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Newsletter

West Virginia Autism Training Center at Marshall University

Spring 2004

# News and Views, Spring 2004

West Virginia Autism Training Center

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# The West Virginia Autism Training Center at Marshall University Celebrating 20 Years of Service

# news and views

Huntington, WV • Spring 2004

# From the Director

Barbara Becker-Cottrill, Ed.D.

In 1983, the West Virginia Legislature had before it a bill to establish a statewide autism training center to be housed at Marshall University. Autism was a little known word then, but that was about to change. Under the leadership of Ruth Christ Sullivan, West Virginia families of children with autism worked diligently to bring an understanding of the syndrome. Citizens of West Virginia with autism deserved to be educated by qualified professionals and to be cared for by their families in their natural homes. Families needed help teaching their children at home and educators needed knowledge concerning best teaching practices for students with autism. The legislature listened to these families, they understood, and in 1984 the center opened its doors.

Twenty years later, the West Virginia Autism Training Center (WVATC) is going strong and still working tirelessly to fulfill its mission to meet the individualized needs of its consumers. Many changes have occurred over the past 20 years. Personnel at the center has increased from 10 full and part time positions to 55. The number of families who are registered for services has gone from about 15 initially to 860 today. There are now two satellite centers, one in Colfax and one in New Cumberland. Resources and programs have expanded based on consumer needs. And, in an effort to determine just how many people autism affects in West Virginia, a collaboration with the Centers for Disease Control was established and is still very active. The prevalence of autism estimates in West Virginia should be available before the end of 2004. Four additional states will be reporting as well and there are 11 other states that will follow. It is exciting to be a part of this most important work.

Perhaps, one of the biggest changes has been to embrace the philosophy of positive behavior support and to approach our work, not as temporary consultants but as facilitators of teams of people who are invested in helping/teaching/supporting/ becoming friends with an individual with autism and their family. As we work together on all of the details of an individualized support plan (which includes strategies for developing and/or increasing communication, social skills, cognitive skills and self care skills), we also work together on finding the right supports to enable the person and the family to participate in events they find enjoyable. Outcomes include increases in targeted skills, but they also include other less measurable outcomes such as singing in the choir at school or church, horseback riding, tap dancing in a recital and going trick or treating for the first time. Participating in the community and enjoying it....that is a great outcome and one that just doesn't happen unless the right supports are in place. We are proud to be providing positive behavior support for our families.

Other aspects of our expansion over the past 20 years include our efforts to establish model programs at the preschool and college levels. We are ready to replicate our Circle of Friends Preschool in the Northern PanHandle and are planning for dissemination of our college program to other universities. And, we have opened the first autism spectrum disorders registry in the United States. We will be able to address many critical questions, among them "Is autism increasing in our state?"

We have much to celebrate in our 20<sup>th</sup> year of service. We have a hard working group of dedicated people at our center,

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# The Ripple Effect of Increased Communication

**By Peggy Hovatter**, Education Specialist Sr.

I have had the great pleasure of learning from a handsome 11 year old named Mitchell. One of his most endearing qualities is looking deep into your eyes prior to gently placing his cheek on your shoulder. He will steal your heart in a matter of seconds.

Mitchell's Positive Behavior Support (PBS) team possesses qualities that will allow continued growth as the future unfolds. His team consists of his parents, special education teacher, special education aide, speech therapist, regular education art teacher, school principal, case manager/1:1



trainer from a local behavioral health agency and Autism Training Center staff. Team meetings encompass exchange of ideas, data analysis, supportive suggestions, open communication and consistency with regard to goal implementation between

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# From The Director

(continued from page 1)

who go the extra mile every day for people with autism and their families and educators. We have had wonderful support from the West Virginia Legislature and Marshall University. We have enjoyed a close relationship with the State Department of Education and appreciate all of their support. Senator Robert C. Byrd has been a major supporter of our mission and has helped us reach so many more families with our model of service delivery, the Family Focus Positive Behavior Process. New donors, such as the Austin family, have enabled us to develop and expand model programs. We have appreciated our relationship with the National Centers for Birth Defects and Developmental Disabilities, Centers for Disease Control. And the best of all possible reason to celebrate is the growth we have seen in so many West Virginians with autism.

There is still a long road ahead with important research to be done to guide our intervention efforts. Going down that road with a strong team keeps all of us moving forward together. In closing, happy anniversary WVATC! Here's to the next 20!

# The Ripple Effect

(continued from page 1)

home and school.

Mitchell's team discussed his areas of interest, current skill levels and family goals. Based upon this information, the following life style outcomes were developed:

- 1. Become a sculptor/potter.
- Live in a ranch-style house close to a beach and park (equipped with a swimming pool/diving board) with indoor/outdoor swings, a maid and a pet dog.
- 3. Mitchell and his parents would like to go on fishing trips to their "getaway" cabin in the mountain.
- 4. Lots of close friends.

  What a wonderful example of PBS.....Mitchell's dreams are very similar to our own!

In relation to his lifestyle outcomes, Mitchell's strengths include an amazing interest in Playdoh with the ability to transform a large piece of Playdoh into numerous tiny dots in the blink of an eye; a

love of swimming and swinging; an enjoyment of people as well as 'alone time'; solid imitation skills and the ability to attend and participate in activities.

Mitchell's team determined the following areas to change in order to reach his goals: the need for a functional form of communication via the Picture Exchange Communication System (PECS); use of an alternative socially appropriate way to communicate when he is upset; increased independence in daily living skills such as dressing and food preparation and increased reciprocal social exchanges with others.

Team members collected baseline data to determine patterns and/or likely times that Mitchell displayed aggression. Information regarding antecedents and consequences were collected as well. Based upon the data collected, the following hypothesis was developed:

When Mitchell is asked to do a difficult/ non-preferred task or when he has to wait, he may hit or pinch others. Mitchell is more likely to hit or pinch from 9:30-11:00 a.m. when 1:1 academic instruction occurs at school. When Mitchell hits or pinches, he sometimes is permitted to stop the activity or he is redirected. At home, Mitchell is more likely to hit or pinch his 1:1 trainer if mom doesn't arrive home at the designated time.

