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Winter 2009

News and Views, Winter 2009

West Virginia Autism Training Center

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THE WEST VIRGINIA AUTISM TRAINING CENTER



@ Marshall University

www.marshall.edu/coe/atc

Winter 2009

From the Executive Director



Barbara Becker-Cottrill, Ed.D.

A very happy new year to all of our WV ATC families, colleagues, collaborators and friends. 2009 promises to be a year of substantial growth for the WV ATC. I am pleased to announce the addition of eight new education specialists to our professional training staff. These positions were made possible through additional

funding from the West Virginia Legislature. Joining our current excellent staff of education specialists are Pat McCoy, Sarah Kunkel, Cam Pulliam, Barbara Hunt, Bonnie Marquis, Julia Haines, Amy Bryan-Chapman and Luke Walker. We are excited about the experience and knowledge our new training professionals will bring to our families and educators of West Virginians with autism spectrum disorders. I am also pleased to welcome Jackie Dewald, administrative assistant for the Family Focus Positive Behavior Support intervention. With background and experience in business and services, Jackie has already made significant contributions to our program.

This winter edition of our newsletter contains articles on a variety of topics submitted by our staff and families. Our lead article is about our main service delivery model, the Family Focus Positive Behavior Support intervention (FFPBS). FFPBS is probably best described through the eyes of the individuals who are participating in it. It is a comprehensive approach to providing highly individualized support through the development of programs that address the unique needs of the person on the spectrum, focusing on their strengths and their desires. Building an effective training and support plan does not happen overnight and it does not happen without the input and hard work of a team of people that know the individual well. Together, we work on communication, social, academic and daily living skills in the context of meaningful and functional outcomes for the person. We look at the big picture, and break it down into manageable steps. FFPBS is a process that continuously builds a road to success, independence and a quality of life tailored by and for the person.

I hope you enjoy this edition of our newsletter. Special thanks to Dr. Jennifer McFarland-Whisman, Kay Scott, Gloria Sage, Charlotte Hays and Gina Broce for their input and dedicated work. Comments and questions can be directed to me at beckerco@marshall.edu.



OUR EXPERIENCE WITH FAMILY FOCUS POSITIVE BEHAVIOR SUPPORT

by Chris Lyons, father

My wife and I have had a real adventure raising our daughters, Shannon and Kasey. Besides the normal ups and downs that are involved in raising children, our kids are both on the Autism Spectrum. In addition to learning how to cope with teething, potty training, and fear of the dark, we have tried to familiarize ourselves with a host of other terms that many parents never hear. Words like sensory diet, nonverbal, and auditory processing disorder were some of the terms we had to learn. We worked hard at being good parents and thanks to the Autism Training Center's Family Focus Positive Behavior Program (FFPBS), we now work smart.

One of the most important aspects of the FFPBS Program was to look at the total child and how to best meet their individual needs. I am a visual person and it was very useful to sit down and put all of our thoughts/concerns/hopes down on paper. By creating the graphic, we were able to prioritize and gain new perspective. We looked at both short and long term items. It gave us a very accurate snapshot of everything that was going on with our children and also allowed us to do some forecasting of future events, both good and bad. We were able to make immediate changes that impacted our interactions with our kids.

Another positive of FFPBS was learning how to improve the things that we were already doing well. For example, my wife and I have always made an effort to keep a routine. However, after going through FFPBS,

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OUR EXPERIENCE WITH FAMILY FOCUS POSITIVE BEHAVIOR SUPPORT

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we learned to space unpopular activities apart. We learned how to minimize frustrations that occur when the routine is broken and even when to purposely disrupt the routine. We also learned to let the girls in on our schedule. The dentist is a lot less of an ordeal when we spend a few minutes of each day in the week before talking about the dentist.

The FFPBS Program is transformative. The chief requirement is a good attitude. Apply what you learn to daily events and build from there. It is a "one-foot-in-front-of-the-other" adventure. The good news is that it is a continuing process. My family is not done; we no longer attend classes but school is most definitely still in session.

Fair Shake Network

By Jeannie Elkins,
Parent and Fair Shake
Network Member

The Fair Shake Network (FSN) is an association of West Virginians dedicated to a "fair shake" for people with disabilities and to the belief that diversity makes our communities stronger. People with disabilities have the right to live, work, and play in their own homes and communities. The Fair Shake Network provides training and systems advocacy on issues affecting people with disabilities through statewide, grassroots efforts, and across disability

activities. Some of the benefits to membership in the FSN include state and federal legislative disability policy updates, training opportunities, and networking opportunities with a diverse group of stakeholders. There are two classes of membership within the FSN; individual membership and organizational membership. Individual members are individuals with disabilities, family members, or other interested individuals who support the philosophy, mission, vision and goals of the FSN. Organizational members are organizations which support the philosophy, mission, vision and goals of the FSN. If you or your organization is interested in membership in the FSN, you may contact the Fair Shake Network Office at 304-766-0061 or 800-497-4746. You may also visit the FSN on the web at www.fairshake.org or contact us by email at director@fairshake.org.

