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Magazine

West Virginia Autism Training Center at Marshall University

Fall 2016

## The West Virginia Autism Training Center @ Marshall University Magazine, Fall 2016

West Virginia Autism Training Center

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### in this issue

### Greetings

- Note from the Executive Director 5
  - Editor's Note

### Trainings, Events, and News

- New WV ATC Training Videos 6
- Upcoming National Conferences 6
- Regional Training and Event Email Lists 7
  - WV ATC Pinterest Facebook Pages 7
  - News from the ATC Lending Library 8
- Meet the Autism Training Center Jim Harris, Ed.D., LICSW 8

### Strengthening Supports

- Temple Grandin Transition Project for Pre-Teens: Angie Kinder 9 10
  - Pathways to the Future: a conversation with Jeff McCroskey 11 12
  - Work Exploration for High School Students with Sallie Askin 13 14
  - Turning the Tassel: Preparing for the Transition from College 15 16
- to Work by Rebecca Hansen and Jackie Clarke of the CPSASD 17

### A Life of Quality

- Quality of Life What Does it Mean? By Gloria Sage 18 19
  - Fifteen Things About Me by Desire Miller 20
- Transitions to Adulthood and Self-Sufficiency by Steven Anthony George 21, 26
  - At the Corner of Jimmy and Blaine with Jimmy Ward and Blaine Seitz 22 23, 26

### Creative Community

So Many Strange Shapes in a Sea by Steven Anthony George 24 - 25

### Autism State Updates

- ASA-WV State Conference a Success
  - WV Team Autism Update 28
    - WV PBIS 28
    - WV ATC FACTS 29
  - WV APBS Network Update 29
    - Project AWARE 30



# WVATC @ Marshall University

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Cover photo of Steven Anthony George



## Greetings

#### From the Executive Director



Greetings, from the West Virginia Autism Training Center!

Transitions – both those small changes in daily routine, and the life-altering transitions most of us experience a handful of times in our lives – can overwhelm even the most prepared among us. For lots of reasons, we tend to be comforted by routine. But try as we might, a rigid routine can't last a lifetime; as we grow and mature we're forced to face transitions in education, relationships, finances, employment, and living environments.

But if we can anticipate and plan for transition, it's inevitable that our life quality will be improved.

We at the WV ATC have focused our Autumn, 2016 issue on the important topic of transition. We hope our articles interest you, and offer encouragement for the future. Mostly, however, we hope the magazine's content inspires you to reflect on your life journey, consider the twists and turns that will take place further down the road, and develop a plan to successfully navigate those curves.

Supports for short-term transitions are highlighted in this issue by authors Angie Kinder and Desire Miller. Their articles describe innovative strategies used to support pre-teen students as they transition along their educational paths. The stories are inspirational to read, and offer insight into how successful transitions can occur with proper planning.

Employment – always a complicated and challenging endeavor – is discussed in detail within several articles. Pathways to the Future: a conversation with Jeff McCroskey highlights a new employment program currently underway statewide, while Sallie Askin explains her approach to providing support for employment with Work Exploration for High School Students. Lee Cloughfeather and Cathy Lee Irizarry-Barron discuss their focus on teaching social and adaptive living skills that serve as a foundation for successful employment. And in Turning the Tassel, Dr. Rebecca Hansen and Jackie Clark discuss an innovative, new summer initiative that supports the transition of college student with ASD to the workforce.

WV ATC's Gloria Sage reminds us to consider the possibilities that may exist as we plan our lifetime of transitions in Quality of Life – What Does It Mean? Steven Anthony George, Blain Seitz, and Jimmy Ward give us a peek into the celebrations and challenges they've experienced in their transitions to adulthood. And Dr. Jim Harris discusses his transition into the role of our center's Associate Director of Training.

We at the WV ATC are proud to bring you this issue. Our mission statement – to "support individuals with ASD as they pursue a life of quality," ensures that we are prepared to support individuals across their lifespans. And that includes, of course, supporting folks through the twists and turns that occur in life.

Editor's Note:

Dear Readers and Friends.

We are looking for artists, comic book creators, writers, photographers, and designers with ASD to contribute to this magazine. Do you create art? Do you know someone who is great at making comics, writing poetry and short stories, sculpting, or taking pictures? Please contact us at the email listed below to learn more about contributing!

As always, we strive to bring you the highest quality magazine experience possible. We want to hear from you and welcome any letters, suggestions or inquiries. Please contact the editor at nelsona@marshall.edu.

Thank you for reading and please keep in touch.

Andrew Nelson

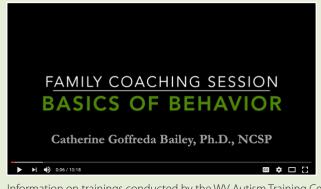
Marc Ellison, Ed.D. **Executive Director** 

The WV Autism Training Center

## Trainings, Events, and News

## **New WV ATC Training Videos**

The WV Autism Training Center staff are busy developing video training resources that all families, teachers, and individuals can access to expand their knowledge and develop supports. Two new videos recently added are a Family Coaching Session on the Basics of Behavior and a video titled How to Build Your Binder, to help individuals organize their school or daily living information. Videos are available on YouTube and can be found at the following link: https://www.youtube.com/user/WVATC





Information on trainings conducted by the WV Autism Training Center can also be found by visiting our full training calendar web page at http://www.marshall.edu/atc/training-calendar/. This calendar is updated regularly.

## **UPCOMING NATIONAL CONFERENCES**

OCALICON: THE NATION'S PREMIER AUTISM AND DISABILITIES CONFERENCE November 16 to 19, 2016

**Greater Columbus Convention Center, Columbus, Ohio** http://conference.ocali.org/

#### 11TH ANNUAL AUTISM CONFERENCE

Behavioral Assessment and Intervention Across the Lifespan in Autism: Translating Research Into Best Practices

January 31 to February 2, 2017

Sheraton Puerto Rico Hotel & Casino; San Juan, Puerto Rico https://www.abainternational.org/events/autism-2017.aspx

THE AUTISMONE 2017 CONFERENCE

May 24 to 28, 2017

Hotel Elegante, Colorado Springs, Colorado.

http://www.autismone.org/content/autismone-cutting-edge-autism-conferencer

## Introducing the WV Autism **Training Center Pinterest Board!**

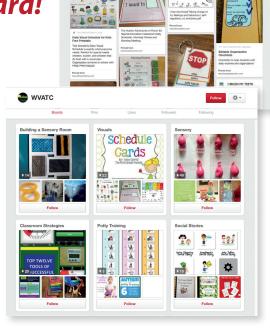
Check out our Pinterest website. You will find great activities to try on a rainy day as well as helpful information for transitional periods. Pins are added regularly so be sure to check back often.

