanism for each screen door (about \$7.00 each).

These I installed one foot above the original handle and locking mechanism. Now, if someone wants to enter or exit our home they must activate both latches on the screen door at the same time, something Ben is unable to do. Ben is far safer than he was with one handle and latch and the locking mechanism does not need to be used. Best yet we are still able to open the door using one hand by depressing the button on the top handle with our thumb while bringing our forearm down to depress the button on the lower handle.

If you have a tip to share with other parents, please write to the WV Autism Training Center or call 304-696-2332 or 1-800-344-5115.



# Supporting Students with Higher Functioning Autism and Asperger's Syndrome In Higher Education

Kimberly Ramsey, Program Coordinator Senior and  
Barbara Becker-Cottrill, Director

There is clearly a need for a specialized program to support college students with higher functioning autism and Asperger's Syndrome. In West Virginia alone, the Autism Training Center has worked with approximately *120 individuals* who might qualify for college entry, if they had the right supports. An informal and brief survey of some of those consumers reveals that going to college is a dream they (the families and the individual with autism) would like to see become reality. Yet, the barriers presented by the academic and social demands of college can be overwhelming.

While a number of college programs offer academic supports, most do not offer social and life skills supports. These supports are crucial for individuals with ASD who may have the academic abilities to succeed in obtaining a college degree but would face too many social and life skills obstacles to make that success a reality. For this reason, many well qualified individuals with higher functioning autism and Asperger's syndrome fail to enter higher education programs. Many, if given the appropriate support, could successfully enter and complete college programs. The implications of obtaining a higher level degree on the quality of life for that individual could be tremendous. Following are key areas which should be carefully considered when developing a university or college program :

## **Academic Supports**

A university or college program to support students with autism on campus will require careful planning which utilizes the learning strengths, abilities and interests of the student. The level of academic support required must be based on the unique needs of each individual. This may range from a full time assistant/tutor who shadows the student throughout the college day to a peer helper, who periodically checks in on the student. Students with autism may need assistance with following the classroom rules established by professors. These rules usually vary from course to course, making it difficult for the student with autism to understand. Assistants may be needed to ensure the student understands the rules of each environment and can comply with them.

## **Social Supports**

Social support is a critical necessity for all students with autism. Individuals with autism most

often have difficulty understanding the social behavior of others. Social difficulties take many forms, from being so socially withdrawn that a student has difficulty asking for help, to being socially "aggressive" where a student may make unreasonable social demands of others, ask repetitive questions of professors or challenge a professor's statements. A variety of best practices strategies, such as social stories, social scripts, visual cues for stress, anxiety and coping, and social rehearsal must be in place and monitored. A social support network must be established based on the interests of the individual (i.e. film club for a student who memorizes old movies or the football equipment team for a student who knows all the football statistics of college teams).

## **Faculty, Staff and Peer Tutor Training**

Equally important in a successful university experience for an individual with autism is an understanding of autism by faculty and students. Appropriate training related to autism, and more specifically, the unique characteristics and learning style of the student with autism is essential for classroom success. Tutors, who may be assigned to assist must also have an adequate understanding of this syndrome and the student's characteristics in order to provide the most effective tutoring program for that individual. Tutors need support too. They need to be able to check in with the program coordinator for feedback and to problem solve.

The West Virginia Autism Training Center (WVATC) is now piloting a higher education program for one student on the Marshall University campus. Using a model of positive behavior support including person centered planning activities, a systematic introduction to university life began early last spring. Plans have been carefully crafted all along the way and the student is now successfully integrated into campus life. Each of the considerations above were individualized for this student and are continuously monitored by his team. The WVATC is planning on slow expansion of the project in the coming years. Initial planning for each student will be intensive and require the commitment of many people. But, with the right supports, our students should expect to experience a college life that they want with all of its lifelong rewards.

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**"The implications of obtaining a higher level degree on the quality of life for that individual could be tremendous."**

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# Some Conferences, Workshops and Projects Related to Autism Spectrum Disorders

news and views  
Winter 2002

## Upcoming Workshops Offered by the West Virginia Autism Training Center

### December Family Skills Training Workshops

(For registered families only-call 1 800-344-5115)

#### Accessing Resources

December 04, 2002 , 12:00pm to 2:00pm  
Clay County Public Library, Clay, WV

#### Sensory Issues (two locations)

December 10, 2002 12:00pm to 2:00pm  
Marshall University Graduate College  
South Charleston, WV  
and Upshur County Public Library,  
Buckhannon, WV

Other training is occurring throughout the state.  
Visit our website and training calendar at  
[www.marshall.edu/coe/atc](http://www.marshall.edu/coe/atc).

## Open Your Eyes Picture Project Sponsored by Unlocking Autism

Pictures of Individuals with Autism are being collected until December 15<sup>th</sup> for the **Power of One Rally in Washington D.C.** next Spring.

The goal is to have 58,000 pictures stretching the length of SEVENTEEN FOOTBALL FIELDS!!

Release forms and mailing information can be found at the Unlocking Autism Website  
[www.unlockingautism.org](http://www.unlockingautism.org)  
or call the  
**WVATC at 1 800 344 5115**

## Some National Conferences and Workshops

Visual Strategies for Improving Communication and Behavior. Linda Hodgon, M.Ed., CCC-SLP  
February 20 – 21, 2003  
Atlanta, Georgia Raddison Hotel Northlake  
<http://click.topica.com/maaaB6zaaUcmYaaaaaab/>  
248-879-2598

5<sup>th</sup> Annual Mississippi Autism Conference  
Keynote Speaker: Carol Gray  
February 6 – 7, 2003  
Hattiesburg, MS Lake Terrace Convention Center  
<http://click.topica.com/maaaB6zaaUcxAa4JOp2b>  
1-888-671-0051

Autism/Asperger's 2003 Conference  
Featuring Dr. Temple Grandin, Carol Gray, Dr. Max Witznitzer, Jerry Newport, Dr. Luke Tsai and Maria Wheeler. January 30 -31, 2003  
San Antonio, TX  
[Info@futurehorizons-autism.com](mailto:Info@futurehorizons-autism.com) 800-489-0727

The Autism Society of West Virginia Spring Conference. April 4 – 5, 2003. Mountaineer Mountaineer Race Track and Gaming Resort  
Chester, WV. 304 696 2332

Solving the Relationship :  
Opening Doors to Friendship to  
People in the Autistic Spectrum  
Dr. Steven E. Gutstein  
March 21 – 22, 2003  
Herndon, VA Dulles Hyatt  
<http://click.topica.com/maaaB6zaaUcnjaaaaaab/>

Applied Behavior Analysis in  
the Classroom. Ron Leaf, Ph.D.  
April 28 – 29, 2003  
Sioux Falls, SD  
800-658-3080

Introduction to Verbal Behavior  
Vincent Carbone, Certified Behavior  
Analyst. March 14 – 16, 2003  
Arlington, VA George Mason  
University School of Law  
[lnicklas@comcast.net](mailto:lnicklas@comcast.net)

The Autism Society of America  
Annual Conference. July 16 – 20, 2003  
Pittsburgh, PA [www.autism-society.org](http://www.autism-society.org)

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## inside news and views

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- A Sibling's Perspective.
- Computer Corner.
- Autism and Higher Education.
- The Ultimate Juggling Act.
- And More!



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