

Spring 2006

News and Views, Spring 2006

West Virginia Autism Training Center

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The West Virginia Autism Training Center

<http://www.marshall.edu/coe/atc>

at  **MARSHALL UNIVERSITY**
Huntington, WV

Spring/Summer 2006

From the Director

Barbara Becker-Cottrill, Ed.D.

This edition of The West Virginia Autism Training Center's (WV ATC) newsletter is among my favorites and I am proud to share our agency's news and views with you. Along with useful and practical information about autism you will be introduced to some very special West Virginia children, families and educators. An important theme across the stories of Daniel, Chris, and Alan is their sheer determination to succeed combined with the active support of their families and team members. That is a powerful combination that can result in, as Alan's mom indicates, "... much happiness and satisfaction as well as a real purpose in life."

The accomplishments of Matt, Blaine, Dylan and Vijay (pages 6 and 7) are also an inspiration. Obtaining a driver's license, success at a job of choice, becoming a spelling bee champion and winning an art award from a prestigious university are indicators of real life success. We are so proud of not only these individuals but also proud of their families and their teams.

I want to take this opportunity to thank the many families and professionals who took the time to write to their legislators on behalf of the WV ATC. Over the last several years, we have experienced a dramatic increase in the number of new families registering for our services. We asked the legislature for additional funding to hire more education specialists. I am happy to tell you we did receive an additional \$200,000 and we will be recruiting new education specialists to the center. Again, thank you to everyone who wrote letters of support. You made a difference! We thank the West Virginia Legislature and Marshall University for their continuing support of our program.

I also want to let our families, colleagues and friends know that Wanda Wells, administrative assistant at the WV ATC will be retiring from her position on July 5th of this year. Wanda dedicated 18 years of her professional life to the WV ATC. We have worked together for the last 16 years and I cannot imagine WV ATC without her! We are frequently told that we have a most friendly and helpful office. Wanda has always set the tone for that atmosphere. Everyone will miss her but we wish her much happiness in her retirement.



Daniel's Story

By Jean Hardman, Education Specialist, and Daniel's Mother

This is a short story about a very handsome young man with big blue eyes and wavy, sandy colored hair. Daniel likes knock-knock jokes and has quite a talent for art. He likes to draw with chalk, markers, and on his magna doodle. I was asked to remember when Daniel started to draw; he was very young, around three years of age. I remember one day I took him to K-Mart. Sitting in the back seat, Daniel drew the highway route and included highway signs, detailing both the front and back of the signs. One Sunday, I took Daniel and his sister, Hope, to church. To help with keeping them quiet during the service, I gave Hope and Daniel books, paper, and markers. Toward the end of the service, I noticed Daniel drawing, "Clifford, The Big Red Dog Book." Daniel drew the whole book, Clifford, Emily, Elizabeth, the title, the trademark, and colored everything the right colors. It was very good. Then he flipped the paper over and drew the back of the book in great detail, including the UPC number!



Daniel's Clifford Book – front and back covers

Last year, Daniel's art work communicated a powerful message to his Positive Behavior Support Team. You see, Daniel's school is located on the same mountain as a major airport. One day shortly after school started, a huge plane swooped down with a very loud noise. Daniel's life became filled with fear; he no longer wanted to go to school or anywhere. Daniel's PBS team members came together and developed proactive, desensitizing strategies to help Daniel through this difficult time. The team developed a sensory diet of calming activities such as massages throughout the school day. *(Continued on page 1)*

Table of Contents

1. Director's Comments.....	Cover Page
2. Daniel's Story.....	Cover Page & Page 1
3. There's Magic in the Northeast.....	Page 1
4. Puberty and Autism.....	Page 2
5. Choosing Work.....	Page 3
6. Asperger's Syndrome and Depression: A Condition Often Overlooked.....	Page 4
7. About Chris.....	Page 5
8. Eat More Chickin.....	Page 6
9. Congratulations Page.....	Page 7
10. JOY.....	Page 8
11. Benefits of Art Therapy for Individuals with Autism.....	Page 8 & 9
12. Peer Mentoring Program Ready to Start!.....	Page 9
13. New Organization in Wetzel County.....	Page 9
14. Our Satellite Centers Have Moved..... (New Addresses for ATC North and ATC Northern Panhandle).....	Page 9
15. What About Me? Information and Strategies to Support the Siblings of Persons with Autism .. and Other Developmental Disabilities—Part II.....	Page 10 & 11
16. Suggestions for Choosing Direct Care Staff.....	Page 12 & 13
17. Family Coaching Sessions Update.....	Page 13
18. Research to Find the Genetic Factors in ASD.....	Page 13
19. Mentor Training Schedules.....	Back Page

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Daniel's Story

(Continued from Cover Page)

He was slowly introduced to various loud noises, including "plane noise," and a "3D" social story, allowing Daniel to take the "plane" off the page and put it back onto the sky page.



Daniel's 3D Story Book

PBS team members dedicated themselves to preparing Daniel for outside experiences and provided a safe and reassuring presence. Eventually, going outside was no longer scary for Daniel. As a matter of fact, the outside became interesting again, as Daniel's artwork, shown below, can attest. In this picture below, Daniel drew a "happy" helicopter flying over his backyard, delivering a payload!



There's Magic in the Northeast

*By Erin Lash,
Educational Specialist Sr.*

I have the pleasure and privilege to serve families in Hardy County and Mineral County. The Positive Behavior Support Lecture series began in August, 2005 for both counties. Many hours went into planning for the lectures, selecting dates and times, securing space and notify-

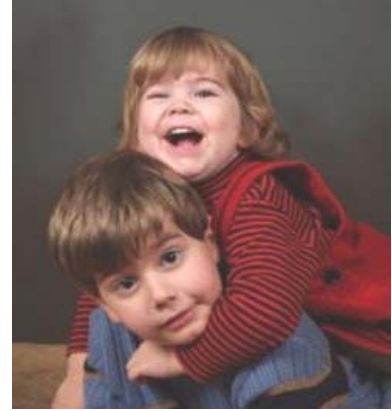
ing the focus families and their team members. What I hadn't planned on was the overwhelming level of participation and the rich tapestry of individuals whom I was to meet.