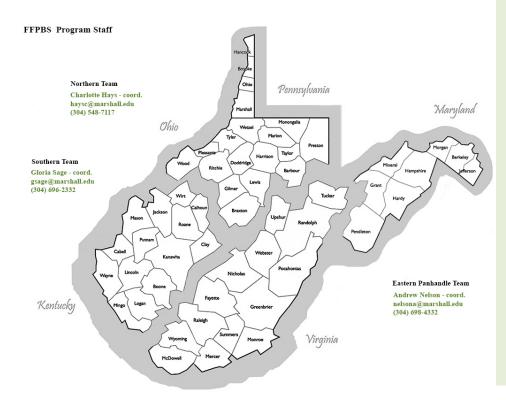
#### www.pinterest.com/WVATC/



We also offer tips, news, strategies, and notices of upcoming events on our West Virginia Autism Training Center Facebook page. Please like our page and join the conversation!









"The WV Autism Training Center provides support to individuals with autism spectrum disorders as they pursue a life of quality"

The West Virginia Autism Training Center continues to offer a free email list designed to help you connect with events, trainings or other important news specific to your region. Please visit this website address to register and click on your region to receive updates relevant to your area! www.marshall.edu/atc/ regional-event-sign-up

## Meet the Autism Training Center Associate Director: **JIM HARRIS, ED.D., LICSW**



How long have you been an employee of the WV ATC: 2.5 years

How did you first become interested in supporting individuals with ASD or working for the WV ATC: I have always been a "why guy." What I mean is, I've always been driven to understand why people do what they do. I remember that even at 5 years of age I would bug my mom with a plethora of questions related to why people did or said certain

things and wondering if they would act the same way if no one was watching them. All of my work, in some form or fashion, has been centered around the driving curiosity to understand "why" people or organizations do what they do, and how to support them to function at the highest level possible. This can range from a preschooler recently diagnosed with ASD to the grant that was written to expand social emotional supports for students in schools across the state.

Originally I joined the WV ATC as the WV School-Wide Positive Behavior Interventions and Supports Coordinator. This PBIS Project is a collaborative effort between the WV ATC and the West Virginia Department of Education's Office of Special Education. The goal of the project is to support the implementation of PBIS in schools across the state. At first, some people struggled to see the direct connection of the PBIS Project and the WV ATC's mission, but a closer looked clearly shows that the implementation of PBIS in schools helps to improve their climate and culture, and creates support systems in schools for all students, including students with autism. I truly enjoyed my work in this position and developed a strong appreciation for the work climate at the WV ATC. When the position of Associate Director opened I decided that I would apply, as I thought my diverse experiences related to mental health, education, community collaboration, and systems change could benefit the agency moving forward.

What are your interests/passions regarding supporting people with autism: Several of the staff here at the WV ATC have committed their entire careers to serving individuals with autism. I am a little different in that I have worked in a variety of settings within the helping professions, which I think offers balance to the agency. This has been especially true as the agency has taken-on new endeavors such as the PBIS Project, an Early Childhood PBIS Project, and WV AWARE, and works to transform its traditional services. My passion is for our agency to pursue our mission relentlessly. I want to push myself and my colleagues to constantly evaluate our work to make sure we are doing everything we can to support families affected by autism in our state. A recent focus for our agency has been to expand our services to serve as many families as we can in a timely manner, and as effectively as possible. This has challenged us to re-evaluate our work and pushed us to think more innovatively. Based on the most recent prevalence numbers and the recent budget cuts our agency is facing, this is no easy task. We all realize that we have and continue to face daunting a challenge, but we appreciate that we have committed our ourselves and our work to a worthy struggle.

What are a few things that you like most about working for the WV ATC: The central thing that I like about working at the ATC is the people. We are fortunate to have a diverse group of people here and I think it creates and environment of passion and innovation. I also enjoy the variety of my work. The diversity of projects and programs that I get to work with helps to keep me feeling engaged and challenged.

Any future trainings, workshops, groups or initiatives in the works: Wow, that question is hard to narrow down! We have such a collection of exciting things going on right now at the WV ATC. The PBIS Project has kicked-off one round of the PBIS Academies, which includes nine different training events across the state between now and the end of the year. The Early Childhood PBIS Project will be conducting its inaugural Early Childhood PBIS Academies, which includes six different training events across the state between now and the end of the year as well. WV Project AWARE continues to offer several Mental Health First Aid trainings across the state

WV ATC staff continue to produce a variety of web-based training videos on such topics as How to Build Your Binder, and The Basics of Behavior that can be viewed by parents and professionals to better support individuals with autism. We continue to expand the offering of regional group supports, such as the Positive Parenting workshops, Make & Take sessions, and social skills groups. We are really excited about how these sessions can offer the opportunity for timely support and as well as opportunities for individuals with autism and their families to connect and support one another. Our college support program, which was the first of its kind in the country, continues to evolve to meet the needs of college students with ASD. We are currently developing support services at Concord University, in southern West Virginia. And we're striving to make our direct service programs even more individualized and person centered.

This is just a snapshot of what we have going on at the moment. We are continually developing new ways to support families and community systems. I am really proud of how active our agency is across the state. Stay tuned...we are just getting started!

## News from the **Autism Training Center Lending Library**



Autism Spectrum Disorders: Identification, Education, and Treatment, 4th Edition (Routledge, 2016) presents a comprehensive look at the autism spectrum including, according to editors, "new information on early identification, transition education from adolescence through to adulthood, neurobiological research, and technology-based solutions," (Zager, Cihak, Stone-MacDonald, 2016). Marc Ellison, executive director of the West Virginia

Autism Training Center, co-authored a chapter in the text. Dr. Ellison, with colleagues from the University of St. Thomas and Edgewood College, co-authored the chapter titled: "The Transition from High School to Higher Education: Inclusive Services and Supports." The chapter describes best practice systems of support for students with ASD involved in the transition to some form of college. WV ATC has a copy of the text, available through Routledge publishing, in our Lending Library for those interested

## Strengthening Supports

## **Temple Grandin Transition Project for Pre-Teens**

by Angie Kinder, Nichols Elementary School



Julie and Brandon Dial with Gloria Sage

The name Temple Grandin was not part of my vocabulary until the summer of 2015. I am embarrassed to say that when I first heard it, I thought it was a place instead of a person. Now, nearly nine months later, I can't imagine teaching my current group of fifth graders without the inspiration of Temple Grandin. This is my story.