After data analysis, Mitchell's team determined strategies that may prove helpful, which include:

- 1. Change types or methods of academic instruction.
- 2. Increase daily number of trials using PECS.
- 3. Teach Mitchell to use a "break" card.
- 4. Teach Mitchell to use a "wait" card.

"Team Mitchell" has done a marvelous job with implementation of PECS. Increasing functional communication has decreased aggressive behavior already!

Mitchell continues to entertain us with antics that show his superb problem-solving ability and provide a glimpse of the intelligence that is so often hiding behind the autism. Here's one example...When working on discrimination between two picture cards with the corresponding items on the table, Mitchell continued to give his aide the picture of the item that he didn't really want. Following the PECS protocol like a trooper, his aide continued to hand him the item that corresponded with the non-preferred picture, which was juice. After several attempts, Mitchell did NOT hit or pinch, he simply took the juice and put it in the refrigerator!

Continue to teach us, Mitchell. We are listening.

# WV Autism Training Center MU and Huntington Featured on National Public Radio Segment

A segment which aired January 26<sup>th</sup> on National Public Radio (NPR) highlighting West Virginia Autism Training Center's efforts to identify children with autism in West Virginia, has drawn attention and accolades from listeners across the nation.

The nearly 10 - minute segment narrated by NPR staff member Jon Hamilton, who visited families of children with autism Huntington to prepare for the feature. After its airing, the story was selected as a "top 3 editors pick" on the NPR



website and was the story most frequently e-mailed for the day.

West Virginia is one of 17 states receiving funding from the Centers for Disease Control in an effort to obtain the first accurate count of children with autism. As the number of individuals diagnosed with autism appears to be increasing, studies are underway to determine whether autism is becoming more common or just more likely to be recognized.

"We must answer questions about the number of individuals with autism because without understanding how many people this affects, we can't tackle the problem itself," said Dr. Barbara Becker-Cottrill, Executive Director of the WV Autism Training Center and Principal Investigator on the study. And West Virginia researchers are finding the counting process both slow and difficult. Autism is not an easy diagnosis to make, according to Becker-Cottrill. "The diagnosis is made solely

based on observation. There is no test for autism. You can't get blood and detect it and you can't give a standard IQ test and detect it," she says. That further c o m p l i c a t e s determining how many people have this condition.

The West Virginia autism monitoring team is headed up by Julie

O'Malley. Ms. O'Malley and her team spend many hours traveling throughout the state to conduct their work. She says just the process of training reliable data collectors or abstractors can take up to 80 hours. But reliability of the data is critical to the study.

In addition to determining how many West Virginians have autism, the results of the project could affect funding and direction of autism research. The story has been archived on the NPR website and can be heard by going to the site and searching autism under archived stories.

The direct link is http://www.npr.org/features/feature.php?wfId=1617147.

"The diagnosis is made solely based on observation. There is no test for autism."

# Legislation Mandates Reporting of Autism Spectrum Disorders in West Virginia

By **Charlotte Hays**, M.A., Program Coordinator, Sr. **Cathy Jo Templeton**, M.A., WVASD Registry Coordinator

Recently, Autism Spectrum Disorders (ASD) became a "reportable condition" in West Virginia. As a result, beginning January 1, 2004, medical doctors, psychiatrists, and psychologists must report diagnostic information regarding any individual who receives a primary diagnosis

included under Autism Spectrum Disorders. For the purpose of reporting, the primary diagnosis must be one of the five following disorders: Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger's Syndrome, Rett's Syndrome, and Childhood Disintegrative Disorder (continued on page 4)





Congratulations to the Portsmouth and Gallipolis, Ohio Walks for Autism!

Each was a huge success!

### Legislation Mandates Reporting

(continued from page 3)

(CDD). The individual with the disorder must live in the state of West Virginia. Anyone diagnosed outside of the State of West Virginia, who is a West Virginia resident, must also be reported.

West Virginia is the first state in the nation to establish an Autism Spectrum Disorders Registry. Four years ago, with the encouragement and support of West Virginia Senator Robert C. Byrd, the West Virginia Autism Training Center at Marshall University began an autism epidemiology program in collaboration with the Centers for Disease Control and Prevention (CDC). To further assist in tracking prevalence and incidence rates, the West Virginia Legislature established Autism Spectrum Disorders as a reportable condition in public health in 2001. Reporting will be conducted through the West Virginia Autism Spectrum Disorders Registry (WVASDR) which is housed at and operated by the West Virginia Autism Training Center at Marshall University. As an agent for the State of West Virginia and the federal CDC, WVASDR must comply with laws related to confidentiality and is fully compliant with the Health Insurance Portability and Accountability Act (HIPAA). Confidentiality is a priority of the WVASDR. No names or any other identifying information are being collected for this registry.

Reporting is mandatory for neurologists, pediatricians, family physicians, and psychiatrists, as well as psychologists. With the help of diagnosticians throughout the State, the WVASDR will allow tracking of the number of West Virginians diagnosed with Autism Spectrum Disorders each year. It will also provide valuable information to inform policymakers about issues related to autism and the services needed in this area. A media and mailing campaign is underway. Further information is available on the WVASDR website at www.marshall.edu/wvasdr.

#### WEST VIRGINIA AUTISM SPECTRUM DISORDERS REGISTRY

### Who is required to report?

Neurologists, Pediatricians, Family Physicians, Psychiatrists, and Psychologists (including School Psychologists),

### When is reporting required?

When an individual receives a Primary Diagnosis of:

Autism

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

Asperger's Syndrome

Rett's Syndrome OR

Childhood Disintegrative Disorder (CDD)

AND is a West Virginia resident, regardless of where diagnosis was made.

The reporting form must be completed WITHIN one month of the date of the diagnosis.

### Where is the information submitted?

WVASD Registry
WV Autism Training Center
Marshall University
Old Main 316
Huntington, WV 25755
304-696-2332
1-800-344-5115

Fax: 304-696-2846

### How can further information be obtained?

For further information about the WVASDR, please visit our website at **www.marshall.edu/wvasdr** or contact:

Cathy Jo Templeton, WVASD Registry Coordinator at 1-800-344-5115 or higgins2@marshall.edu.