The Hardy County lectures brought 22 participants, including 4 parents and one focus child. One mother's journey into the world of autism had begun four days prior to the first lecture when her son received the autism diagnosis. All of the Hardy County Preschool Special Needs Teachers and aides attended the lecture series as well as all of the county Speech/Language Pathologists. This series also brought six professionals from the Birth to Three Program including Service Coordinators and Developmental Specialists along with Behavior Specialists from the Potomac Highland Guild.

The Mineral County series brought a diverse group of 29 participants which included 9 parents and 4 grandparents. For one family in this group, autism had entered their world six days previous when their son was diagnosed. The Mineral County group also included Preschool Special Needs Teachers and aides, Speech/Language Pathologists, Teachers, both regular education and special education, professionals from the Potomac Highland Guild and a student teacher.

The participants in each of these counties gained a lot of information but also brought a great deal to the lectures with

their own experiences. It was a pleasure to observe the way the participants embraced the PBS process. It was a privilege to be a part of the climate of strength and support these wonderful people offered to one another and to the parents who are new



Mark and Grace Wratford
of Hardy County

to the world of autism.

When people inquire about our agency and my role as Education Specialist, more often than not, they comment on the amount of travel involved. My reply as of late has been, "There's magic in the northeast."

Give Now!

Donations to support the Autism Training Center can be made on-line at:

www.marshall.edu/coe/atc



Mineral County PBS Lecture participants

Puberty and ASD: You Can Run but You Can't Hide

By Dr Jennifer McFarland,
Associate Director / Training

It's not uncommon for us to receive calls around the time that a young person with an Autism Spectrum Disorder (ASD) enters puberty. Many times, parents, teachers or others are concerned about a change in the individual. Perhaps a normally quiet, complacent individual is suddenly more active, vocal and/or aggressive. Many times we receive calls about inappropriate touching, masturbation and public nudity.

As hard as it is to imagine, our cute little kids grow up. As a parent, perhaps one of the hardest topics to talk about with any child is that of puberty and sexuality. Having an ASD doesn't change how an individual will mature physically. Persons with ASD mature physically along the same timeline as everyone else. **All** persons with ASD, regardless of where they fall on the spectrum, need information. Without this information, those with ASD will be unprepared to deal with physical and emotional changes.

The purpose of this article is to provide some tips and resources to those who may be thinking about how to provide information about puberty and sexuality to their child with ASD.

- **Start early.** From about age 3, a child should be given information about their body. Teach children to name body parts appropriately and teach them about appropriate/inappropriate touching. Young children should also begin to help with hygiene skills (e.g., wiping after toileting, washing hands, changing clothes, etc). As your child matures, they should take more and more responsibility for independently taking charge of hygiene issues.

- **Be sensitive to learning style.** Some individuals with ASD learn better with visual information. Use pictures and words to convey information, if needed. Read and adapt materials before you present them to the individual. A variety of resources you might find useful are provided below. Be sure you are comfortable with the content before going over it with the individual.
- **Keep it simple.** Provide factual information gradually over time. Don't overwhelm the individual with a lot of information all at once. This is a topic that should be discussed as the individual matures, not all at once when they reach puberty. As the individual grows, the amount and depth of information can increase. While you may be working on labeling body parts and hygiene early on, you will need to begin teaching the individual more about body changes, appropriate touching, privacy, and relationships as they reach puberty.
- **Face your own fears.** Some times the hardest part about teaching our children about puberty and sexuality lies within us. How we were raised and cultural and religious beliefs may make it hard for us to address the subject with our children. Before taking on this challenge, you may have to recognize your own fears and concerns about puberty and sexuality. It may help to ask for support and advice from others. It may also help to write a script or think through what you'll say regarding a specific topic.

There are many wonderful resources to help you provide information about puberty and sexuality to your child with an ASD. Some of these materials are developed specifically for persons with disabilities, while others are materials developed for any child.

Books and Curricular Materials:

The What's Happening to My Body Book for Girls by Lynda Madaras

The What's Happening to My Body Book for Boys by Lynda Madaras

Personal Hygiene? What's that Got to Do with Me? By Pat Crissey

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel

Autism-Asperger's & Sexuality: Puberty and Beyond by Jerry and Mary Newport

Sex, Sexuality and the Autism Spectrum by Wendy Lawson

Learn about Life: Sexuality and Social Skills Program from Attainment Company

American Girl Collection (books for girls):

The Care and Keeping of You

The Feelings Book

A Smart Girl's Guide to Boys

A Smart Girl's Guide to Starting Middle School

On the web:

All about puberty: http://kidshealth.org/kid/grow/body_stuff/puberty.html

Cool Nurse: <http://www.coolnurse.com/puberty.htm>

I wanna know: <http://www.iwannaknow.org/puberty/>

For girls: <http://www.gurl.com/>

Sexuality Education Training for persons with Disabilities: <http://www.fddc.org/HOME/Sexuality%20Training.asp>



Choosing Work

By Jeannie Elkins,
Alan's Mother & Disability Activist

Our son, Alan, (age 22) has had much success in his school program and as a result has had several newspaper articles written about his school program and his school-to-work program. The articles were all positive stories but, unlike his parents and teachers, he really did not seem too impressed with this recognition. The recent photo of him in our local paper for his recognition as "Boone Memorial Hospital's December Employee of the Month" was the first time he has shown any interest in a story written about him. He looked forward to getting the "Coal Valley News" and read the story through and through.