It was early summer and, like a good teacher, I was enjoying a lazy day trolling social media. My friend, Tammy Light, sent a text with the exciting news that Subaru had

classroom sets of books available for teachers and that her husband, Ikie Light of River City Subaru, was willing to purchase a set for me; I just had to choose one. I quickly scanned the list. Most of the titles were on subjects that were familiar to me. Then I stumbled on Temple Grandin. My first instinct was that it must be one of those Egyptian Temples. Since Tammy didn't need an immediate answer, I put my decision on hold and returned to Facebook. Next, I noticed a posting and photo from my dear friend Diana Whitlock, Director of Autism for Wayne County Schools, saying she had met her hero, Temple Grandin. Boom! That got my attention. Now that I knew Temple Grandin was a person – and admired by my friend, Diana – I immediately wanted to know more about her.

My best friend and research ally, Google, informed me that Ms. Grandin is a person with autism who overcame many obstacles to become a successful, independence adult. The term autism got my attention because I knew Brandon Dial would be in my class for reading and science each day for the next school year. Although I have taught students with autism in special needs classrooms, I knew I would be in for a challenge because Brandon is a top-notch student.



Students learning about

Call this Providence, good timing, or whatever you want to call it. This book about Temple Grandin was dropped into my lap at the perfect time. Fifth grade is a tough year of transitions and changes for children. To have this book written specifically for preteens,

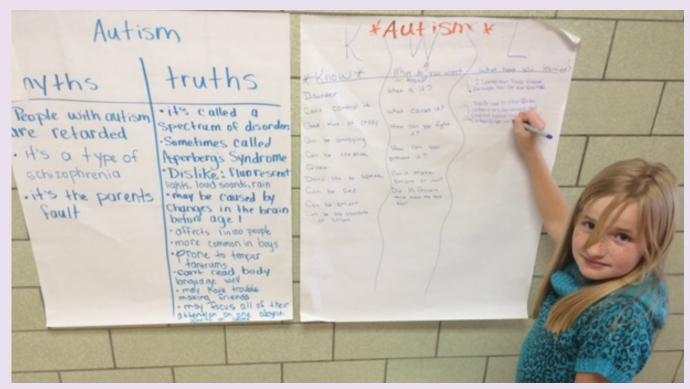
about a girl who overcame many obstacles, challenges, and failures to achieve her dreams, was a godsend. Not only would it provide insight into this student's needs, it also would also offer perspective which would help my students accept and value their classmate who has similar special needs.



Lessons underway to better understand ASA

On the first day of school, we just dove right into the first chapter. I did not want to put Brandon on the spot by making him the center of attention, so I let him take the lead. While his parents have been rather forthcoming about his autism, to his classmates he was just Brandon. So I never pointed out the fact that just like Temple Grandin, Brandon is also autistic. The beauty of childhood is that even when labels are blatantly obvious, many times children do not use them. Several times throughout the story, when we would read characteristics of autism, Brandon would interject, "Just like me," but the children never picked up on it. At the end of our unit, I invited Brandon's mother, Julie Dial, and Gloria Sage, Brandon's friend and autism guru, to speak to the class on autism. As Julie was waxing eloquently on the virtues of autism and other spectrum disorders, a student questioned why Julie knew so much about autism. Brandon then informed the class that he was autistic. What a joy to see the shock on their faces at the news. After being in class with Brandon for six years and doing research on autism for several weeks, he was still just Brandon to them.

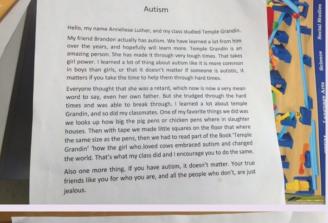
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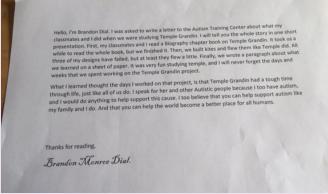


Demystifying and understanding ASD

Not only did the book, Temple Grandin: How the Girl Who Loved Cows Embraced Autism and Changed the World by Sy Montgomery provided reading and language arts materials for my students each day, it taught them to think in a scientific manner. Engineering is a fairly new topic to be covered in the fifth grade curriculum and I do not have any formal training on the subject. This story of Ms. Grandin's "outside of the box education" is the epitome of engineering training. Her first love of building things like paper airplanes and kites lead to science units in my classroom in which my students planned, designed, gathered materials, used trial and error, and redesigned until they had a prototype that pleased them. Our back lawn was full of children running with kites flying behind or dragging on the ground. Kites were launched from various pieces of playground equipment with the goal of keeping a plastic figurine safe inside. When students became frustrated, I would remind them of the frustrations Dr. Grandin endured in school and the workplace. Most of the time, this inspired them to keep trying.

I have taught for over a quarter of a century in regular and special education. While I have been a huge advocate for integration, I have always hated the fact that I was unable to fully educate the typical peer about various differently-abled peers. I would like to have been able to explain the reasons for delays, behavior, and other limitations for my students who had Down's Syndrome, ADD, ADHD, autism, and other disorders, so that their peers could have a better understanding of them. However, privacy laws have prevented that. I believe Julie Dial has done a huge service to her son by being transparent about his autism. I am also thankful that Temple Grandin has published her book so that she can become an inspiration to educators, parents, and students. Speaking of students: a few of mine have written their thoughts on what this unit has meant to them.





Brandon Dial participated in the Family Focused Positive Behavior Support Program through the WV Austism TrainingCenter during 2013-2014.

## Pathways to the Future: a conversation with Jeff McCroskey about creating systems that help students succeed after high school

by Catherine Goffreda Bailey, Ph.D., NCSP, Positive Behavior Support Trainer, WV Autism Training Center

Julie Pratt met Jeff McCroskey in the early 1990s, when she was the director of the West Virginia Developmental Disabilities Council and Jeff was seeking a grant to help students with disabilities transition from school to work. More than two decades later, they're working together again on a project Jeff is directing called Pathways to the Future. The project, funded by the West Virginia Division of Rehabilitation Services (DRS), aims to strengthen transition services and achieve better outcomes for students



#### **OUR GOALS**

- 1. Assist school districts in setting up Work Exploration Programs.
- 2. Develop a statewide parent training network utilizing the Parent Educator Resource Centers (PERCs) and other parent groups.
- 3. Develop a network of transition specialists to work with the Division of Rehabilitation Services, Workforce West Virginia and local school districts.
- 4. Develop a statewide crosssector outreach program with a strong emphasis on underserved populations.
- 5. Strengthen partnerships between government and private stakeholders to better identify, enroll and serve eligible students.

Visit www.pathwayswv.org for resources, tools and people to help students with disabilities through their journeys from youth to adulthood

Julie: When we first met, you were a special education teacher with Kanawha County Schools and were excited about a new program that helped your students get community-based work experience. How did that program come about?

**Jeff:** A lot of times the curriculum we offered back in the 1980s could be pretty boring. The most enthusiasm I would see all week was on Monday morning when students would come in and say: "Hey, Mr. McCroskey I got paid ten dollars for mowing my neighbor's lawn." They were very excited about the work. And I'd say: "Okay, that's great, let's get to the worksheets," and the enthusiasm level would go way down.