### news and views

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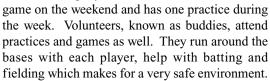
# Miracle League Baseball Swings Into Morgantown

By Adam Bullian, Director, WV Miracle Sports Complex

Miracle League Baseball is set to begin its second full season in Morgantown. This unique baseball league is designed for players with all types of disabilities. It is played on Miracle Field, at the West Virginia Miracle Sports Complex, one of only a few baseball fields of its kind in the country. It is equipped with a Mondo surface similar to those used for indoor and outdoor tracks but designed for easy mobility for people using wheelchairs, walkers, and other mobility devices. It also provides a more cushioned surface than dirt, reducing cuts and scrapes. Completed in May 2003 Miracle Field was home to the inaugural Miracle League Baseball season in West Virginia with forty players.

The League is open to both adults and children and the first season was a resounding success according to players, parents, and the community. It gives players an opportunity to acquire new skills in baseball but also learn sportsmanship and be a part of a team. It gives parents peace of mind by knowing that their children are not only participating in a sport, but are doing so in a safe atmosphere with special attention paid to their specific needs.

A Miracle League Baseball game is different from a traditional baseball or little league game. There are no winners or losers, no outs, and each inning everyone bats, gets a hit, and scores a run. Each team plays one



Preparations have already begun for the 2004 Miracle League season beginning May 1 and extending into August. Any adult or child with a disability is welcome to play, and volunteers are always needed. Miracle Field is located only 1.5 miles off of Interstate 79 exit 155 providing easy access to almost anywhere in West Virginia as well as Pennsylvania and Maryland. Anyone interested in participating or volunteering can call Adam Bullian, Director of the West Virginia Miracle Sports Complex at (304) 296 – 0150.



# MIRACLE SPORTS COMPLEX

### Rudd Equipment Company Donates Funding

The WV Autism Training
Center received a \$1500
donation from the Rudd
Equipment Company. The
money will be used to
purchase additional books
and videotapes for the
center's family lending
library. The staff and clients
of the WVATC extend their
sincere appreciation and
gratitude to Rudd
Equipment Company.

If you, your company or someone you know is interested in donating funding, materials or equipment to the WVATC, please contact Dr. Becker-Cottrill, Executive Director, at 304/696-2332.

# Reaching Out to All Children with Special Needs: Grace Covenant Presbyterian Church Holds an Inclusive Vacation Bible School

by Pastor Doug Minnerly

Grace Covenant Presbyterian Church, on Charleston's West Side, put a new "spin" on an old theme with their "Weekend Extravaganza: A Vacation Bible School Experience for All God's Children," held last summer. Opting for a weekend rather than the more traditional week-long Vacation Bible School program, Grace Covenant recognized a need and sought to fill it, at least in part, through this ministry.

Pastor Doug Minnerly and his wife Susan are the proud parents of Nathan, an 8-year-old who happens to have autism. Prompted by their own experiences of exclusion due to Nathan's condition, and those of others they know, Pastor Minnerly decided that Grace Covenant's program would be fully inclusive and that the church would make every effort possible to provide for the special needs of any children who might come their way.

"It is providential that several years ago, the church made physical improvements to the facilities to make them accessible," Minnerly said. Consequently, the church facilities were already set up to handle physical needs based on issues of mobility. To the end of meeting other needs, Joyce Armentrout, church member, elder, and early-intervention specialist, began to recruit the aid of a variety of professionals. In addition, a number of volunteers were lined up to serve as "special



The Kentucky Autism
Training Center Will Host
AUTISM INSTITUTE:
Strategies Series 2004

June 28 - 30 2004

"Asperger's Syndrome Across the Lifespan: Practical Strategies for Parents and Professionals"

Featuring

Peter Tanguay, Stephen Shore and Brenda Smith Myles

Hosted in conjunction with the Kentucky Department of Education

AND

July 20 - 21, Lexington, KY July 22 - 23, Covington, KY/ Greater Cincinnati

"Promoting
Communication, Social
Skills and Cognitive
Development for Children
with Autism Spectrun
Disorders"

**Featuring** Linda Burkhart

Hosted in conjunction with the Kentucky Department of Education and the Ohio Department of Education For registration information call 502/852-7277 or email klfrar01@louisville.edu

# Reaching Out...

(continued from page 5)

buddies" should any participants need one-on-one assistance.

The weekend consisted of an "opening rally" with singing and a family movie, complete with popcorn and cookies, on the first evening. On the second day, the children were treated to a lesson in acceptance through the use of the parable of the Good Samaritan as a basis. They learned songs and rehearsed for a presentation in worship for the next day. The children made great craft projects and they had some good recreation time too. Sunday morning's worship was a special celebration of the special event, followed by a hot-dog lunch topped off with ice cream sundaes.

Grace Covenant Presbyterian Church, located in Charleston, plans to continue this program this

coming summer and hopes to reach more families. If you would like to stay informed, please call the church at 304-346-7489 and ask to be placed on our VBS mailing list, or you can e-mail Pastor Minnerly at **RevDougM@Juno.com**.

"In all, God brought us about a dozen wonderful, beautiful kids who had a great time, found love and acceptance, and, we hope, experienced God's love in our church," Pastor Minnerly told the congregation.

During a sermon, Rev. Minnerly made the statement, "Kids are great!" and Patrick, a very precocious 4-year-old replied so all could hear, "Yes they are!"

Amen to that!

# Perspective from an Asperger's Point of View

By a College Student

There are some individuals out there with differences, notable differences which put them into separate categories. I am one of those individuals. I hear too well and sense things so greatly it is displeasurable. I have a form of higher functioning autism called Asperger's Syndrome. It may put me into a category now, but it gives me extraordinary abilities and hardships to live with.

When one looks up at a bright sunny day, what does he usually say? "Ah the nice warm breeze, the bright sun is shining ever so brightly!" But no! I look at a hideously bright day, and ask the question, "Where are my sunglasses?" This illustrates two points of life with Asperger's: losing things and sensory overload. The former is due to chronic unorganization. The latter is due to factors unknown to scientists but suspected to be a type of short circuit in the brain's sensory wiring.