He has worked as a part-time Laundry Aide for Boone Memorial Hospital in Madison, WV for nearly 2½ years and has received excellent job evaluations and gotten several pay increases. He lives for his job. He feels truly valued and needed there. In September, on his 2-year anniversary, the Hospital organized a party for him and his supervisor Rosetta Thurmond. Rosetta has been a very valued BMH employee for 16 years. This is a common practice for all their employees' anniversary of employment. There is a bulletin board in the entrance of the Hospital dedicated to the employees with photos and a place for other employees to add their congratulations, a designated parking space, and free lunch in the Cafeteria for that month. Alan kept all the notes of congratulations from his co-workers. Recently he and I were shopping at Wal Mart when Alan saw a BMH employee from one of the offices on the second floor of the Hospital. She told me that the hiring of Alan and the recent hiring of another young man who has autism is, in her opinion, one of the best ideas BMH has ever had. They are both well liked and are excellent workers.

I believe that in West Virginia where

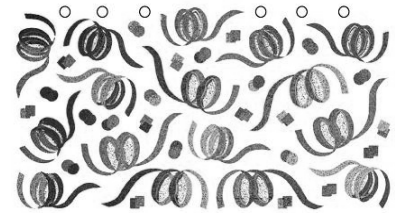
"Second Anniversary Party at Boone Memorial for Alan Elkins"

we have smaller communities and everyone knows everyone, there is such fertile ground for employment success for individuals who have disabilities. Some individuals will have the need for short-term support, natural supports, or long-term support. Whatever it takes to make it successful for the individual and the employer is well worth it. A Regional Counselor from the Division of Rehabilitation Services should assist with securing an appropriate job match and making certain the supports are in place when needed. DRS pays for a limited amount of job coaching hours then a Supported Employment Provider Agency pays for long term job supports if they are still needed.

Alan's dad and I have seen such a remarkable difference in him since he became officially employed by Boone Memorial Hospital. It is a sacred ritual for him to get everything he needs ready for his next day. In January he was sick and it was difficult for me to convince him to miss a day of work. He is convinced that the BMH Laundry department will fall apart without him there.

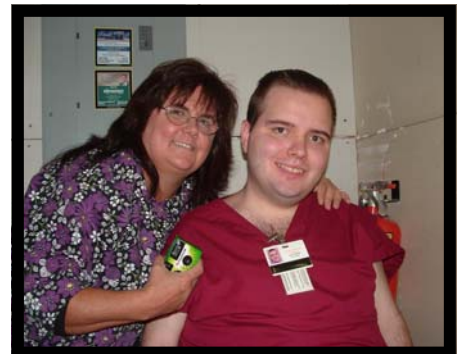
I believe there is often a misconception within some employment programs that serve individuals with limited receptive and expressive language regarding their need to have real valued work rather than just work to keep them busy. I am convinced by our experience that Alan and others with his disability understand when their work and contribution is truly valued. Alan has had a gigantic boost in his self-confidence since he began this job. He is the happiest we have seen him in his lifetime.

Alan also still has his wonderful circle of friends from his years in



school. Even though some of them have busy college or work schedules now they still keep in touch and spend some time together. He also enjoys being a member of the WV Fair Shake Network and recently changed his work schedule to be able to attend "Disability Advocacy Day" at the Capitol.

Having a job he loves and good friends to hang out with gives him much happiness and satisfaction as well as a real purpose in life.



Rosetta Thurmond and Alan both celebrate their employment anniversaries.

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Lighting the Way to H O P E

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Rhode Island Convention Center
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Register on-line at:
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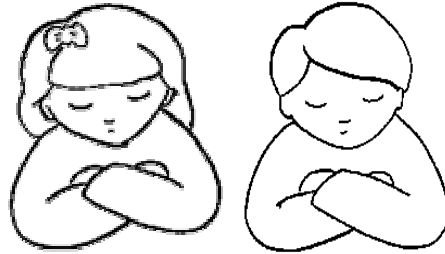


Asperger's Syndrome and Depression: A Condition Often Overlooked

By Dianna Grueser,
Educational Specialist

In recent years it has come to light that individuals with Asperger's Syndrome are at risk for depression. Because the symptoms for Asperger's Syndrome and depression can overlap, it is often difficult for a parent, teacher, or even a therapist who does not have experience with Asperger's to overlook the signs. For example, if the individual is isolated, it is easy to contribute that to the Asperger's Syndrome. Another problem with recognizing the signs of depression is that the individual may not be able to put into words how he or she is feeling or his/her description of how he/she is feeling may be inconsistent, and difficult to interpret. The individual might also express his/her depression in a change of behavior that again could be attributed to Asperger's Syndrome.

Although it can be challenging to determine if an individual with Asperger's is experiencing depression, there are some factors that can lead to an accurate conclusion. One way is to understand some of the factors that put an individual with Asperger's at risk. As with any of us, a family history of depression or other mental illness can greatly increase the risk that the individual with Asperger's may develop de-



pression, anxiety problems or possibly other mental illnesses. Another factor that puts the individual at risk is if they have experienced bullying, particularly if it was consistent or severe. The onset of adolescence can also be a time that the person becomes susceptible to developing depression. This is often because the individual with Asperger's is faced with a great deal of change around this time, often an increase in demands academically, and major changes in social expectations. Coupled with this is the fact that the individual with Asperger's is generally becoming more aware that he does not quite fit in with his peers. All of these factors have the potential to bring on depression.