Public Law 94-142 (Education for All Handicapped Children Act) did a good job of getting students with more significant disabilities into school, but what were they getting out of it? They still had very little functional programming and very high unemployment rates after high school.

So Kanawha County Schools started what's called a Work Exploration Program in 1985, when Sandra Barkey was the special education director. I became the program coordinator in 1986. The thing I most enjoyed was to see the students succeed. You would often have students who were not learning much back in their special education classrooms, but when you got them matched to jobs they liked they just blossomed.

We started with a handful of students and three or four businesses. When I retired from that job a couple years ago, we had about 140 students participating and about 80 full-time businesses and 20 or 30 businesses we would use part-time.

Julie: How were able to get so many businesses to participate?



Mr. Jeff McCroskey

Jeff: We worked hard to build up the business partnerships and a good variety of job sites for the students. One of our first employers said he'd try it for a semester and see how it went. Then he went on to having students every semester, and

by the time he retired he was one of our biggest advocates

We see that routinely with businesses. It's just a matter of familiarity. When you get students out there interacting with regular coworkers, relationships develop and it's just the way it should be.

Programs like that aren't built over night. You slowly build the relationships with the businesses and get more students to participate. There are still counties that don't have Work Exploration Programs, and that's one of the things we need to push.

**Julie:** In the early years, you were worried about what your students would do after they finished high school and were no longer in the program, and that's how I came to meet you while I was working at the Developmental Disabilities Council.

**Jeff:** Yes, it soon became very apparent that a lot of the students that we knew to be great workers, great candidates for employment, would fall through the cracks when they left high school. Unlike the school system where everyone gets services, adult services are based on eligibility. Even our best workers were falling through the cracks and not getting the follow-up with adult services that led to employment. So I started Community Access in 1992 to help students transition to

continued on page 12

#### Pathways to the Future continued from page 11

employment, with the help of a grant from the Developmental Disabilities Council.

The Student Transition Employment Program (STEP) initially came about because I would use my company to hire Kanawha County school teachers or aides to work with their own students after they graduated and help them become employed. We were able to do that because I was a vendor with DRS. They would pay my company for the service, and I would then pay the teacher.

That worked absolutely beautifully. The teacher had worked with a student for at least a couple years, and they knew each other well. By virtue of being out at a lot of different job sites, the teacher, student, and parent had a real good idea of what was a good job match and, just as important, what was not a good job match. That built-in rapport is what made it so successful.

So I approached Debbie Lovely, the director of DRS at the time, about DRS paying the teacher directly as the community rehabilitation provider. Then they could get rid of paying my company as the middleman. So we did a several-year pilot, which was funded by DRS and the West Virginia Developmental Disabilities Council. Working closely with DRS staff, particularly LuAnn Summers, we placed over 140 students, trained over a hundred teachers, and then turned it over to DRS. They're still doing it and, to their credit, we're the only state that does this.

**Julie:** I recently had the pleasure of interviewing two alumni of STEP in Monongalia County, which is based in part on Kanawha County's program. The woman I met loves to work with children, has been a teacher's aide at a child care center for six years, and has earned additional certification in child development. The man I met landed a part-time job at a business where he'd done work exploration during high school and, later, was able to get a different job with more hours. When I talked to his former employer, he said they still missed him and would hire him back in a heartbeat. What impressed me most was how both people were not only employed, but still growing in their careers.

**Jeff:** Right. We're huge proponents of the stair-step methodology. Whether you have a disability or not, most people do not keep that first job. Most people have a number of things they do before they find just the right



This Pathways WV billboard near Grafton, WV is one of the many billboards placed around the state.

job. We want to make it real clear as part of the self-advocacy training that if you see something else you want to do and you want to take a shot at it, we will support you

**Julie:** What about people with the most significant disabilities, who may not be able to find paid employment, at least not right away?

**Jeff:** We believe that everybody has skills, has talents and can do something. I recently helped a young man with a significant brain injury, who had very limited endurance and couldn't get out easily. But he didn't want to sit at home the rest of his life, which the research clearly shows is very detrimental to your mental and physical health.

This young man is a "people person" and interested in working with older folks, so I got him a part-time volunteer position at a nursing home. He really loves to talk, so they assigned him to three patients who didn't have much family visitation and were lonely. So it's a win/win situation. I'm a firm believer in trying to engineer situations like that, even if it's not for pay. It's still meaningful. It still helps people.

**Julie:** One of the things I appreciate about you, Jeff, is that you always have one eye on the forest and the other on the trees. You've done a lot of work to help systems become more responsive and effective in helping people reach their goals. And your advocacy is always based on real people's experiences and the approaches that have been the most successful. That seems to me to be what your newest project - Pathways to the

Future – is all about. What do you hope to accomplish? [Also see sidebar]

**Jeff:** The new Workforce Innovation and Opportunity Act (WIOA) gives states tools to help a lot of people, especially those people in that 14 to 21 years age range. Under WIOA, eligible students will receive services from a DRS pre-employment transition services counselor by the 10th grade, rather than starting senior year as had been done in the past. Another major change is that WIOA requires state vocational rehabilitation agencies to spend at least 15 percent of their overall budgets on this transition age group. So these are really significant and beneficial changes.

Our Pathways grant is through DRS, and it affords us a golden opportunity to make positive change, get more students into the system and at an earlier age, and achieve better outcomes. It is a collaboration of major state agencies, including DRS, the Department of Education, the Department of Health and Human Resources and Workforce West Virginia.

My hope is that, working closely with our partner agencies, we can get the word out and let people know what's available. These big system changes do not happen overnight, but over the next two years I hope that by virtue of DRS taking students earlier and our project assisting with some good ideas and innovations, it will become a more seamless system. The bottom line would be that more students with disabilities have access to the services they need for jobs and careers and to be contributing members of their communities.

## **Work Exploration for High School** Students with Sallie Askin

by Andrew Nelson

We were tremendously inspired by the article Julie Pratt and Jeff McCroskey submitted for this magazine detailing the Pathways to the Future project, Student Transition Employment Program (STEP), and the early beginnings of the Work Exploration program in West Virginia Schools. We were so inspired, in fact, that we wanted to learn more so we arranged to spend the day with Ms. Sallie Askin, Berkeley County Schools Work Exploration Program Coordinator, to learn more about the program and see it in action. We walked away from the experience inspired and informed and wanted to help our readers understand more about Work Exploration and how it can impact their students and community.