My Work With Animals

By Clay Friel, Self-Advocate



My name is Clay Friel and I am 12 years old. I have Aspergers. As part of my Family Focus Positive Behavior Support PATH, I got involved in a special activity.

My county's humane society has a new facility and I am donating my time helping with the ani-

mals. We have seven cats at the facility.

I really enjoy working with the cats. They are glad to see me and know that I am there to help them. I clean their cages and bathe them. Most of the cats are kittens but some are grown.

My greatest hope is that the cats will find new homes.



A.U.T.I.S.M.

By Desiree Britton, Sister

A suppression of words and wondering eyes,

Ubiquitously exploring the unrecognized,

Temperamental play times chosen to be spent alone,

Insatiable spinning in lonely circles, no expression shown,

Stemming into a world you made your own, keeping out all who try to break in,

Meekly waiting to be discovered within.

Autism has changed my family from the beginning and for days to come. We shall only grow to learn more, making us stronger as a whole. I'll never view Autism as a hinder for my little sister Kaycee, but something making her special and in need of her family's love and guidance to share a gift with the world. In my eyes, completely perfect with nothing to critique; she will always be.



Applied Theatre and Autism Spectrum Disorders



By Andrew Nelson, Northern Education Specialist



Throughout history individuals have used the arts to express their feelings and ideas about the world. Music, visual arts, literature, dance, theatre, and film are mediums through which those interpretations have been shared. The arts allow individuals to respond to their environment in new ways, and profound healing can result.

What is Applied Theatre?

Applied Theatre is a growing field within the theatre realm. The Centre for Applied Theatre Research (CATR) defines applied theatre as “the practice of theatre and drama in non-traditional settings and/or with marginalized communities. It refers to theatre practice that engages with areas of social and cultural policy such as public health, education, criminal justice, heritage site interpretation and development.” (The Centre for Public Culture and Ideas, 2007). Several Applied Theatre research organizations and journals have been created including: The Centre for Applied Theatre Research (CATR), International Drama/Theatre Education Association (IDEA), American Alliance for Theatre and Education (AATE), *The Applied Theatre Researcher*, and *Research in Drama Education (RIDE)*. With conferences, events, and projects occurring world-wide, Applied Theatre is reaching many people with diverse backgrounds. Persons who are incarcerated, elderly, or low income or who have vision impairments, behavior disorders, or Down syndrome, as well as others, have participated in Applied Theatre projects.

Is Applied Theatre Being Used with Individual's with ASD?

Until recently, Applied Theatre techniques have not been a common treatment intervention for individuals with autism. An analysis of the component aspects of theatre and the deficits common to autism listed in the Diagnostic and Statistics Manual-IV helps make a case for applying theatre techniques to help individuals with ASD (see table below).

Theatre Aspects	ASD Problems
Body Awareness	Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
Emotional Expression	A lack of spontaneous seeking to share enjoyment, interest or achievements with other people
Empathy	Lack of social or emotional reciprocity
Group Dynamics	Failure to develop peer relationships

How Can Theatre be Applied to Help Individuals with ASD?

Parents, professionals, and researchers are always searching for new ways to help individuals with ASD, and there is a growing interest in using theatre to do so. Theatre activities can be used to teach emotion recognition, emotion expression, non-verbal behaviors and gestures, listening skills, eye contact, conversation skills, strategies to handle social situations, and several other critical social skills. Practitioners and parents are using masks to promote eye-contact and

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WELCOME TO OUR NEWEST STAFF MEMBERS

Our staff is growing! We are excited to welcome a very talented group of new employees to our WV Autism Training Center team. Additional funding from the West Virginia Legislature was awarded to the WV ATC on July 1, 2008, and we began recruiting aggressively. Eight new education specialists and an additional administrative assistant have been hired. Our new education specialists have participated in intensive training on the implementation of the Family Focus Positive Behavior Support (FFPBS) process. In addition to providing FFPBS for families who are registered and have applied for this service, they will also be providing in-service and workshop training across the state. Each new education specialist will be working with families and educators in their counties of residence in addition to surrounding counties. We anticipate a very productive and happy new year!