On a personal note, I feel strongly that all autism is genetic and that the spectrum of autism reflects a spectrum of additional ailments. Someone with severe autism is suffering from multiple non-genetic ailments in addition to the genetic ailment of autism, which itself causes increase in intelligence (i.e. Albert Einstein, Thomas Jefferson, etc). These non-genetic ailments go undiagnosed because the family wants them to. Which would you rather your child have a diagnosis of: severe autism or autism and severe mental impairment.

After going on the offhand note, I want to bring to your attention a big thorn in my side. I have to

live with a disorder that if I told any of you I had it, you would likely think me mentally impaired. If you knew me you wouldn't, and probably after reading through this article and finding out English is my weak point you wouldn't think so. Still, how many of you started reading this article thinking I had an IQ of 80? Well I don't and most people with Asperger's Syndrome are well above normal in the intelligence area. It's just the daily living skills and social areas that need work.

Humans are social beings. Believe it or not, but people with autism are humans and therefore are social beings as well. We just didn't wake up with the wiring for socializing. People with autism have trouble understanding gestures and hidden language. Just within the past year have I started to get these signals, and most people have gotten them from a very early age.

Daily living skills are essential. Unfortunately for many with Asperger's syndrome, they're hard to grasp. I've just recently learned how to work a washer and a dryer. I don't have a driver's license or permit! There are two other students with Asperger's on campus, and they live on campus. They are both older than me and have had more life experiences than I have. But we all share the same label, which I hope you all understand better now.

### news and views

Spring 2004

# Acceptance

By Douglas & Alice Martin, Parents

When approached about submitting an article about our son for the newsletter, I spent the following weeks and months torturing myself to come up with an original approach to our view on autism. Creativity, at one time, came fairly easy for me as an art major in college, even under the harshest of deadlines and workloads. Under my self-imposed deadline for this article, I suffered. It is not the writing about my son, Dominic, diagnosed with moderate autism at age 2 + years, that is so difficult. It is my never ending battle with accepting his disorder that proves to be the obstacle. If only I could view my child as a child for more than a moment without analyzing his every movement, word, or lack thereof. As I wander through his maze of strategically placed toys, I realize he is quite content with his uniqueness and that creativity comes easily to his 4 year-old mind. That is, at least, until his imaginary world is interrupted, usually by the big paws of the family dog knocking over his work. Homeostasis interruptus.

We can move about our little world in our little home and our little lives quite well until the balance is upset. Everyone who has a child, any child, recognizes how easily this can happen. As an older first-time mother, amnios were required for each of my three sons. Each time we blissfully received results that were found to be normal. Considering our first two sons have done and continue to do so well in all respects, we expected the same, barring sickness or injury. When we received the first inclination that something was amiss—we could not accept it. How could this be?

The next 2 years were spent battling the odds that our son might have a chance of overcoming autism. We ebbed against the flow of proclaimed hope of diets, therapies, causes, and miracles. Inching our way, day-by-day, through the autism darkness is the challenge well understood by all those with children with autism. We must live with our decisions and the guilt that the responsibility for Dominic's success lies primarily on our shoulders. The tell-tale bruises that frequent the middle of his forehead lets the world know that not all is well. Although he has altered behaviors for the better or worse, the underlying irritation remains. Until a year ago, he had limited communication, especially verbal. The family struggled to translate his tantrums to calm the storms. In sickness, his small fevered body could not convey to me where it hurt when it hurt. My only consolation was that I was his safe person and I knew at least that he needed us. I could not look at or think of Dominic and not feel guilt and frustration over something that I might not be doing to make life better for him, for us. I could not see that progress was being made right under my nose. Although EVERYONE assured us that he was progressing quite well, we had nothing to compare him with other than two "normal" siblings.

With love and laughter we learned to fight our battle against autism and focused on enjoying the life and variety that Dominic brings to our world. We have learned that this decision is the best choice for us. To say that children with autism are devoid of emotion and bonding is far from true with Dominic. To see him flap wildly over the sight of his brothers coming in the door from school is the only expression that we need to recognize his love and devotion. Our older sons have been, by far, our greatest blessing in the fight against autism. The crude teaching methods of an 8 and 6 year old couldn't be more realistic. Turn taking, interaction, and the pecking order are our primary subjects each and every day. It is with much pride that we watch the three brothers huddled in one chair in front of the computer delighting in some small amusement usually discovered by Dominic. Echolalia of his brothers, for better or worse, has become his own, appropriately without intervention from us. Giggling rides in the car when Dominic discovered that he can "make a funny" has won the admiration of his brothers. We are not devoid of the normal brotherly quarrels and, like us, autism is not always easy for Duncan and Dedrick to understand or accept. However, they are genuinely eager to guide and protect Dominic when we are away from the home turf. The lack of a means of communication was our greatest and most challenging hurdle. PECs training was extremely difficult to initialize since Dominic resisted our efforts to teach him. Dominic's brothers learned early that modeling for Dominic also gains reinforcement for them. Constructing his simple sentence strip has evolved from "I want pudding" into the most glorious "I love you, Mommy" in perfect clarity.

Our acceptance can be attributed to the individuals and organizations who came into our lives along with the autism. Within the political and marginal confines of this page we wish to thank Chris Toth for her eyes and heart that persuaded us to see what we refused to see. Her work and guidance through Easter Seals steered us toward help that we would not have discovered on our own accord. Thanks to Dr. Susannah Poe for her wisdom and comforting reassurance that "we are doing the best that we can do" and for sending Shannon Haag's magic in Applied Behavior Analysis to



The Huntington Area Autism Society is sponsoring The Walk For Autism May 1, 2004 Ritter Park

Activities begin at 9 am Walk begins at 10 am

Come and show your support for Autism!



# The West Virginia Autism Training Center at Marshall University: A Journey Through Twenty Years

Jennifer McFarland, Associate Director of Training Barbara Becker-Cottrill, Executive Director

After considerable effort and the tireless work of many parents of individuals with autism, the West Virginia Autism Training Center (WVATC) at Marshall University opened its doors in 1984. Since that time, the center has grown from having a staff of less than 10 to a staff of 55 who provide services throughout the state. Originally, services were predominately provided on-site at Marshall University. The WVATC staff resided in or near the Huntington area. Families stayed at the university in an apartment for up to 3 weeks receiving in-depth assessment, program planning and training. Follow-up services were provided within the family's home community. During the first year, the WVATC provided training services to approximately 11 families. The preschool training project, under the direction of Dr. Glen Dunlap was also housed at the WVATC during the early years of the center.