Signs of depression in Asperger's Syndrome are virtually the same as they are for any individual; however, the symptoms may manifest themselves in a way that is different (Tantam & Prestwood, 1999). For example, the person with Asperger's might increase or decrease their obsessive behavior. They might increase their preoccupation with their favorite activity. They also may become more emotional either with increased sadness or melancholy or an increase in rage or agitation. Other indications could be a gradual or sudden change in sleep patterns, eating or enjoyment of activities. The individual may also become preoccupied with death. It is important to note that their preoccupation with death may or may not include references to hurting themselves, but this should be taken seriously and the advice of a trained professional should be sought.

If you suspect your child with Asperger's is displaying signs of depression, it is important to seek help. If the child is talking about hurting himself and/or preoccupied with death, seek assistance immediately. With proper treatment, it is possible for the individual with Asperger's to overcome depression and develop skills that will improve their quality of life, reduce anxiety, and decrease the risk of a relapse of the depression. A complete list of signs of depression can be found at most doctors offices and any agency that treats depression. You can also go to The National Autism Society website at www.nas.org and click on Mental Health and Asperger's for additional information.



On-line Autism Certification Coursework Available

Marshall University now offers two of the three courses needed for the autism teaching certificate on-line. Courses available include:

Fall, 2006 CISP 427/527E Introduction to Autism

Spring, 2007 CISP 662E, Instructional Characteristics of Autism

Also, available during the fall and spring semesters, CISP 664, Practicum in Autism.

To learn more: www.marshall.edu/coe/atc

To register: www.marshall.edu/registrar



About Chris

By Sharon Korringa, Parent

I never thought I'd ever get over my son, Chris, being diagnosed with Autism Spectrum Disorder. All my hopes and dreams for him seemed to fade away into oblivion and all I wanted to do was cry. What was God thinking? Giving me this child, I didn't feel I had what it takes to help him. Then my great grandmother said something to me. She said, "God will never give you more than you can handle. If He thought you couldn't do it, He wouldn't have given Chris to you." She was right. With the support of my grandparents and other members of my family, it was time to fight for Chris.

Now before his diagnosis in 2004, Chris had previously been diagnosed as having a speech problem at age 2. So by age 3, I had him in speech therapy at a local hospital. Once we finally had a diagnosis, I was given a folder with lists of people to call, things to order; you know, the whole protocol that I had to follow. Chris was enrolled in the local special needs preschool, pull-ups were ordered with a prescription, and many calls were made to the Autism Training Center, along with signing Chris up for Title XIX Waiver. Let's not forget the research done on the internet, which is where I learned about vitamin therapy.

Since 2004, Chris has been in speech therapy and occupational therapy, both privately and through

the school, along with physical therapy that he receives through the school. In addition to everything else, vitamin therapy is administered by me at home. We were also part of ATC's Family Focus Positive Behavior Support Program, which was such a wonderful resource to help us within our family and with the local school system. It has all paid off because his speech is back and he talks to me about everything he can think of, especially Pokemon. Potty Training was finally conquered right before preschool started. With kindergarten this year his hand writing has improved, along with his social skills.



This past spring Chris played T-Ball, and this year he is in kindergarten and plays basketball on the kindergarten inter-league team. He even has friends who he likes to play with. Birthday parties are a big favorite for Chris too. The first one he ever attended, he wanted to leave right then and there, but I made him stay. We just sat away from everyone and watched. After 30 minutes he was up and playing with the other kids.

So far, the hardest thing that I've had to deal with has been his growing up. Chris does not allow me to kiss him in public when I drop him off at school or walk him to the main door at school. When I asked him why I can't, he says, "Big boys don't need kisses and I can walk into school all by myself." I still sit and watch him walk into the school before I drive home, just to make sure he gets in okay.



I see a future for him now, one filled with hope and endless possibilities. I know he will be able to graduate from high school and that he will go to college and become what ever it is he wants to be.

With the Support of my grandparents and other members of my family, it was time to fight for Chris!

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10 a.m. to 4:00 p.m.

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Eat Mor Chikin!

By Peggy Hovatter,
Educational Specialist Sr.

As the well-known "Chick-Fil-A" cow, Matt Marino is as popular as Santa Claus! Children who enter the restaurant on Patterson Drive in Morgantown will wave with great excitement and exclaim, "It's the cow!!" Matt obliges by waving, nodding yes and no, giving hugs and posing for pictures. He occasionally enjoys creeping up behind coworkers and giving them a surprise hug as well, which is no easy task being a slim 5'9" teenager in a 7 foot cow costume!

Matt was constantly looking on the internet for a job. He found the Chick-Fil-A website and asked his mom, Jacki, if he could apply. She said, sure and soon afterward they were headed to the restaurant for an interview. The Chick-Fil-A owner, Lisa Holt, inter-



Lisa Holt, owner of the Morgantown Chick-Fil-A, helps Matt into his costume.

viewed Matt, then spoke with Jacki, who explained Asperger's Syndrome. Lisa and Jacki discussed Matt's abilities. The next day Lisa called Matt and offered him the job.

In addition to his 'cow duties', Matt also cleans tables, refills drinks, greets guests and bags food. His goal is to learn to use the cash register. Lisa reports that "Matt's a likeable guy and is very conscientious about his duties." Another coworker stated that Matt "makes us laugh and keep us on our toes." I can certainly attest to Matt being a good employee...when I was preparing to leave Chick-Fil-A after taking pictures and speaking with Lisa, Matt said, "You're going to order something before you leave, aren't you?"



Lisa quizzed Matt as to what the standard Chick-Fil-A employee response was when a customer says "Thank you". Matt immediately responded with "My pleasure." It is certainly MY pleasure to say "Well done, Matt Marino." We are very proud of you!"