Amy Bryan-Chapman,
Northern Education Specialist



Jackie Dewald, Administrative
Assistant, Main Office



Julia Haines,
Northern Education Specialist



Barbara Hunt,
Northern Education Specialist



Sarah Kunkel,
Northern Education Specialist



Bonnie Marquis,
Southern Education Specialist



Patricia McCoy,
Southern Education Specialist



Cam Pulliam,
Southern Education Specialist



Luke Walker,
Southern Education Specialist

CONGRATULATIONS!

Amy Holliday is a home-bound 10th grader at Oak Hill High School (OHHS) in Oak Hill, West Virginia. In addition to dealing with the challenges of being a teenager with autism, Amy also deals with severe sensory processing disorder. This disorder has plagued her for the past four years and has caused her to go home-bound with her high school classes.

Amy participates in a partial block of chorus weekdays at OHHS. She loves to sing and also plays the piano. Instructing Amy in piano lessons the past five years is a wonderful, patient teacher, Lynn Tracy.

On November 20, 2008, Amy participated in the OHHS school talent show, playing *Castle on a Cloud* from *Les Miserables* before

a full auditorium. On December 14, 2008, she participated in the high school's choral play, "I Love Christmas," performed before a full OHHS auditorium as well. These were major accomplishments considering the struggles with sounds that Amy deals with on a daily basis. She is always saying she hears "too-too-well," and the world has too much sound. Many unavoidable sounds we take for granted are torture to her ears. Amy Holliday, like her family and friends, is continually praying and waiting for the day that this world's sounds will be easier for her to bear.

Amy, We're Proud of You!

By Betty Holliday, Parent



Amy Holliday & Pam Shroder, OHHS Choir Director

Amy was a FFPBS participant in 2003-2004.



CONGRATULATIONS DOMINIC RODIGHIERO!



Dominic and Tim Irr, WSAZ anchorman, at the 2008 Walk, Run, Ride for Autism in Huntington.

Congratulations go out to Dominic Rodighiero of Logan County, who was successful at gaining part time employment. One of Dominic's goals has been to get a job at the theater. This has been a process that his family and team have been working on to make sure that he was supported and the whole experience would be successful. Dominic is now working at the local movie theater. He works every Sunday afternoon and is really doing well. We are SO proud of you Dominic!

Dominic's family would like to thank everyone who has

been involved in the journey. Dominic's mom shared this with us: "At the time of his diagnosis and for years afterward, I had doubts that we would some day be dropping him off at work. I never gave up faith. Like the plaque in my living room says, "Faith makes things possible, not easy".

Dominic was one of our first FFPBS participants.



How to Make a Travel Sized Weighted Blanket

By Erin Lash,
Southern Education Specialist

Travel experiences can be intimidating for the child with autism. A weighted blanket can help to calm and comfort your child during these stressful times. (http://www.fraser.org/tip_sheets/index.htm)

Tools

- ◇ Sewing machine
- ◇ Scissors
- ◇ 2 standard sized pillowcases
- ◇ Thread
- ◇ Velcro
- ◇ Thick cord or shoestring
- ◇ Material to fill your blanket (pony beads, dried peas, beans etc). You will need filler equaling five percent of the child's body weight, not to exceed fifteen percent.

Instructions

1. Decide how many pockets your blanket will have and divide weighted material evenly into the same number of piles.
2. Turn one pillowcase inside out and sew the Velcro to the outside of the opening (Hook on one side, loop on the other),.
3. Turn the second pillowcase right side out and sew three to four vertical lines, evenly spaced most of the way up the long side of the pillowcase.
4. Add one pile of material into each column that you have made.
5. Sew a horizontal line across the case just above the top of the material.

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6. Add another pile of material into each column.
7. Repeat until the material has been distributed evenly in the pillowcase.
8. Sew pillowcase shut.
9. Place the weighted case into the empty case and secure Velcro.
10. Cord or string can be used to tie the blanket into a portable roll.



Front and back of a travel-sized weighted blanket.

Center of Excellence Looking for Research Study Participants

The **NIH Autism Center for Excellence at the University of Pittsburgh and Carnegie Mellon University**, funded in August of 2007, is studying how people with autism, ASD and Asperger's Syndrome think. The study hopes to learn how areas of the brain communicate with each other and how this alters the way people with autism see the world and process information. We now have many new studies that require a broader range of participants than ever before and new enrollment is critical to our success.