This September I walked into the local Martin's grocery store in Martinsburg, WV and began searching for my friend and colleague, Sallie Askin. I have known Sallie for many years and always admired the Work Exploration Program she and her team operate in Berkeley County public schools. During my travels around the eastern panhandle I have often seen students working in community businesses and witnessed the smiles and looks of pride on their faces when they talked about their work experiences. On this particular day, I planned to meet Sallie, a job specialist, and a new Work Exploration student named Kimberly. They were somewhere in the store re-stocking shelves. A text from Sallie reading "Aisle 21" came in and it wasn't long before I found the crew working on new skills and supports together.

Kimberly was working 1:1 with her job specialist and asked questions as they walked along locating store items. I asked how she was doing and Kimberly responded with a smile and said "Great!" "Students learn important life skills in addition to work skills." explained Sallie, "they are learning how to navigate a store, how much daily living items generally cost, and how to ask for help if they need support." When Kimberly wrapped up her duties for the day she and her job specialist went to the work van, provided by Berkeley County Schools, and left to go pick up fellow classmates from their various job sites around the area.



Sallie Askin making calls to coordinate Work Exploration activities for the day in Berkeley County, West Virginia

As Sallie and I drove to the next work site she provided some of the facts about how the program began. "I had taught off and on in the county...substitute teaching, teaching high school students and elementary aged gifted students, when I came on board to my current position in January, 2006. I was very new to the field of transition. The Special Education Director at the time, Dr. Brown, felt I would be outgoing enough to pull off this work. He had gone to Marshall County (WV) Schools and learned about how they recruited businesses for their Work Exploration programs and realized you had to be a bit



Kimberly looking happy on the job at Martin's

of a salesperson. Dr. Brown gave me a pile of folders with materials from conferences he had attended that he thought were valuable. I then went out to visit other counties that were doing Work Exploration and had real hold on how to help students in special education transition to adulthood. I went to Kanawha County, Marshall County, Beckley, Parkersburg, and that is where I got all of my beginning materials from! Jeff McCroskey, Belinda Bennett and many others were very helpful. I got the ideas for my brochures and transition summits from them and the others running programs around the state."



Student Brenda, Sallie and Job Specialist talk over new job tasks to practice.

#### Work Exploration for High School Students continued from page 13

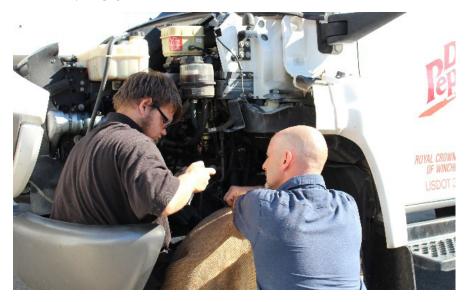
We arrived at the next job location, Burger King, and found yet another happy student and job specialist working away. Brenda was a three-year veteran in the program and had done a variety of jobs over her tenure. Sallie explained that "last year we closed out the year with 131 students and 140 businesses involved in our program! Students must be at least 16 years old to participate. We serve 30 students per high school in the county. Beginning Work Exploration students go out a minimum of one hour per week but many of our seniors go out for three hours or more. It's not enough. It's just a taste. Students are exploring the world of work and realizing that they too can work." We then observed Brenda finish up her daily tasks and headed out the door to stop number three for the day. As I processed the student and business involvement numbers Sallie shared it became very apparent how a program like Work Exploration can positively affect the culture of an entire community.

Sallie pulled her car around to the back of Opequon Motors in Martinsburg to reveal a student and his work mentor elbow deep in a very complicated diesel engine. The student, Chad, listened intently as the lead mechanic coached him through the



Jamie hard at work, Haircut Place in Martinsburg





complicated process of changing a solenoid in a large delivery truck. The employee of the business was patient, precise, and kind in his approach with Chad who was executing a task many of us would never be able to accomplish. It was inspiring. The job specialist helped when she was needed, but at each site the job specialists were adept at knowing when to provide support and when to fade back and let the student run the show. "We have four full time and four part time job specialists across the county," Sallie said, "and those numbers have not changed since we started with 40 businesses and 50 students. They don't want to leave, they're like me. This almost becomes an addiction. It can be a 24/7 job. Our students call us early in the morning when they are going to be absent, just like they would if they were calling in to their jobs." After marveling at Chad's talent and his mentor's teaching ability, we moved to our final site visit of the day.

The Haircut Place in Martinsburg was alive with activity when we arrived. Employees were busy helping customers, stocking supplies, and maintaining the look of the shop. One student, Jamie, was at work preparing linens and hair washing basins for the full time stylists. She was as happy as the other students we visited and the ladies running the shop were genuinely excited to have Jamie's help. This was a recurring theme everywhere we went. Businesses and employees seemed truly appreciative of the students and staff of the Work Exploration program. This is how community is developed, from the ground

up, through hard, consistent, and sensitive work. "I tell families and friends all the time to take the time to support the businesses that support our students in Work Exploration," Sallie emphasized, "parents love to support businesses that support their children! We are trying to get our program into new businesses now and we often tell business owners that 30 students in a high school program each know at least ten other people and as a result potentially 300 people will want to frequent your business when they see that you support Work Exploration. Each business is given a window sign that shows they support Work Exploration and it becomes a source of pride for all involved. People go to businesses that have been dedicated to our program!"

As we concluded our visits and conversation I was hit with the profound sense that everyone benefits from a program like this. When you participate in your community, wherever that may be, look for businesses that are helping students with disabilities explore work options. Promote those businesses. Thank them for their support and let them know you notice all they are doing. If you find yourself in a county or community where Work Exploration is not an established program, reach out to your Special Education Directors, county Transition Coordinators, and folks like Sallie Askin or Jeff McCroskey. I know they will help answer any questions you may have to get an initiative started...and I know the students and businesses in your community will benefit as a result.

## Customized and Supportive Employment with Lee Cloughfeather and Cathy Lee Irizarry-Barron

We often hear about the "services cliff" young adults in transition experience once they graduate from high school and enter the work force or post-secondary system. Work exploration programs in the state of West Virginia prepare individuals for this transition by exposing them to a variety of work experiences before they graduate but job placement is not a focus. One group in the eastern panhandle of West Virginia is helping to fill the employment gap for individuals with autism and other special abilities living in Morgan, Berkeley, and Jefferson counties. Daily Companions Inc (DCI) was founded by Lee Cloughfeather and started providing Intellectual Developmental Disability (I/DD) Waiver Services on July 2 2004. Ms. Cloughfeather had a brother named "Arty" who wanted the ability to explore and enjoy life on his terms. Arty would state "Don't tell me what I can't do... let me show you what I can do." DCI operates according to Arty's motto. The DCI staff works to assist with developing an individual plan to address the interests and dreams of the individual and the needs of the family. We recently met with Ms. Cloughfeather and Certified Employment Support Professional Ms. Cathy Lee Irizarry-Barron to talk specifically about employment and independent living supports.