News & Views

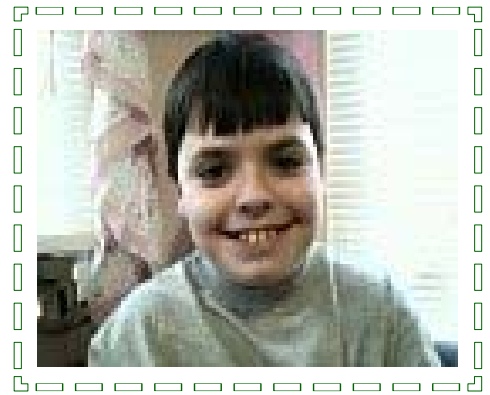
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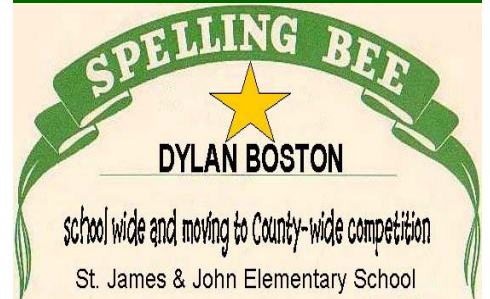
.....To Blaine Seitz, who was struggling with passing the written test for his learner's permit. Turns out the difficulty was visualizing the conditions stated in the diagrams of driving scenarios. He changed his way of studying and not only got his learner's permit, but his driver's license shortly afterward!



.....To Vijay Patnaik for winning 2nd place and 5th overall in a national art contest.



....To Dylan Boston, a 4th grader at St. James and John Elementary School in Marshall County, which services children in grades K through 8. Dylan won the SCHOOL-WIDE spelling bee! Dylan will move on to county wide competition.



JOY

By Peggy Hovatter,
Educational Specialist Sr.

Scene 1: Brooke County. Our team is taking a break during our training/ small team meeting. Kyle, our four year old focus person, has finished pre-school for the day and joined our group. JoAnn (mom) is busy entertaining Kyle with his favorite pastime of counting and identifying letters, as well as giving him many examples of facial expressions while they play.

The joy in her face is apparent as she watches her son learn. Once again the thought crosses my mind... "What a great mom." I am so fortunate, as I prepare to begin my 7th year with The Autism Training Center, to have this thought countless times as I see moms give their all to help their children.

Scene 2: We're still on our break. I then witness a scene that once again fills my heart with joy. Kyle spies his dad (Mark) and climbs on his lap. What follows is fatherhood in its' greatest form....a man singing the entire theme to "Blues Clues" for his son. I exchange a knowing glance with my community partner, Melanie Corley. We're both thinking the same thing.... "What a great dad".

Mark and JoAnn are involved with the Easter Seals fundraisers in Weirton West Virginia. For more information, go online to www.easterseals.com

Mark is also starting "Team FOP/ Easter Seals." As a member of the Fraternal Order of Police (FOP), Mark will be participating on May 27th in the Ogden 20K Classic Running Race in Wheeling, West Virginia (one of the most challenging and competitive road races in the United States). Mark states: "I decided several months ago that I was going to participate with special needs children in this year's race, in order to educate the public that everybody can compete and be included in everyday life." Mark will

be pushing special needs children in a 'jogging wheelchair'. Mark's eventual plan is to race throughout the United States as Team FOP/ Easter Seals.

I look forward to joy once again filling my heart on May 27 when Team FOP/Easter Seals is at the starting line.



The Benefits of Art Therapy for Individuals with Autism

By Angela Bryson,
Parent Support Coordinator

In 2001 my son, Vijay, started his first art and craft class outside of school. The class was held over a 6 week period and had regularly 6 participants. The beautiful crafts made included song bird mobiles and origami birds. These eye catching works of art were sold as a fund raiser for the first Walk for Autism and the proceeds went to purchase books at the Autism Training Center lending library. The participants of the class received a Christmas party with gifts, food and lots of fun. Since then my son has shown a keen interest in art activities. Although his favorite activity is painting, he also works on making walking stones for the outside of our house. These stones are each individual works of art that my son takes great pride in. He loves mixing the concrete and adding colored stones, colored glass and beads while creating his masterpiece. Each day I have incorporated art as a part of his daily routine.

Vijay is 22 years old now, non-verbal and needs assistance throughout his day but he can express himself well through the colors of the palette. He has an eye for blending colors into a beautiful abstract piece of art. He stays on task with his paintings until he fin-

ishes the piece and helps with clean-up. If you witness him at work, you can see the thought processes he is going through in making his decision about what will be on his canvas. Sometimes he chooses deep hues of red and purple and sometimes he chooses green or blue pastels with a splash of red.

Last year my son presented a painting on canvas to Delegate Margaret Leach at the Disability Awareness Day at the State Capitol. The title of the painting was Storm Warnings with mix of red, orange and yellow. This year during the same event I spoke to Delegate Leach who commented on Vijay's beautiful art work and stated that she had it professionally framed with gold and red hues that brought out the best of his work. Delegate Leach bragged on my son's talent for color and told me the framer exclaimed what a wonderful eye for abstract color Vijay has. I was very proud of Vijay's wonderful talent of expression.

This year my son received a national award for his artwork through the University of California, San Diego. His submission won 2nd place within his age group and 5th place overall. As a 2nd place winner, the UCSD Autism Research Program mailed him a baseball Padres T-shirt, visor, poster, figurine, pictures frame, magazine and pin. My son was selected from many submissions and his art work will hang in the UCSD laboratory. Vijay has also sold his works of art on E-bay and to several local parties. The money he receives goes back into funding his art supplies and allows him to go into the community for activities.

This year for Christmas, Vijay painted an art piece for each individual person. When I put the canvas in front of him I would tell him who the piece was for and he created his gift for that person. On the back of each painting I would assist him to put his signature and together we would name each piece.

(Continued On page-9)

Peer Mentoring Program Ready to Start!