We are accepting:

- ▶ Verbal Individuals between the ages of 5-45
- ▶ Individuals with IQ higher than 80
- ▶ Individuals with High-Functioning Autism, Autism Spectrum Disorder or Asperger's Syndrome

If you or your child participate, you will receive a research diagnostic report including; IQ, language and problem-solving, and social thinking tests. Testing times are scheduled based on the participant's availability. Participants are compensated for each test they complete. Travel expenses are also paid for by the study. There are no costs involved for participating in this research. The studies may include any or all of the following:

- ▶ Diagnostic Testing
- ▶ Computer Testing
- ▶ Paper and Pencil Tests
- ▶ Imaging

No Medications Involved

It is hoped that the results of these studies will make significant improvements in diagnosis and treatment in the future. To determine if you or your child are eligible, please call 412 246-5485 or 1-866 647-3436 or email autismrecruiter@upmc.edu.

Visit our website:
www.pittautismresearch.org

The center is also conducting a longitudinal infant and toddler research study that will help determine the earliest indicators of ASD in infants who have an older sibling with or without an autism spectrum disorder. To receive more information about the infant/toddler study, contact Stacey Becker, 412-246-5486 or beckersc@upmc.edu.

From the Advisory Board Chair...

By Jeannie Elkins, Mother and Advisory Board Chair

As we embark on a new year, I am optimistic about continuing West Virginia Autism Training Center's mission of effectively serving even more individuals and families in 2009. I am proud to say that our Executive Director and entire staff of devoted professionals have maximized the 2008 increase in funding to the fullest extent possible and continue their tireless work to make remarkable differences for families who often face tremendously overwhelming challenges in today's tough economic times.

When my 25-year-old son, Alan, was younger and the incidence of autism was 1 in 10,000, a significant challenge at that time was the lack of public awareness of autism. Although no one wanted the number of individuals to increase, we can at least know that this has created some opportunities for increases in services and awareness. The Autism Training Center Family Focus Positive Behavioral Support Model is a solid tried and true research based intervention that has made an extraordinary difference in many lives including that of my own son and family. Another opportunity brought on by the increase in autism occurrence in school age children is the exciting collaboration with West Virginia Autism Training Center and the WV Department of Education Office of Exceptional Children and almost countless other state disability and early education agencies for the WV Team Autism Network. The focus diversity of the various Seamless Services Teams combined with the intense involvement of so many dedicated families and professionals has such tremendous potential to impact how individuals with autism are served throughout their lifetime in West Virginia.

It is our responsibility to do our very best to see that individuals who are affected by autism receive the specific research based service and educational program that will allow the individual to become all that he or she can be. It is my hope that we can continue toward that end in 2009 by making the best use of the resources we have and hopefully increase those resources in this new era of "Change" to insure that West Virginia families get the best possible assistance for their son or daughter.

An Update on House Bill 4091: Required Insurance Coverage for Autism Spectrum Disorders

By Two Concerned Mothers in Morgantown, WV

As parents of children diagnosed with an Autism Spectrum Disorder (ASD), we must not only cope with the emotional stress of rearing our children but the additional financial burden of providing treatment for them. Depending on the diagnosis, parents may spend thousands of dollars on therapies and treatments while others may only utilize services received through the public school system, the Autism Training Center and the Center for Excellence in Disabilities. Therapies and treatments for ASD may include the following: changing one's diet (gluten/casein free), developmental models, structured teaching, speech and language skills therapy, social skills therapy, occupational therapy, sensory integration therapy, and applied behavior analysis (ABA) therapy. As an example, one parent has provided a list of therapies along with the out of pocket expenses incurred for her son's treatment.

1.	Vision Therapy	\$ 3,500.00
2.	Sensory Testing	\$ 400.00
3.	Sensory Therapy	\$ 230.00
4.	Speech Therapy	\$ 2,000.00
5.	Auditory Integration Therapy	\$ 2,500.00
6.	Medical Testing, Consulting, Etc.	\$ 3,000.00
7.	ABA Therapy	<u>\$ 4,000.00</u>
	(TOTAL)	\$15,630.00

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An Update on House Bill 4091: Required Insurance Coverage for Autism Spectrum Disorders

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Many parents who have children on the spectrum are aware that insurance companies do not cover behavioral treatment such as ABA. This is very unfortunate since ABA is a proven technique that has been used to teach children on the spectrum. For parents who wish to learn about this approach, workshops in ABA training, can cost between \$175-1,000 per person. Using a therapist or student at home, who has had ABA training could also be expensive ranging from \$5,000 to 20,000 a year, depending on where one is located. Given the rising cost of basic necessities, insurance coverage of behavioral therapies, nutritionist, and all prescription drugs for the treatment of autism would be most welcomed by parents and caregivers.