**WVATC:** Tell us what DCI is doing to help adults achieve employment and other aspects of a life of quality?

Ms. Lee Cloughfeather: We have a day program that starts with working on manners, socialization, independent living skills, and learning about the community the individuals we support live in. We go out every day of the week to integrate into the community and work on personal goals. We work to help individuals learn about museums, organizations, special events in our community, and how those systems work and who is participating. It is important that they integrate fully into the community and learn about available options. We want them seen as first class citizens just like anyone else. The next phase of our supports are pre-vocational. We work to identify an individual's skills and often tie this work to the Division of Rehabilitation Services (DRS) who are able to do things like trial work assessments and other job coaching and supports. This helps identify skill sets, interests, and endurance on the job. We also have a Customized Employment Grant that has less direct on-the-job supervision than our DRS-based services but focuses on job development and placement. Our goal here, really, is to be the next step for those who are in Work Exploration to do trial work, volunteering, and ultimately job placement out in the community. Our services are person-centered and offer high degrees of choice for the individuals we support.

**WVATC:** What are some of the things you feel people transitioning into adulthood value? What makes for a good transition?



Lee Cloughleather and Cathy Lee Irizarry-Barron of DCI

Ms. Lee Cloughfeather: I think the most important thing is choice. People do not want to be treated like they are a child. We treat our program's individuals as adults. We have planned activities but there are downtimes where we build in times that are not designated for anything specific and we ask individuals "what would you like to do for the next hour?" When on an outing they choose the restaurants they want to visit. We don't tell them what to choose. They work together and work on compromising. I think it is important that individuals feel like they are part of the process and that they are heard.

Ms. Cathy Lee Irizarry-Barron: I think three things individuals value most is their independence, having a sense of self-worth, and getting financial independence. Anytime we are helping a consumer, the more classes we can point them toward the better off they are. I'd like to see more of the individuals we serve going to "money matters" or "rental market" classes. Renting right now is so competitive and we need to help individuals find housing that is affordable for them and meets their needs. We would like to do that preferably before they actually need to know those things. I think those factors make for a good transition. The more people we can get involved prior to the transition process the more supports individuals will have once they are there.

**WVATC:** What is the current landscape in West Virginia for independent living supports and what can we do to improve them?

continued on page 16



Friends at DCI on a community outing

Ms. Lee Cloughfeather: The one thing I share with all of the families I come into contact with is that I understand they are afraid for their children to live on their own. I had a brother (the reason I started Daily Companions) and before he died in the hospital he told the nurse "my parents raised me, but my sister let me grow up." As scared as I was I helped him get an apartment. I've been through it. I think we need to understand that they need to grow just like any other children in the home. There is an evolution here, it's a journey. They are entitled to that journey. Daily Companions focuses on working with individuals who want to find employment and we provide a job coach if we cannot find natural peer supports for them. Unfortunately, due to a lack of transportation if individuals do not live on existing public transportation routes, they cannot afford a taxi, etc. This is another one of our biggest hurdles. We need to work on finding more transportation. We also need to somehow get more recognition to businesses that do employ individuals so it makes other businesses want to employ as well.

Ms. Cathy Lee Irizarry-Barron: I can tell you in Berkeley County Daily Companions has a really good rapport with landlords and other contacts. We have proved with the clients that we have in our housing and rental situations that the rent gets paid, utilities get paid, they don't make too much noise. In West Virginia as a whole we need to continue to provide clean, safe, spacious living arrangements. Some of the issues more often than not that come up for them in their living situations are issues with transportation. Berkeley County busing doesn't always go out as far as our clients live. We have several clients that live in the same apartment environment who would have to walk on a road a good distance to get to busing stops, which is not safe for them. The Berkeley County transit does have "on demand" options but if they are not being transported to a doctor's appointment but instead are being transported to work it is not a priority. Some individuals work at night and are not finished until after the bus has already passed. A lot of our individuals do not have a smart phone, which is needed for transportation services like Uber or Lift. We've got to be able to network to get public transportation as far out as it is needed. Unfortunately we lose job opportunities for some individuals because of these issues.

**WVATC:** What exactly is customized employment?

Ms. Cathy Lee Irizarry-Barron: Customized employment can be two things. It can be taking a job that is already there and customizing it to the individual's skills but maintaining the integrity of the company. For example, if a job description says the employee will need to be able to lift 50 lbs. but they are physically only able to lift 25lbs. we ask what kind of an accommodation can we give them where they will still be able to lift the 50lbs. per the job description. Can we reduce the demand to 25lbs. for the individual? Can we take that piece of the job description out entirely and add something else in? If someone is doing the lifting for them can they do the packaging for that employee as a swap, etc.? The other aspect of customized is employment is creating a job where there isn't currently one. As part of customized employment I will go into businesses and actually just sit and watch to see if there missing aspects of a business where someone could come in an hour a day and complete a job for the business. I go in and try to see what company needs are and approach the business in a diplomatic manner to see if someone can come in and complete tasks for them. Even five hours of pay a week can mean financial freedom for an individual and five hours a week could grow into more and bigger employment opportunities. One of the best parts of the Customized Employment Grant supports we offer at DCI is that these services are free. We want to help individuals find a job!

**WVATC:** What are your visions for the future?

Ms. Cathy Lee Irizarry-Barron: My vision for the individuals out in the world is not an impossible vision. I often hear that my wishes are impossible. But I don't think what I am asking for is anything more than humane. That vision is to open the doors of employment to more people, whether they have a disability or not. I know we hear about budget cuts and business' inability to hire, but sometimes companies could fill jobs and increase employment for people if they would just look outside of the box. If we could do this, through the creative use of part-time position employees to meet the equivalent of one full time position or other creative adaptations, we would be able to give so many more people so many more opportunities. If we could tweak job descriptions or cut things out and add other elements it would still maintain corporate integrity as well as honor the individual's skills. I don't think that is an impossible vision.

**Ms. Lee Cloughfeather:** Our vision for the future is to really focus on our day program and help individuals progress through each level in order to get them working. I believe that everybody who wants to work should be allowed to work with the right skill preparation. We spend so much time in the community talking and educating and the corporate world is just starting to open doors for what we are doing. Ultimately, Daily Companions is looking to assist the individual in the "self-authorization of their life."

The WV Autism Training Center now has a satellite office in the Daily Companions Inc. building in Martinsburg, WV. To learn more about Daily Companions Inc. please visit www.dailycompanionsinc.com.