A peer mentoring program will be starting at North Elementary in Monongalia County. The overall goal is to match special needs children with typically developing peers to facilitate social skills learning on the part of the child with special needs, as well as fostering an understanding of differences in the typically developing peer. Social norms affect all situations and are interwoven into all aspects of human relationships. The issue with special needs children, particularly children with autism, is not whether social skills are present, but to what degree. The peer mentoring program will address foundation social skills including fundamental skills, social initiation skills, social response skills and getting along with others. Best of luck to this wonderful and much needed program!

The Benefits of Art Therapy for Individuals with Autism

(Continued from page 8)

I would tell Vijay the title and he would agree if that is what he wanted to name the piece by shaking his head yes or no.

Vijay communicates volumes with his art work and I am so proud of every one of his accomplishments!

New Organization in Wetzel County

By Peggy Hovatter,
Educational Specialist Sr.

We are called Spectrum because our base of members in some way have come to love an autistic boy, be it parent, teacher or sitter. Spectrum automatically conjures an image of the autism spectrum. But the name also applies so well because we are not just talking about the autism spectrum. There is an entire spectrum to our lives on this Earth, which encompasses all people of all ages and abilities. We welcome anyone to our group. Come if you need autism support. Come if your child has another condition. Come if you don't know anyone at all who requires special care, but are interested anyway. Our goal is community awareness of autism, and awareness of special needs in general. We want to lift our kids up and show everyone how many of us there are, that we are not the wallpaper or background of society, to try to blend in and not disrupt 'normal' life too much. We are here to enjoy it too, with all the same considerations and rights as everyone else. We want everyone in the community to get to know us, and to share the love and fascination

that comes with knowing these kids. We can be reached at autismspectrum@verizon.net or by phone at 771-2595.

There is an entire spectrum to our lives on this Earth, which encompasses all people of all ages and abilities.



Spectrum Members



Our Satellite Centers Have Moved !



The ATC satellite centers in Fairmont and New Cumberland have moved to new locations. Autism Training Center-North, formerly in Colfax (near Fairmont), has moved closer to downtown Fairmont. Autism Training Center-Northern Panhandle is now located in a new state building in Weirton. For those in the area, please stop by and see us!

Autism Training Center – North

Rt. 250 Fairmont, WV 26554

Phone: 304-363-7642 / Toll Free 1-866-826-9933 (WV Only)

Fax: 304-363-6394

Autism Training Center – Northern Panhandle

100 Municipal Plaza – Suite 650, Weirton, WV 26062

Phone: 304-797-0294 /

Toll Free 1-800-213-7562 (WV Only)

Fax: 304-797-0295

What About Me? Information and Strategies to Support the Siblings of Persons with Autism and Other Developmental Disabilities — Part II

By Gloria Sage
Program Coordinator Sr.

In Part I of this article, which appeared in our Spring 2005 newsletter, information was presented from siblings about what they would like parents, teachers, and service providers to know about their lives and what they need. In Part II, we will provide developmental considerations of each age group and present ideas on ways to support siblings from preschool through adult.

Developmental Considerations of Preschoolers (before age 5):

- Children of this age are unable to articulate their feelings—they will show their feelings through behavior.
- They will not understand their sibling's special needs, but will notice differences and may try to teach their brother or sister.
- They have not learned to be judgmental and will likely enjoy their brother or sister.

How Do We Support Preschool Siblings?

- Give simple definitions of disability- use concrete examples; visual aids
- Give siblings "permission" to feel and express various emotions (ask child how he feels, use "emotions" pictures, draw or paint, have child dictate a story to parent/teacher expressing feelings)
- Teach the child ways to interact with their sibling
- Facilitate play and turn-taking activities with the child and sibling

- Teach simple behaviors for coping

Developmental Considerations of Elementary School Age Siblings (6-12 yrs.):

- These siblings are starting to venture out into the world and are acutely aware of differences.
- Can understand a definition and explanation of their sibling's special needs—*if* explained to them in terms they can understand.
- May worry that the disability is contagious or wonder if something is different with them, too.
- May experience guilt for having negative thoughts or feelings about their sibling.
- May experience guilt for *not* being disabled.
- May become OVER helpful and well-behaved or become non-compliant in order to get parent's attention.
- Will have conflicting feelings about their sibling throughout this age span.

How Do We Support Elementary School Age Siblings?

- Provide more detailed explanations of the disability.
- Explain the strengths and weaknesses of the disability.
- Develop and practice responses to common questions that may be posed from friends. (Provide "scripts" for what to say; use role play).
- Discuss ways to cope with stressful events such as public reactions. (Role-play situations; provide "scripts" for what to say).
- Network with other siblings (SibShops; support groups;

online support groups, etc.)

- Encourage child to have activities unique to him/her (art, sports, drama, science, dance, etc.)
- Parents should participate in activities outside of the disability world/community
- Parental recognition of child's strengths and accomplishments is important.

Ideas for Sibling Activities:

- Start a journal
- Family scrapbook/photo album
- Provide lots of praise/reinforcement (coupons; tokens, etc.) for helping out/taking on extra responsibility
- Have a family game night or family activity night
- Provide age-appropriate books about the disability
- Watch movies together with a character who has a disability- talk about what happens
- **One-on-one time with parents.** Children need to know from their parents' *deeds* and *words* that their parents care about them as Individuals.
- Parents should schedule time for an activity or just to "hang out" with their typically-developing children. This conveys the message that parents "are there" for them and provides an opportunity to talk about a wide range of topics.

Developmental Considerations of Adolescents (13-17 yrs.):

- Can understand more elaborate explanations of the disability.