Around 1987, on-site services were discontinued and the agency worked toward providing community-based services. Until 1992, the WVATC staff, most of who still lived in the Huntington area, traveled great distances to communities across the state to provide consultative services. In 1992, staff living in the Morgantown area were hired to better serve the northern portions of West Virginia. While this change decreased the distance that staff was traveling, ever increasing numbers of clients needing services stretched staff to their limits. Between 1992 and 1995, approximately 225 families were served per year.

Perhaps the most critical turning point in the WVATC's history occurred in 1995. At that time, the center applied for and received a grant from the Centers for Disease Control to develop and provide a model of Positive Behavior Support (PBS) called Family Focus PBS for families of children with autism under the age of 8. Approval of this grant allowed the agency to hire additional staff to work intensively with a select group of children. During this same year, the WVATC developed a model preschool with support of Cabell County school system and started providing autism mentor training. Other WVATC staff continued to provide community-based consultative services.

With the development of the Family Focus PBS program, a seed was planted. Evaluation data and reports from staff and families indicated that families served under the Family Focus PBS program were more satisfied with services than those receiving traditional WVATC services. Staff seemed to be happier too as they had the opportunity to intimately get to know families, work proactively with teams on problem issues and collaborate with a variety of professionals. Those providing traditional WVATC services were typically just responding to crisis situations and not providing the level or intensity of services that families wanted and needed.

By 1998 it was clear that Family Focus PBS was the direction that the WVATC needed to go. With advisory board and staff support, the agency's direct service model became Family Focus PBS in 1999.

Today, 14 Positive Behavior Support Facilitators and 7 Community Partners, parents of individuals with autism, provide Family Focus PBS services to approximately 50 families per year across the state. For the most part, staff live throughout the state and serve families who live closer to them. In addition to the Family Focus PBS model, the center offers a lending library, referrals and information on autism, a newsletter, a webpage, higher education coursework in autism, autism mentor (paraprofessional) training, and inservices/workshops. The WVATC continues to run a model preschool with support of the Cabell County school system, is assisting Hancock County schools in the development of a preschool, and has developed a model college program at Marshall University for students with higher functioning autism. In 1999, WVATC also added the surveillance of autism in West Virginia to its list of projects and in 2004, the first legislatively mandated registry for autism spectrum disorders was opened and is housed at the WVATC.

While services have expanded in intensity, quantity and scope throughout the years, so much more needs to be done. Autism is one of the most challenging of all syndromes and is only now finding true recognition as a syndrome that must receive research and intervention attention from federal authorities. The WVATC will keep pushing forward to develop and collaborate on research projects and will continue to expand services that meet our consumers' needs. We are fortunate to have excellent supports in place and a staff dedicated to the families and educators we serve.

# news and views





Fred Reenstjerna, Delayne Plata, Gabrielle du Verglas, and Glen Dunlap confer on procedures of ATC





Left: Legislative Reception, Glen Dunlap and Kent Bowker (February 19, 1986) Right: Legislative Reception, JW Hunnicutt, Frank Robbins, and Delayne Plata (February 19, 1986)



Some of the ATC Staff (December 2003)



# Something New to Chew On!

By M. Nathalie F. Henchey, MBA, Parent

Being a mother of an autistic child, even before he was officially diagnosed, I had to educate myself very quickly. I had to learn to cope with all the sensory issues and behaviors that are associated with this disorder. My son, named Olivier who is now almost 5, was mouthing everything. For many years, I lived on constant alert mode. That is what I called the great risk of daily choking. It was a daily struggle and even today I have to watch him closely. He still likes to eat glue, crayons, sand, and paper, etc. He definitely loves to taste everything (edible or not).

After his teeth erupted, he chewed right through teething rings and non-edible items. After failing to satisfy his need to mouth for many months, an occupational therapist suggested that I get him some non-toxic dog toys! You should have seen the look on my face. Having a nursing background and an open mind to new ideas, I finally felt comfortable with this idea and from that day, I shopped for my son with a different vision!

From the time he was ten months old, I worked with him everyday. Most people who saw him with those dog toys were probably wondering if I had lost my mind. As my son grew older, I quickly realized that he was seeking greater input through

his mouth. I knew exactly what he needed, but I couldn't find it.

Years past and frustration built up. I decided that somebody needed to do something, and that was me! What I came up with was the OliCreever, now with a patent pending. I developed this new idea, an oral sensory integration device designed for oral stimulation and self-organization. It is shaped for easy access to the mouth. It vibrates

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### Acceptance

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ascertain our success. Thank you WV Autism Training Center for the miracles you have to offer. Thank you, Peggy Hovatter and Marshall County Preschool, for teaching us to cherish our son for who he is and for removing our doubt that he will do well. Most importantly, you have shown us that he may continue to "march to the beat of a different drummer" without repercussion. May we all revel in his uniqueness. Thank you, my son, for opening our hearts to a world that many will never see. All this—we accept!

# The College Program for Students with Higher Functioning Autism at Marshall University

The College Program for Students with Higher Functioning Autism is in its second year. Students participating in the program have met acceptance criteria for Marshall University and have been admitted to the College Program for Students with Higher Functioning Autism through a separate application process.

The program uses a positive behavior support approach to assist participating students. Social, communication, academic, leisure and personal living skills are assessed through person-centered planning. Personal goals are identified and strategies are developed based on the individual needs of each student. The program seeks to help students learn skills which will help them earn a college degree, work in their chosen field, and live a productive, independent and quality life. For more information, please contact:

Kimberly Ramsey, Ed.D.
College Program Director
Autism Training Center
One John Marshall Drive
Huntington, WV 25755
Email: ramseyk@marshall.edu

Telephone: 304/696-2332

# Mike, Get Your Tap Shoes.....

by Teresa McDonough, Parent

Last year, as part of the Individualized Program Parent Plan (IPP) process and filling out an application for the Title 19 waiver program, we tried to think of an activity that my son, Michael, could participate in. We wanted some socialization, exercise and something to help with his sensory issues. Now keep in mind Michael is not exactly what you would call athletic. I've always said even if he didn't have autism he is more of the book reading, computer surfer, and game cube man. I guess being at that tender age of 10 when the lazy gene kicks in doesn't help much either.