During the last legislative session, Delegate Ralph Rodighiero of Logan County and several other legislators, sponsored House Bill 4091 which required insurance companies to cover autism spectrum disorders including the following neurobiological conditions: Autism, Asperger syndrome, Retts syndrome, and Pervasive Development Disorder. Essentially, the bill included all prevention, early detection, diagnosis and/or treatments and therapies that are approved by the Federal Drug Administration. This bill was introduced in January 2008 but was not passed by the legislature at the last session.

If you are interested in House Bill 4091 being passed, we urge you to contact your Delegates and Senators. In order for this bill to pass, parents and caregivers must raise their voices and let their representatives know that they are adamant that this or a similar legislation be passed. You may wish to take a moment to phone your representatives or send them an e-mail and/or letter explaining the positive impact that such a bill will have on children with ASD. You may contact your representatives by February of 2009 and continue to do so until April 11th which is when the legislative session closes. They may be contacted at the following address/phone number:

West Virginia State Legislature

1900 Kanawha Blvd. E.
Charleston, WV 25305
(304) 347-4836

<http://www.legis.state.wv.us/>

If you go to the web site, there is a place in which you could type in your zip code and the picture and contact information for your representatives will appear. If you call the number listed above, you may receive additional information, such as a home/work phone number.

Web Resources:

http://en.wikipedia.org/wiki/Autism_therapies/
<http://autism.healingthresholds.com/therapy/applied-behavior-analysis/>
http://www.legis.state.wv.us/bill_status/bills_1



Eighth Annual Autism Awareness Event

Saturday, April 25, 2009

Please **DO NOT FORGET** to attend our eighth annual 5K Walk/ 5K Run/ 25 Mile Bike Tour at Ritter Park in Huntington. The event is sponsored by Huntington Area Autism Society (HAAS), Autism Services Center, and the WV Autism Training Center.

On-line Autism Endorsement Coursework

Marshall University offers two on-line courses needed for the autism teaching endorsement. Courses available include:

Summer and Fall, 2009 CISP 527
Introduction to Autism

Summer, 2009 and Spring, 2010
CISP 662, 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

Register early, classes fill quickly

Brooke Shines

By Butch and Lora Lockhart,
parents



Brooke Alexandria Lockhart

Brooke Alexandria Lockhart, a 4th grade student at Jaeger Elementary School, is learning to cope with her autism. She has overcome many obstacles in her life and has a bright future ahead of her. With the support of the Autism Training Center's Positive Behavior Support program, family, and friends, she is doing exceptionally well.

She enjoys writing stories, drawing, singing, swimming and says that she would like to be an author when she grows up. Brooke has already titled her first book "Take A Deep Breath" and says that it will be about "Strategies on How Children Can Calm Themselves Down." We tell her she is going to help so many people someday. We are already so proud of how far she has come and excited to see what the future holds for her.

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MOVING?

WE WANT TO KEEP IN CONTACT

If you move or change your contact information, please don't forget to let the WV ATC know. Please call 1-800-344-5115 to make changes in your contact information.

Negotiating the Budget Process in the MR/DD Waiver Program

By Angela Bryson, Intake & Family Resource Coordinator

With the changes in the MR/DD Waiver annual assessment process you might experience a change in your child's budget. Just to keep you informed, there is a negotiation process in place provided by APS Healthcare System, the agency that handles your child's MR/DD Waiver budget. Once your child is assessed, the budget is developed and given to the Individual Program Plan (IPP) Team who purchases services for your child. In this situation, APS Healthcare System is the reviewer and negotiator for your child's budget.

The key is to have your annual IPP meeting before the due date so you have room to negotiate your budget, if needed. Ask the Service Coordinator to schedule the annual review several weeks before the IPP deadline.

The following is a breakdown of what occurs during the negotiation process, should you need to do this:

Level 1 Negotiation

An APS Registration Coordinator will ask your Service Coordinator to submit written documentation explaining why you and your team are requesting to exceed service limits or increase your overall budget to purchase services.

- If the documentation submitted justifies the budget increases, then additional services can be purchased.
- If the documentation does not justify the requested budget increase, APS can suggest a different value of services for your child.

At this time the IPP Team can accept APS suggested budget for services or resubmit another purchase request with a higher negotiated amount.

Time Frames:

The budget will be reviewed by APS Healthcare Systems and a decision will be sent to the Service Coordinator within 5 business days. This ends the Level 1 negotiation and starts the Level 2 negotiation process.