Professionals advising college student with ASD on workplace strategies

## Turning the Tassel: Preparing for the Transition from College to Work

by Rebecca Hansen and Jackie Clark, College Program for Students with Autism Spectrum Disorder

It is logical to presume that obtaining a college degree provides greater opportunities for employment; however, that is not always the case for college graduates diagnosed with Autism Spectrum Disorder (ASD). College-degree-holding students with ASD may experience the transition out of college differently than typical college graduate, predominantly due to social communication challenges. Research indicates that college graduates with ASD have the intellectual capacity and intrinsic motivation that employers seek, but often lack the skills necessary to meet the social aspects of employment. A difficult economy, coupled with increasing competition from others holding similar degrees, creates an aggressive environment where college graduates with ASD must possess employment-readiness skills to make themselves more desirable in the job market.

In an effort to address these employmentreadiness skills, The West Virginia Autism

Training Center's College Program launched its inaugural "Summer Employment Workshop" in June, 2016. Participants spent three days learning from various campus and community partners about how to access and maintain employment. Day One of the workshop included activities related to preparing for employment. Participants began by creating LinkedIn and Job Trax accounts that help with job searching and networking skills. Next, each underwent a round of speed networking sessions with Marshall University's Career Services Center staff. The day ended with individualized cover letters and resume building sessions.

Day Two focused on issues surrounding disclosure and self-advocacy, facilitated by WV ATC's Andrew Nelson. Andrew provided an interactive dialogue that included how sensory issues can affect overall functioning in the workplace. A highlight of the day included participants responding to a hypothetical job posting that included a mock interview with College Program staff.

Day Three provided participants an opportunity to ask questions to a variety of local employers who had experience working with individuals with ASD. Five professionals with experience ranging from the private sector to the non-profit world answered questions and related them to their workplace expectations. After, College Program staff lead sessions on finance management, access and use of transportation, and stress management in the workplace.

Evaluations from the workshop indicated that participants felt they now had access to adequate employment resources, an increased knowledge of their needs including how and when to advocate for accommodations to meet those needs and ultimately became better candidates for employment.

To learn more about the 2017 Summer Employment Workshop, please call 304-696-2332.



by Gloria Sage, Senior Program Coordinator, WV Autism Training Center

Quality of Life is a term that is heard often today, but what does it really mean? Most of us have an idea what a good quality of life means to us, but what about QOL for individuals with autism? Is it the same or different? What makes up quality of life and why is it important to address when planning programs and services for people with ASD?

There are a number of ways to define QOL, but one way of looking at it is "the degree to which a person enjoys the important possibilities of his or her life." These possibilities result from the opportunities and limitations each person has in his or her life and reflect the interaction of personal and environmental factors. What one person thinks is a good quality of life for them might not be for another person. Individual likes, dislikes and goals all part a part. Sometimes, parents may have a certain standard that they think should be met while the individual themselves would be quite satisfied with a more relaxed standard.

For school-age individuals, parents and teachers may be solely focused on academic skills, improving communication, and increasing daily living skills like eating, dressing, hygiene, and others. Addressing challenging behaviors is also a top priority. As students leave school and move out into the larger world, finding employment, attending higher education or job training, living outside the family home and finding programs and services to address adult needs takes priority. Addressing QOL issues can impact all of these goals for individuals with ASD. Although there may be additional domains, the following seven domains are most often identified with increased quality of life:

- Increased access to community activities
- Stable, reciprocal relationships
- Access to interesting materials or enjoyable activities
- Making choices
- · Filling respected roles
- · Pleasant, safe environment
- Unconditional acceptance and love

Having access to community activities, especially with typical peers, can be important to increasing QOL for both children and adults. Finding the "just right" activity that the individual with ASD enjoys and training the adults and peers who will be supporting the individual will help to make sure that the activity is successful. Starting early will increase the chances that the individual will continue to engage in community activities with peers as they grow and will also help them learn the skills to navigate in these environments.

Having *stable*, *reciprocal relationships* is important to having a good quality of life for all individuals, including individuals with ASD. This can be difficult at times to achieve. Most often, these relationships are with parents, teachers, or paid staff. While these are the key people who love and support the person with ASD, it is not surprising that many individuals report having a friend is a top goal for them. Friends are important at any age, but especially as persons enter the teen years and become adults. Once persons

have left high school, having a friend to spend time with and share interests and activities is extremely important. This post-high school transition can be very difficult due to a lack of services available for adults with ASD.

Having access to interesting materials or enjoyable activities directly relates to QOL for all persons. Everyone has hobbies they engage in or activities they participate in, whether it is sports, the arts, reading, exercising, etc. Ensuring that the individual is able to access the materials or activities that they enjoy is important. However, sometimes individuals with ASD need support so they do not spend twelve hours a day playing video games or only engaging in that one activity to the exclusion of any other. Helping people find the balance is important.

Being able to make choices about one's life not only contributes to a higher QOL but is also a major life skill. Sometimes, individuals with ASD do not know how to make choices. Other times, parents, teachers, or others do not allow them to make choices. While it is understandable that adults may think they know what is best for the person, if they are not taught to make some choices or allowed to do so, they are likely to become highly dependent adults who cannot do anything for themselves or who may do whatever anyone tells them to do, even someone who does not have their best interests at heart. Learning to make choices starts when children are very young and can be built upon and expanded as they grow and mature. Put yourself in the shoes of someone with ASD: if someone else controlled everything you did in your day, you would not be too happy about that! You might even "act out" in protest. Allowing and supporting individuals to make their own choices increases their self-confidence and dignity.

Filling respected roles improves QOL for individuals with ASD in a variety of ways. We all want to feel that we are important and that we contribute to our family, our school, our community, or our job. Supporting individuals in finding ways to fill these roles through having responsibilities at home, at school, or in the community can increase self-esteem and confidence. It shows that parents, teachers and others have faith in the individual, believe that they have important skills and abilities to share, and improves how other students or family members view the person with autism.





Most everyone would identify having a pleasant, safe environment as important to a good quality of life. Making sure that students feel safe and welcomed in their school and do not have to be victims of bullying is extremely important. Creating schools that are welcoming to all students and that find ways to make sure that all students are a part of the school community should be a priority for teachers and administrators. Supporting individuals in finding or creating a safe and comfortable living situation should also be a priority and can sometimes be a challenge. Early planning for these life transitions is crucial and having a good team to support this process is essential to a good outcome.

Finally, unconditional acceptance and love is probably at the top of the list for what makes a good quality of life. We all desire to be loved and supported just for ourselves, not contingent on anything we do or do not do. Having unconditional love and acceptance gives us strength and courage to face our challenges and move forward in life. This is true for everyone and especially for those living with autism.

Whether planning for programs and services, planning for transitions or just working toward a better life for someone with ASD, be sure to address these seven domains to ensure the best possible quality of life outcomes are achieved.

The Mission of the WV Autism Training Center is: "To support individuals with autism spectrum disorder as they pursue a life of quality".