One thing Michael has always been is a HAM! He loves to play characters from movies and act out scenes. He also loves music. When the team put all this together the logical thing to try was tap dancing. We were very fortunate to find Rose McDonough, no relation, owner of RM Productions in South Charleston. She had had experience in working with people with disabilities before and was more than willing to give Michael a shot. He had his first private lesson in October, 2002. To our blissful amazement, he could keep rhythm. Even more exciting he could pick up steps, even more complex ones, very easily. That was it. We were all convinced that Fred Astaire would have to turn over his tap shoes to Michael. O.K. so that's overdoing it a bit. After a few times we, including Michael, decided that he was going to be part of the recital in March 2003, and would be doing a duet with Cari Green. She had worked with us as part of the Family Focus Project (WV Autism Training Center), during the Fall of 2002. She also happened to take tap for her personal enjoyment, and had recommended Rose. Two Saturdays a month, Michael took additional lessons with Cari, along with his weekly private lesson.

Everyone at the dance studio was very supportive of Michael. Rose often would have him "perform" his tap number, what he had learned up to that point, and their cheering and clapping was always very encouraging for him. Now I don't want anyone to think everything was "rosie" every week (Sorry, I couldn't help the pun). We did a lot of working for rewards. He enjoyed doing the dance, and learning the steps. The length and his attention is what we had to work on the most and still do. When he first started he could only participate for 10 or 15 minutes. He worked up to half hour sessions.

He also likes it when Rose includes little moves he throws in

It was hard for him to foresee the future of what a recital would be so Rose dug out some old videos, I rented the standard *Singin' in the Rain* starring Fred, and *A Chorus line* and *Tap* with Christopher Hines. All this helped keep his interest up for a while.

As it was getting closer to the recital we started looking at costumes. Michael decided on a tux with tails and a top hat. Rose threw in the cane. After we ordered his tux he wanted to know "Will my big black car pick me up?" and "Will my fans in the audience have signs with my name on them?" We became concerned. What had we created? I had to explain there would be no limo (to Michael and my mother) and he would have family and friends watching and cheering for him when he was done. Recital day finally arrived. He looked so handsome in his tux, tails and top hat. He was so proud. Oh and Cari looked cute too. Early in the show it was time for their performance to Sunny Side of the Street. For four glorious minutes the world only knew Michael, the tap dancer, not Michael, the boy with autism. I don't know who cried more, Rose or me. He had a great time. But that wasn't his only performance. A week later his elementary school had a talent show. He had the honor of getting to perform the duet with Rose herself on her birthday. I can't tell you the overwhelming

response from the entire student body, teachers and parents. The other Charleston Daily Mail even did a story on him and he made the front page, fulllength picture and story. For a long time we would go places and people would say something nice to us when they would see us in public. He even signed autographs at his doctor appointments declaring to his father, "You know. Dad. I'm famous now."

There have been many people over the years involved in getting Michael to this point in his life. Thank you just isn't enough. We still have much work to do for his

plans for his future. Shining moments like this are sometimes far and few but we'll take them. I'm busy now trying to find a ZOOT Suit for his dance solo this year to the song *ZOOT Suite Riot*. You know, I took dance (tap included) in elementary and jr. high. I'm sure he gets it from his mother!

### news and views

Spring 2004





### APRIL IS AUTISM AWARENESS MONTH!

You can help teach others about autism

Information about autism is available to distribute to schools, doctors, neighbors or any group, please call the WV Autism Training

Center at

1-800-344-5115

to order

### Something New to Chew On

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(adjustable), has lights, multiple colors, textures, replaceable batteries, on/off switch and is designed for any child with teeth. It can also be used as a body massager for children who are seeking constant tactile sensory input. It is specially designed for children who have passed the developmental age of mouthing, but still have the need to do so.

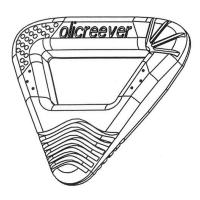
Working at IDEA (Institute for the Development of Entrepreneurial Advances), Marshall University, as a Research Associate, it was possible to bring this idea closer to life. The students in the manufacturing engineering technology program got involved and are developing a working prototype in conjunction with The Robert C. Byrd Institute for Applied Flexible Manufacturing. A few other business major students are working in developing the business plan and are looking at the market. I am amazed to see how this project is moving forward. Every time I talk about the device, I get a good response! This is very encouraging. I am determined to bring this safe product to the market for any child or adult who has a need to mouth. Hopefully my son will not need it anymore, but many more children will! And if he does, we can say good-bye to dog toy world!

As I showed my red, blue, and green triangle, pointing out how the device could help a child with autism searching for sensory input, I quickly

realized that the device could be used for not just sensory issues, but also for challenging behaviors, feeding issues and probably many other things!

Working in conjunction with Marshall's Autism Training Center, we hope to learn whether the device fulfills the needs of our children. Using this information, I will finalize the OliCreever design and hope to get it on market quickly. I strongly feel that sometimes a good product can only be developed by a parent who had to struggle with a need, but it is only with other parents' input that we can assure the product is right! Please let me know what you think about the OliCreever or if you wish to become involved in the testing process.

For more information Nathalie can be reached by phone at 304-696-4365 or by e-mail at **farandhenche@marshall.edu**.



# Every Reason Not To

By Jean Hardman, Educational Specialist Sr.

In recent years McDowell County has been hit with two devastating floods. The latter, this past spring, took innocent lives, destroyed homes and entire communities. Wading through mud waist deep and seeing all of your life's possessions destroyed is an experience few of us will ever have to face.

What McDowell County does have is beautiful scenery and most importantly, McDowell County has the best kept secret in the state. It has wonderful, compassionate people.

In September, a family, the McDowell County Board Of Education and WV Autism Training Center came together in the Family Focus Positive Behavior Support Training process to support a little boy name Chandler. Chandler is an adorable 8 year old child with autism.

Chandler likes books, to draw, watch TV and is good with a computer. Chandler's PBS team identified areas to increase support and continues to work monthly on those goals.