Level 2 Negotiation

If the IPP Team does not accept the negotiated amount, the IPP Team re-submits a purchase request with the original budget plus any additional documentation to justify the purchase of services. The request is then reviewed by a manager at APS to determine the appropriateness of APS decisions to decrease the budget. The reviewer looks at the additional documentation to determine if the budget should be increased. If the reviewer denies the increase, the original authorization decision for your budget will still be in place.

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Negotiating the Budget Process in the MR/DD Waiver Program

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At this step, the IPP Team can accept the negotiated amount of the original budget or refuse the decreased budget and request a Fair Hearing. The Service Coordinator then contacts a Fair Hearing representative and explains concerns related to the decreased budget and services.

The Service Coordinator will assist the individual on the Waiver Program and their parent/guardian in making a determination as to whether to accept the decision or pursue a Fair Hearing through the Bureau of Medical Services.

Time Frames:

The time frame for second level of negotiation is 5 days.

Fair Hearing Process

The decision to pursue a Fair Hearing should be made by the IPP team, but ultimately the final decision rests with the individual and/or their parent/guardian. At this point, the individual or parent/guardian can either accept APS Healthcare decision denying additional services or not accept the denial of services and sign and return a letter to APS Healthcare Systems and the Bu-



reau for Medical Services indicating the intent to pursue a Fair Hearing.

The Fair Hearing Officer makes the decision to either uphold APS's decision and decrease the budget or determine that the provider's original budget was appropriate and authorize the increased budget and requested services or recommend a different service.

The originally requested service budget is authorized for the duration of the Fair Hearing Process. During the Fair Hearing Process it is important to note that your provider agency may look at providing services at the reduced budget which will eliminate many services your child is receiving on his IPP. It is up to the provider agency to make the decision about providing services using the old budget with the expectation of being reimbursed once the budget is approved or not to provide full services but purchase only the amount of services the reduced budget will allow. Many agencies fear that they may not be reimbursed for services if the increase in budget is not approved. You might have to sit down with your IPP Team to decide what services are essential and what can be eliminated until the decision is made.

If the parties are still unable to agree on the budget deter-

mined during the Fair Hearing Process, the next step is to go to a circuit court.

Time Frame:

10 days to 2 weeks

Conclusion

As a parent and your child's best advocate, the best thing you can do is to be vigilant and stay on top of where you are in the negotiation process. Below is a list of contact persons who can provide technical support.

- 1) Your local service coordinator
- 2) Director of APS Healthcare Systems, Inc.
1-866-385-8920
- 3) Waiver Program Manager, Bureau for Health & Health Facilities (BHBF)
304-558-0627
- 4) WV Advocates
1- 800-950-5250
- 5) Legal Aid
1-866-255-4370

WV ATC FAST FACTS

- * WV ATC serves the entire state of WV
- * WV ATC provides training in autism for approximately 1000 people annually
- * WV ATC services are at no cost to registered families
- * WV ATC, through Marshall University, provides autism teacher endorsement coursework

Don't Miss Out

On upcoming trainings provided by WV ATC. Check out our website at: www.marshall.edu/coe/atc



GIVE NOW !

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

www.marshall.edu/coe/atc



BOOK REVIEWS



Children with Autism Spectrum Disorders: A Structured Teaching and Experience Based Program for Therapists, Teachers and Parents

by Vera Bernard-Opitz, Published by Pro-Ed

Reviewed by Brenda Smith-Myles

Children with Autism Spectrum Disorders: A Structured Teaching and Experience Based Program for Therapists, Teachers and Parents by Vera Bernard-Opitz, Ph.D. is a book that recognizes that all children with ASD are unique and may require specific teaching methods that are compatible with their learning style. She offers the STEP approach: Structured Therapy and Experience-Based Programs that attempt to ameliorate "therapy camps" and place focus on where it should be -- the child's needs. This comprehensive and easy-to-read book offers instructional strategies to teach a myriad of skills, including joint attention, language comprehension, play and social behavior, and self-help skills and independence. It also addresses important issues, such as managing behavior problems and using effective reinforcement. Step-by-step information on how to implement strategies and data collection forms are included in this book. This groundbreaking book is a must read for anyone interested in providing a comprehensive and appropriate education to young children with ASD.