(Continued on page 11)

What About Me? Information and Strategies to Support the Siblings of Persons with Autism and Other Developmental Disabilities — Part II

(Continued from page 10)

- They may ask detailed and provocative questions.
- Having a sibling who is different MAY be embarrassing in front of friends and dates.
- May feel torn between desires for independence and the need to maintain a special relationship with their sibling.
- May resent the amount of responsibility they have (girls typically bear greater responsibility than boys).
- May begin to worry about their sibling's future.
- May begin to worry about how the sibling will affect their own future—will they be responsible for the sibling when parents can no longer care for them?

How Do We Support Adolescents?

- Have open discussions in the family where members can freely express positive and negative feelings and siblings can ask questions about the disability.
- Will need to expand on previous explanations of the disability, as well as its treatment and implications.
- Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come.
- Parents can reassure their typically developing children by making plans for the future of the child with a disability, and by listening to

and including siblings in those plans.

- Parents and agency personnel should invite (but not require) brothers and sisters to attend IEP, IFSP, transition planning, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers.
- Parents should be understanding of teens' embarrassment of their sibling—this is just a stage that all teens go through and will pass.
- Journaling, writing stories or poetry is a good way to express feelings. Stories and poetry can be submitted to newsletters or online sites for publication, if the teen desires.
- Sibling support groups or online sibling chat rooms are a good way to connect with others who are going through the same thing.
- Be aware of the warning signs for depression and anxiety.
- If child displays a number of these symptoms for a prolonged period of time (2 weeks or more), discuss the situation with the child's physician or a mental health professional.

Adult Siblings:

- Become educated about your brother/sister's disability.
- Develop an understanding of your sibling's needs and desires. Use person-centered planning tools to help discover your sibling's "Dream" for the future.
- Research adult services, such as housing, job

training, supported employment, community activities, etc.

- Bring together the family and professionals to discuss options and create a plan.
- Become involved with a support group/network with other adult siblings.
- Serve on an advisory board/ become politically involved in advocating for persons with the disability.

References:

Sibling Needs-Helpful Information for Parents, Timmons Schubert, Ph.D.

Web article taken from Center for Study of Autism.

What Siblings Would Like Parents and Support Providers to Know, Donald

Meyer. Article taken from The Sibling Support Project website.

Sibshops: Workshops for Siblings of Children with Special Needs. Meyer,

Vadasay, (1994). Paul H. Brooks.

Schubert, T. Sibling Needs – Helpful Information for Parents. www.autism.org/sibling/sibneeds.html

Parents and Support Providers to know. www.thearc.org/siblingsupport/



Suggestions for Choosing Direct Care Staff

By Angela Bryson,
Parent Support Coordinator

Whether you are working with a behavioral health center or not, choosing a staff person to work with your child can be frustrating, frightening and a bit confusing. Do you choose only someone with experience? Where do you look? Who do you ask? Who can you trust?

Some suggestions from years of experience:

First of all, work with your behavioral health center and establish a partnership in choosing direct care staff to work with your child. How you address this relationship is entirely up to you. If your child is on the Title XIX MR/DD Waiver program, the behavioral health center will find the person, train them and monitor their service to your child. You as a parent can have great input in choosing staff and having the staff trained. Your best approach to this is through the Individualized Program Plan (IPP). At the IPP meeting, you can provide input on what the staff does with your child, how often they provide services and if that service will be provided at home or in the community. This same rule applies to hiring non-agency staff through Waiver. The biggest difference here is that you must find the staff and then they apply through the behavioral health center. Non-agency staff will obtain the same standard certification needed, (e.g. CPR and First Aid). It is your responsibility to monitor staff and provide the necessary programs they will need in working with your child.

If you are not on the Title XIX MR/DD Waiver program and you are hiring staff, finding and paying for staff may prove to be a bigger problem. Your options may be to request funding through the Family Support Program, the Laura Center, etc. Some agencies have a special mandated state fund they can tap into for respite funding. If this special funding is requested and approved, an Interdisciplinary Team Meeting (IDT) must occur to develop a plan for how the staff will work with your child and how this plan will be

monitored for success. Also, like other funding sources, this is for a limited number of hours. Staff hired who are funded through the Family Support Program or the Laura Center do not need CPR or First Aid because billing for their services is not an issue. However, these staff funded by the state fund need CPR and First Aid certification. Of course, it is a good idea for all staff to have CPR and First Aid training.

Locating a good staff person:

Behavioral health centers provide general training for staff and usually new staff shadow existing staff for a two-week period of time. Is this enough? What I have done in the past is to talk with the Community Program Manager through the behavioral health center who hires the staff and get the person's background, then I set up an interview at the behavioral health center's office. I ask the person three important questions:

1. Why do you want this job?
2. Do you have any personal obligations that would keep you from being available for my child?
3. Is transportation an issue? Not having transportation may be a serious problem if you have scheduled many community activities for your child and you live in a rural area with no public transportation access.

After the interview, if I feel good about the staff person, I will have them shadow my other staff people for the next two weeks. I am available to answer any questions and give needed input. Since every staff has a different approach, it is important for the new staff to shadow each staff for at least three shifts. The Waiver program will accept this 2-on-1 billing as direct training. In addition, I work very closely with my staff and we have constant communication about how my son is doing every day. If you have more than one staff person, a good rule of thumb is to schedule monthly staff meetings and include the Community Program Manager. The meetings do not have to be more than one hour in length but it is a good idea to keep everyone on

the same page and solve any current issues.

Where else to look for hiring non-agency staff:

University students who are in education or psychology can make good staff. Post an ad on the campus community board or ask an instructor to inquire. Churches or other organizations you are involved with may have good leads. Ask your teacher if there is a peer helper or classroom aid who might be interested. If your child is receiving additional therapies such as speech or occupational therapy you may want to put a notice on the community board at their office. You may not want to post an ad in the paper or at the local grocery store because you may have to eliminate a lot of people. Networking with other families sometimes works, as well as asking close neighbors and friends.