As a part of the PBS process, participants attend four-six hour lectures for the purpose of increasing their understanding of this complex disability. Somehow, someway the county board gathered funding for the school personnel to attend these lectures on four Saturdays throughout the fall and winter months.

At the lectures, class motivation and participation remained high. The post test average proved to be well over 75%.

- Chandler's teacher, Mrs. Brown, remarked to me recently, that she has learned to continue to try to draw Chandler out more and keep him engaged in more activities.
- Mrs. Smith, school principal, shared with Chandler's team her discovery when Chandler spontaneously at lunch, one day, decided to purchase a snack independently after a year of seemingly no interest – the team just laughed and rejoiced!

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# Computer Corner Voice Output Communication Aides

By Kent Moreno MA/BCBA

news and views

Spring 2004

In this issue of the computer corner, I want to discuss voice output communication aides. Voice output communication aides, also known as "vocas", like the Picture Exchange Communication System (PECS) and sign language, are categorized as alternative augmentative communication systems. In effect, alternative augmentative communication systems give nonverbal or minimally verbal individuals a way to communicate. Vocas are basically small computers that are able to speak. What makes vocas so attractive is their ability to provide the individual with a voice. With the current research on autism suggesting that between 37% and 53% of all individuals with autism are non-verbal, vocas could potentially play an important role in the lives of many individuals with this disorder.

Vocas range in price from fairly inexpensive, \$50.00, to well over \$10,000. The top of the line vocas such as the Liberator, are quite impressive. In 1994, at the National Down Syndrome Congress' annual convention, I listened to an individual with cerebral palsy give an almost 90 minute speech using a Liberator.

Considerations when looking at vocas include: the size of the device's memory, the type of display (paper overlays versus liquid crystal displays), the number of grids, battery life, synthetic speech (computer speech) versus digitized speech (recorded speech), and a host of other variables.

Essentially, vocas can be used in two ways. A voca may be used as a tool to facilitate an individual's participation in life. For example, at circle time, the group sings "Old MacDonald had a Farm." A voca such as a "Big Mac" or a single switch "Cheap Talk" could be programmed with the chorus of the song. When the rest of the kids are singing "e-i-e-i-o," the non-verbal child activates the voca and is able to participate in the song. Another possible use for a voca, as a means of facilitating participation, might be that the teacher records a message for the front office (lunch count, who's absent...). The teacher then sends the student to the office. When the student arrives, he or she activates their voca and delivers the message. The voca could also be used to record a "joke of the day" (or perhaps something exciting which happened to the individual) on the voca and the individual then uses the device to tell their joke (or story) to his or her peers or family members.

The second and more common use of a voca is as a device to communicate for the individual in lieu of their natural speech (or to supplement the individual's natural speech). Unfortunately, vocas are not perfect and the current technology has certain limitations. These limitations may have a

significant impact as to how appropriate vocas are for many individuals with autism and other developmental disabilities. Sadly, the limitations of vocas are frequently overlooked and a very common result is that 2 months after the voca was obtained, it's gathering dust in some corner.

The first big problem is that while a huge amount of effort is expended to obtain a voca, very rarely has a sound methodology been identified to teach the individual how to use the device. Given the unique learning profile of individuals with autism, this is a serious problem. The good news is that one can, with little difficulty, adapt the PECS methodology to teach the individual how to use their voca.

With regard to autism, one technology to be wary of is "minspeak". Minspeak is available on vocas manufactured by Prentke-Romich. Minspeak is an attempt to increase the efficiency of a voca by giving icons multiple functions. For example, there may be a picture of a "frog" on the overlay. If one pushes the frog icon, the device says "frog." The frog icon might also represent the color green so if the person hits the "frog" icon and then the "tree" icon, the device will say "green tree." For individuals with autism, using minspeak will most likely be a nightmare. The good news, on vocas made by Prentke-Romich, minspeak is an option not a requirement.

Like any complex device, vocas are subject to breaking or, at the very least, someone forgetting to charge the batteries. There must be a back up system (another voca, sign, PECS, etc.) available to the individual should their voca not be in proper working order.

Another consideration when selecting a voca as an augmentative communication system is "who will be trained to program the device?" There need to be a number of individuals in each environment who know how to program the device. A few years back, I consulted with a young man who had cerebral palsy. This young man used a Delta-talker to communicate. At least every 2 months I'd get a call from the sheltered workshop informing me of a problem with the device and could I please come and re-program it. There was more than one occasion where I was not able to get to the sheltered workshop for 2 weeks at the very earliest. This was particularly terrible because due to severe mobility restrictions, an inexpensive back-up system was not an option for this man and the family couldn't afford a second device. As a result, the individual was without a means to communicate until I could get to the workshop. My personal recommendation is



First Annual
Bicycle Ride for Autism
Awareness

9 a.m., May 1, 2004 Ritter Park Huntington, WV

Call 696-2332 for registration information



Marshall

University

Looking for teaching materials? Check out these websites:

www.shareware.com

www.tucows.com

www.crayons.com/ links.html

www.winsite.com

www.shareware.miningco.com

www.nickjr.com

www.trollbridge.com

www.download.com

www.macshare.com/ sftwre.html



### Computer Corner

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that there be a minimum of two people per environment (home, school, work, etc.) who can program the voca.

This next limitation is in my opinion the most significant problem with vocas at this time. The upper end vocas have grids that go from 1 - 128spaces. The 32 space grid has pictures which are reasonably sized and discrimination is usually not a problem. Traditionally, the next sized grid after the 32 space grid is the 128 space grid. The size of the pictures (or words) in the 128 space grid are extremely small (more or less the size of the tip of your pointing finger) and can be very difficult to locate. Herein lies the problem. With a good instructional methodology, even most individuals who are profoundly retarded can be taught how to request access to more than 32 things. Yet in order for them to communicate more than 32 things with their voice output device, the overlay must be changed and the corresponding sub-menu activated (this is easier to do with vocas using liquid crystal displays). This is something even a moderately mentally impaired person will not be able to do (there are a lot of typical adults who can't do this).