Girls Under the Umbrella of Autism Spectrum Disorders Practical Solutions for Addressing Everyday Challenges

There is an abundance of literature available on a variety of topics about autism spectrum disorder (ASD); however, most of these materials are written with males in mind since they comprise most of the population diagnosed with ASD. There are some excellent personal perspective stories written by women on the spectrum such as Dr. Temple Grandin, Donna Williams, and Liane Willey, but there are few books written about working or living with females with ASD. *Girls Under the Umbrella of Autism Spectrum Disorders* fills this gap well by highlighting issues for females from the early years to young adulthood. Author Dr. Lori Ernsperger, an autism and behavioral specialist, provides the issues and strategies information

by Dr. Lori Ernsperger and Danielle Wendel

Reviewed by Maureen Bennie,
Parent and Director,
Autism Awareness Centre Inc.
www.autismawarenesscentre.org

while mother, Danielle Wendell, gives us the important parent perspective and what parents experience on the life journey of raising a daughter.

The ratio of boys to girls with ASD is 4:1; it is as high as 10:1 for Asperger Syndrome. Little is known about gender differences in ASD yet my own experiences suggest observable differences exist. Most diagnostic and assessment tools were developed by observing traits in males. Girls on the spectrum present more subtly and therefore, can

go undetected. My daughter Julia, who has autism, does not exhibit the same characteristics as my son Marc who has the same diagnosis. Julia is soft-spoken, does not engage in self-stimulatory behavior, has strong imaginative play skills, and is not aggressive. She can be ignored at school because of her compliant behavior, whereas my son will get more assistance due to being more overt with his behavior.

For parents of daughters, the ASD journey can be a more isolating experience because there are fewer girls on the spectrum, making it difficult to meet other parents in the same boat. One of the strengths of this book is hearing from other mothers and

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Girls Under the Umbrella of Autism Spectrum Disorders Practical Solutions for Addressing Everyday Challenges

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their experience of raising a daughter. The candid re-telling of trying situations and feelings around ASD make you feel like you are listening to a good friend. Girls with ASD from elementary age to adulthood also speak about their lives – childhood memories, school and community experiences, and frustrations. Hearing their stories provides perspective and insight for both parents and professionals.

Girls Under the Umbrella of Autism Spectrum Disorders introduces you to girls with ASD, the early years, school years, adolescence, early adulthood, and finally what the future may hold. Each chapter is broken down into manageable sub-topics supported by charts, lists, and important points to remember. A summary of the main thoughts ends each chapter.

The overview of the early years to early adulthood experience guides parents and professionals through the myriad of issues and concerns one will encounter. The Early Years chapter covers sleep problems, toileting, eating habits, and problematic behavior. The behavioral strategies are sensible and supported by the appropriate literature.

The School Years discusses IEP's, social skills, emotions, the OT and speech therapy portfolio, sensory processing disorder and tips for starting the school year. Bullying, a topic often overlooked in other ASD books, is touched upon. The Adolescence/Early Adulthood chapter focuses on self-determination, dating, transition planning, work and college.

The reference section of the book lists some of the best books and articles on topics covered within this book. The appendix contains great websites, a behavioral plan template, a positive environment checklist, and social skills objectives.

The College Program for Students with Asperger Syndrome

By Marc Ellison, Coordinator, &
Rebecca Hansen, Assistant Coordinator

The College Program for Students with Asperger Syndrome held its 3rd Parents' Weekend Get-Together on October 4, 2008, with a brunch on campus in the John Marshall Room. More than 60 attendees enjoyed the camaraderie, and terrific musical performances from students.

Chris Tucker, a Marshall University Music Composition major and pianist, played a brilliant rendition of *Beethoven's Piano Sonata in F Minor - First Movement*. Bach's



MU 2008 Parents' Weekend College Program Brunch

Prelude from Cello Suite in G Major was played masterfully by Jason Breslin, a Marshall University Music Performance major and guitarist.

The annual Marshall University Trivia game was hosted by freshman Eren Niederhoffer who kept the crowd entertained with his great game show voice and clever wit. Thanks to each of these students,

along with freshman background pianist, Christian Carlsson, who made the Parents' Weekend Get-Together a smashing success!

Please visit the College Program's blog for more information about the program at <http://mucollegesupport.blogspot.com/>.

International Art for Autism Festival in Madurai, India



Andrew Nelson, Education Specialist, gives a talk in India on art and autism.

Local Artist's Work Featured in India



Vijay Patnaik



The art work of Vijay Patnaik was recently honored at the International Art for Autism Festival in Madurai, India. His paintings were featured in greeting cards, brochures, the e journal ArTRAN, and on several large festival banners around the huge city of Madurai, India. Mr. Patnaik has also been the recipient of several national art awards. He resides in Huntington, West Virginia .