Staff's responsibility:

This is up to you. First of all, staff should receive on-going training. I also have staff attend the IPP meeting for their valuable input and it gives them a good idea of what program plan is in place. If the staff is implementing programs this will reflect in their contact notes and data that is being collected. If additional training is needed contact the Community Program Manager. You must decide what is and is not important to you. For example, if preparing a meal is part of the IPP person plan, then you must decide whether experienced staff should also clean up their mess and take out the trash.

Payment above the salary rate:

If you decide to pay above the pay rate this is your choice. I decided to pay staff's entrance fees to movies, restaurant tabs, and any other activity fee that includes my son. I also remember the staff on holidays and birthdays. I know of some people who have paid staff extra money or washed the staff's laundry or helped buy their groceries.

(Continued On page-13)

Suggestions for Choosing Direct Care Staff

(Cont'd. from page 12)

How close should you get to the staff person?

Will they become an extended member of your family? A staff person is in your most personal life. It is hard for them not to be involved with your family. The extent of the relationship is up to you and your family. It is a good idea to be friendly but professional. That means to be nice, but be aware that the staff have a life too and may not be available all the time. Be sure to monitor your child's program closely and communicate any issues you may have. Also, be positive and let them know when they are doing a good job.

What if the staff person is not working out?

Always try to problem solve. The staff may need additional training. Be sure to let the Community Program Manager know if a problem exists and especially one that has not been resolved. If the issue continues, have the staff member removed. Unless it is a safety issue, try to remember that this staff person may not have worked well for your child but may work well with other individuals. Also, it is important to keep a list of all staff people you have worked with and the date they provided the service. Believe me, after 5 or 6 years you may not remember if staff has worked with your child before, especially if they were in place for a short period of time. If the staff person has been removed or left, note that in your list and the reasons why.

Final tip:

Direct care staff has been a blessing for my son and me. The Title XIX MR/DD Waiver program has been a godsend. One staff person I had was with us for 4 years. Sadly, he graduated from college and moved away. The average amount of time that staff has worked with my son is about 2 years.

Just be sure to remember the basic concepts of hiring staff:

- ♥ screen
- ♥ train
- ♥ monitor
- ♥ praise



It has worked for me !

Family Coaching Sessions Update

By Angela Bryson,
Parent Support Coordinator

Community Partners (CPs) at the Autism Training Center provide Family Coaching Sessions to assigned families while they are on the Family Focus Positive Behavior Support Program (FFPBS), or waiting for FFPBS. The Family Coaching Guides are one-hour sessions provided by the CP to the family by phone or in the family's home. These sessions are optional and are completed only at the family's request.

Sessions covering topics listed below can be selected by the family for a one hour coaching session:

- Accessing Resources
- Basic Letter Writing
- Guardianship
- How To Start an Informational Support Group
- Individualized Education Plan (IEP) Checklist
- Individual Rights and Processes
- Public Benefits
- Service Coordination
- Transitioning to Adulthood
- Website Directories

Since October 2001, CPs have provided 360 training sessions to families in 25 counties. The overall consensus

from the families has been favorable and these guides have proven to be a wonderful tool for CPs to provide support and resources for our families. For more information, contact Angela Bryson at the ATC at 304-696-2332.



DUKE center for
HUMAN GENETICS

Research to Find the Genetic Factors in ASD

The Duke Center for Human Genetics (CHG) is conducting research into the genetics of autism and related disorders. The goal of these research efforts is to discover the genetic factors that contribute to the cause of autism and related disorders.

Please join us in our research efforts to find the gene(s) that contribute to autism spectrum disorders. In order to detect these genes, many families are needed to participate in this study.

For more information in the WV, OH and KY area:

Scott Short at: 1-866-308-3032 or
scott.short@duke.edu

Duke CHG at:
<http://www.chg.duke.edu> and
www.exploringautism.org



Duke Center for Human Genetics
DUKE UNIVERSITY MEDICAL CENTER

Save the Date

Friday, August 4, 2006

10 a.m. to 4:00 p.m.

The West Virginia Autism Training Center at Marshall University

Proudly Presents.....

**BRENDA SMITH
MYLES**

TOPIC: "Strategies for Success
in a Complex World"

LOCATION: Radisson Hotel
1001 Third Avenue
Huntington, West Virginia

REGISTRATION: \$75.00

Includes a Box Lunch

Watch for more information at:

► **Autism Mentor Training I and II**

June 12, 13, 19 and 20, 2006

9 am – 4 pm

Location: The Marshall University Graduate College,
South Charleston, Wv

\$30.00 per day

Call the WV Autism Training Center

To register: 304/696-2332

► **Autism Mentor Training I and II**

July 31, August 1, 7 and 8, 2006

9 am to 4 pm

Location: The Marshall University Graduate College,
South Charleston, WV

\$30.00 per day

Call the WV Autism Training Center

To register: 304/696-2332

► **Autism Mentor Training I and II**

July 31, August 1, 7 and 8, 2006

9 am to 4 pm

Location: WV Autism Training Center North
State Route 250, Fairmont WV 26554

\$30.00 per day

Call the WV Autism Training Center North

To register: 304/363-7642

► **Autism Mentor Training I and II**

July 10, 11, 17 and 18, 2006

9 am to 4 pm

Location: Raleigh County Board of Education
105 Adair Street, Beckley WV

\$30.00 per day

Call the WV Autism Training Center

To register: 304/696-2332

► **Autism Mentor Training I and II**

June 12, 13, 14 and 15, 2006

9 am to 4 pm

Location: WV Autism Training Center–Northern Panhandle
100 Municipal Plaza

Rm. # 806, (2nd Floor)

Weirton, WV 26062

\$30.00 per day

Call the WV Autism Training Center–Northern Panhandle

To register: 304/797-0294



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