Thus we have a device which lacks the flexibility necessary to adequately meet the communication needs of the individual. One possible solution that might work for a small percentage of individuals is to program a space on the voca that says "change overlay" when the desired item or concept is not available on the current overlay. An adult or other person would then have to determine the page on which the appropriate item is located, switch the overlay and activate the appropriate sub-menu. Depending on the abilities of the individual, this could potentially occur a number of times during a single conversation. For this reason, unless an individual is capable of changing their own overlays and submenus. I believe that PECS would be a much more functional and effective augmentative communication system.

For those individuals for whom a voca is an appropriate alternative augmentative communication system, the commitment needs to be made to jump in with both feet. Many times the preference is to start out with a smaller device and work up to a more complex device. The problem

here is three-fold: 1) the less expensive device will, in a very short amount of time, not be able to meet the needs of the individual; 2) funding sources aside, it will take some time to acquire the new device and this is a period of stagnation and the learner may become frustrated with using a voca as a means of communication; 3) once the new device is acquired, it will be substantially different from the previous device and the individual will need to be trained to use the new device. This can be hugely problematic.

Given the cost of vocas, many funding sources are going to be hesitant to pay for an expensive device which may or may not be successful for an individual. One option is to borrow a device. There are a number of agencies in West Virginia who will loan out vocas, including: the Birth to Three program, the RESAs (Regional Educational Service Agency), and WVATS (West Virginia Assistive Technology System). An option for those with children under the age of 8 is Camp Gizmo, a week long assistive technology camp that is held every summer on the grounds of the WV Schools for the Deaf and Blind. At Camp Gizmo, there are almost a hundred voice output devices, all of which are available to try out with an individual. The main underwriters of Camp Gizmo are the Office of Special Education and the WV Birth to Three Program. Information about Camp Gizmo can be obtained by contacting either of the agencies at their Charleston, WV, offices.

A final suggestion when using vocas: the voice selected should be age and gender appropriate. Thus, if Tom is a 12 year old male who uses a voca, the voice which comes out of the device should not be that of a 52 year old woman.

In conclusion, vocas are wonderful tools for facilitating the participation of nonverbal or minimally verbal individuals in everyday activities. As an augmentative communication system designed to supplement or replace speech, they offer some significant advantages but also possess significant limitations. Unless the individual is able to change their own overlays and sub-menus, PECS or other alternative augmentative communication system will most likely be more appropriate.

# Every Reason Not to

(continued from page 12)

This county had every reason to not take on this initiative. They spent the entire summer cleaning up their schools from the flood and had few

resources left, but they took on the PBS process and Chandler is benefiting.

# What's new in the ATC Library?

By **Debbie Price**, Intake Coordinator **Amanda Messina**, Graduate Assistant

#### **BOOKS**

#### On Autism:

- Souls: Beneath and Beyond Autism
- Autism Spectrum Disorder: Understanding the Diagnosis and Getting Help
- Growing Up Severely Autistic: They Call Me Gabriel
- The Speed of Dark: A Novel

### On Asperger Syndrome:

- A Parent's Guide to Asperger Syndrome and High-Functioning Autism
- What is Asperger Syndrome and How Will it Affect Me? A Guide for Young People
- Asperger Syndrome and Long Term Relationships
- Asperger Syndrome and the Family: Redefining Normal

### For the Family:

- SOS Help for Parents: A Practical Guide for Handling Common Everyday Behavior Problems
- Getting Services for Your Child on the Autism Spectrum
- Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Caregivers
- A Different Kind of Boy: A Father's Memoir About Raising a Gifted Child with Autism

### **VIDEOS**

### For the Family:

- Refrigerator Mothers
- I Am Sam
- Inclusion: A Service, Not a Place

### For Children:

- "The Wiggles" videos

Children love to dance and sing along with Australians, Greg, Murray, Jeff and Anthony, in The Wiggles Wiggly Safari, The Wiggles Magical Adventure: A Wiggly Movie, The Wiggles Wiggle Time, and The Wiggles: Wake Up Jeff

#### Audio Cassettes

- "Bridges to the Future," 2003, Autism Society of America Conference Cassettes

To check out any of these or other ATC Library materials, just call our toll-free # 1-800-344-5115 and request books, videos or audio cassettes you'd like mailed to you. (ATC registered families only please.) Coming soon! View ATC Library holdings from our website!

### AUTISM AWARENESS DAY Hillbilly Hot Dogs

Sunday, April 25th 1:00 p.m. - 5:00 p.m.

6951 Ohio River Road • Lesage, West Virginia • (304) 762-2458 101.5 The River will be broadcasting Live

### **LOTS OF THINGS GOING ON!!**

- Robert Trippett & The Country Good Times Band
  - A 50/50 Drawing
  - Hillbilly hot dog, chips and coke \$2.50

(Special thanks to SS Logan and Coca Cola for all their donations)

- Huge Auction (Please help with donations to the auction. Everything and anything accepted)
  - Cookies, Pies, Cakes and Other Sweets
  - Steve Evans Cookin Up Some of His Great Sausage.

Come out and show your support for a great cause and have fun at the same time! Sharie and Sonny Knight (304) 762-2458

### news and views

Spring 2004

### **NOW ONLINE!**

The West Virginia Autism Spectrum Disorders Registry website www.marshall.edu/coe/atc/ wvasdr

# **IMPORTANT**

# AUTISM SOCIETY OF WEST VIRGINIA CONFERENCE SCHEDULE CHANGE

### Temple Grandin's

presentation has been changed from 3:20 pm to 8:30 am on Friday, April 16th.

### **Eustacia Cutler's**

presentation has been changed from 8:45 am to 3:20 pm on Friday, April 16th.



The Huntington Area
Autism Society of West
Virginia invites everyone to
participate in its 3rd
Annual

### WALK FOR AUTISM

Saturday, May 1, 2004
Ritter Park, Huntington, WV
Registration begins at 9 am
Walk Starts 10 am

Let's make this year's walk the biggest and best! Call 304/696-2332 for more information



**WV Autism Training Center** 

College of Education and Human Services Marshall University One John Marshall Drive Huntington, WV 25755-2430 Non-Profit Org. U.S. POSTAGE PAID Permit No. 206 Huntington, WV

# inside news & views

- The Ripple Effect of Increased Communication
- WV Autism Training Center and Huntington Featured on NPR Segment
- Miracle League Baseball Swings Into Morgantown
- Computer Corner
- What's New in the ATC Library
- And More!!