The WV Autism Spectrum Disorders Registry

By Julie O'Malley, WV ASD Registry Coordinator

The West Virginia Autism Spectrum Disorders Registry (WVASDR) is now in its sixth year of operation. Autism Spectrum Disorders for the purpose of this registry are Autistic Disorder (299.00), Rett's Disorder (299.80), Childhood Disintegrative Disorder (299.10), Asperger's Syndrome (299.80) & Pervasive Developmental Disorder-Not Otherwise Specified (299.80). These are reportable conditions of childhood as per Legislative Rule 64, series 7, category 11A, 3.5.b.2. The WVASDR is housed and managed by the West Virginia Autism Training Center at Marshall University, as per the protocol in the legislative rule. We practice strict confidentiality rules and do not ask for specific identifiers such as names or addresses.

When clinicians diagnose individuals residing in West Virginia with any of these five autism spectrum disorders/pervasive developmental disorders we ask that they report these new

diagnosis. After the diagnosis is made, a reporting form should be received by the West Virginia Autism Training Center within 30 days. Failure to report can result in a fine. More information related to the WVASDR and additional reporting forms can be obtained at our website at www.marshall.edu/wvasdr. For specific questions, please do not hesitate to contact Julie O'Malley, Coordinator of the WV ASDR, at 1 800 344 5115 or email lynch29@marshall.edu.

West Virginia was the first state in the nation to establish Autism Spectrum Disorders as a reportable condition of childhood. Additional states have developed similar legislation and it is expected many more will follow. As other states begin similar registry procedures, our combined efforts will help us understand more about the incidence of this most challenging syndrome.

Applied Theatre and Autism Spectrum Disorders

Continued from Page-2

social skills, creating exercises to train individuals to refine observation skills, teaching body awareness through movement, building friendships through performance projects, etc. Particular features of theatre-based strategies make them especially useful when working with individuals with ASD:

- The theatre is a safe place for individuals to try new things and make mistakes
- Theatre is inherently fun and motivating
- Theatre is highly STRUCTURED (an actor has prescribed lines and actions)
- Theatre strategies are usually inexpensive (just need an idea, space, and time)
- Theatre activities allow for repeated practice of specific skills

If you are interested in learning more specifics about theatre and autism, have questions, or need help finding resources to begin using theatre with individuals with ASD, email Andrew Nelson at nelsona@marshall.edu. Also, the Applied Theatre Research and Autism Network (ATRAN), a new collective helping parents and professionals share ideas and develop best practices, has been developed to unify the theatre-autism field. You can visit ATRAN by going to www.autismtheatre.org.

References: The Centre for Public Culture and Ideas (2007). What is applied theatre? Retrieved August 22, 2007, from The Centre for Public Culture and Ideas <http://www.griffith.edu.au/centre/cpci/atr/>

Diagnostic and statistical manual of mental disorders (DSM-IV). (1994). Washington, D.C.: American Psychiatric Association.

Brooke Shines

Continued from Page-8

Poem by Brooke Lockhart

Autism
 It's easy to get out of Autism.
 First, you need to think about your
 behavior.
 Next, teach yourself how to be
 taken care of.
 Then, start to believe that you can
 do it.
 Last, face your problems.
 You might want to avoid mega fits,
 jealousy, and quitting.
 You might trap yourself in Autism.
 I have Autism, but I deal
 with it. I learned how to get
 out of Autism. I almost got trapped.
 Brooke Lockhart



Help Find the Genetic Factors in ASD

The Miami Institute for Human Genomics (MIHG) is conducting research into the genetics of autism and related disorders. The WV ATC is an outreach site for this important study. 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, please contact Scott Short toll free at:

1-866-308-3032
 or sshort@med.miami.edu

Don't Miss These Upcoming Events

Association for Behavior Analysis

35th Annual Convention
May 22-26, 2009
Phoenix, AZ

Association for Positive Behavior Support

International Conference
March 26-28, 2009
Jacksonville, FL

Autism Society of America

40th National Conference and Exposition
on Autism Spectrum Disorders
July 22-25, 2009
St. Charles, IL

Autism Society Of America West Virginia Chapter

2009 Annual Conference on Autism
September 18-19, 2009
Huntington, WV

WV Council for Exceptional Children

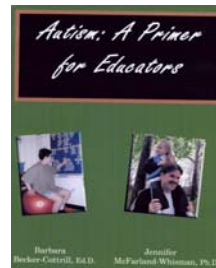
2009 Annual Conference
October 7-8, 2009
Oglebay Park, Wheeling, WV

*For more information on these and other
events: www.marshall.edu/coe/atc*

WV Autism Training Center, MU

College of Education & Human
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Huntington, WV 25755-2430

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By: Drs. Barbara Becker-Cottrill &
Jennifer McFarland-Whisman

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