## Fifteen Things About Me

## by Desire Miller

When your child first receives the diagnosis of autism, there are so many thoughts that race through your mind. "What does this mean for him and for our family?""What kind of obstacles will he have to face throughout his life?" And above all, "What on Earth do we do now?" My son Avery was diagnosed with Asperger's Syndrome when he was four years old, and I asked myself those very questions. What I didn't know then was for every obstacle and every fear we would face- there would be so many people who would be there to encourage us and to help him achieve everything he is capable of. The West Virginia Autism Training Center, at Marshall University, employs a group of such people, and they, with the hard work of our Positive Behavior Support Trainer Tracey Vincent, were crucial in helping Avery with his complex transition from elementary to middle school.

Avery attended a very small elementary school, which normally has 150-160 students enrolled. It made for a great environment for him: classes were typically on the smaller side, and he knew which teacher he would have the following year well in advance. There were few surprises. However, we knew leading up to his 5th grade year, that this small, safe environment may make his transition to middle school even harder because it would be such a complete change from everything he knew. As luck would have it, the summer prior to him beginning 5th grade, his name came up on the waiting list to begin services with the WV ATC. We were thrilled, because as much as we were trying to prepare him for the changes, we needed someone with experience to guide us all through the process, and to help Avery feel as comfortable as possible starting in his new school. The entire year, Avery's "team" – comprised of myself, Tracey Vincent, his principal, his teacher, and other support staff from the school – met frequently to plan for his move. Together, we ironed out the specifics of how things would change for him, and what we could do to best prepare him. Tracey guided us, helping us outline as many details as possible that we could address- everything from his move from class to class to the logistics of providing sensory items when he wouldn't be remaining



Avery at his school.



Avery reads his 15 Things About Me letter.

in the same room the entire day. She also developed a Positive Behavioral Support Plan to provide to his new teachers. Avery said: "Tracey coming to help us made me feel calmer about going to a new school. She had good ideas, and I liked when she would come visit me at school." In May, Tracey, Avery, and a few of the other team members traveled to Elkins Middle School for his Transition Meeting with the staff members there. We presented our plan, our questions, and our concerns, and Avery was able to meet several of the EMS teachers, which did wonders to set his mind at ease.

In August, Tracey helped us coordinate a presentation that Avery gave to his new team of teachers, called "15 Things to Know About Me." In this, he explained things about his autism that they may not have been aware of, along with his likes, dislikes, and things that may trigger a very bad day for him. It was the perfect ice breaker for both Avery and the staff members. Though he was extremely nervous at the beginning, by the end of the presentation he was laughing and had entirely loosened up. I credit this with giving him a very positive feeling about the beginning of the school year. "I wasn't really worried about going to middle school after we met all my teachers and I talked to them," Avery said. "It was a really good idea to tell them things about me, because they didn't know me yet."

Avery is now in his second month of middle school, and I can easily say that this is the best progression from one year to the next that we have ever had. I credit this entirely to the process of transition that the WV ATC and Tracey Vincent took us through. Avery was prepared for each step and change he would be facing. When there are no surprises, there are very few triggers that would mean a huge setback for him. I cannot say enough how grateful we are for the services that the WV ATC provides, and for the wonderful coordinator they have in Tracey. She truly understands the spectrum, and embraces each case as passionately as if it were her own child she was advocating for. The tools and skills we have all learned will aid us in helping Avery face challenges for years to come.

# <u>ransitions</u> dulthood

by Steven Anthony George



When I was in high school, there were no IEPs, and though there were (inadequate) equivalents, I was not diagnosed on the autism spectrum until I was an adult, so no form of assistance or accommodations were provided for me. Still, from Kindergarten through high school, my parents were responsible for my well-being and teachers were as much authority figures as they were instructors, so guidance was always available. My parents provided structure and discipline that I wanted

and needed, but after graduation that was left to me to provide for myself and, like most young adults with autism, I was unwilling to leave home because I had no understanding of how to take care of myself. Neurotypical children learn from example, but autistics do not usually observe the world around us with an objective sense of curiosity; our extreme degree of self-absorption leads us to miss most of those unspoken lessons.

I grew up in a rural area, so there was little to see or do. I wanted very much to experience places and people outside of home, but there was no way that I was going to do that without consistent help. Strange people were confusing and being in unfamiliar places was often frightening. I was not ready to have a job and a place of my own, but I was even less prepared to go to college where I would be subjected to precisely the same difficulties I had in high school, but without the safety nets.

High school involved bullying and ridicule, which meant I loathed being there. The lessons were often confusing or ambiguous to me and I had no friends to consult, so as a result, I often did not complete them. This led to my decision to delay college. I saw little purpose in it when I would receive no support at all for the many problems I had been experiencing. As it turned out, when I finally did go to college, I learned there was an ADA office, which did offer some help with



completing work, but not with navigating the overall process.

While the work environment can, and often does, afford accommodations, they do not help with relations with coworkers, and here I was in a bind. Those on the Spectrum struggle with how much to reveal to those they work with. I was initially not open about my autism, because I assumed that no one would

understand, and if they did, they would see it as largely a social deficit and would fail to understand how it affected the work I was doing. I thought that it was better that I just did the best job that I could do and then fake the rest like I did in school, but my inability to be sociable or approachable led to the problems I tried to avoid by delaying college.

At work, I was receiving accusatory memos three or four times a week and having my job responsibilities taken away without explanation. At one point my boss conducted a staff meeting in which my coworkers were permitted to tell me why they disliked me. That on top of my usual stressors was too much; I went into what I later discovered was shutdown (I was not familiar with the term before this). I could not eat, sleep, sit, stand, or anything outside of pacing a line on the floor and reciting numbers. In one of the few moments that I could break away from the repetitive behavior, I called a friend to ask what I should do. He suggested that I go to the hospital, because there was something obviously very wrong going on that I didn't have control over. The only positive was that I got a month's leave.

The problem we all face in the work environment is that, by the time we are hired, we are already assumed to be competent and able to handle the tasks required, so there will be a brief training and a probationary period, but no one will metaphorically hold our hands and help us through what is most difficult. Yet, autistics do expect that. I was notorious for making excuses or just missing work altogether if I either failed to understand a procedure or if the work was just too stressful. Yet, I continued to stay at each job, no matter how inappropriate, because once I was accustomed to it, resigning and beginning a new one would be far more stressful.

Help has never been available to autistics with mild disabilities to transition into the adult world, and perhaps this is why many celebrities and pundits don't recognize that autistic adults even exist. Those of us on the shallow end of the Spectrum have inadvertently made ourselves invisible by doing the best we can to fend for ourselves, which often means being underemployed in unskilled jobs, despite our intellectual gifts. This, in turn, means we will often live in substandard housing and we can be taken advantage of by unscrupulous landlords. We are confused and overwhelmed by bills and budgeting, and so we often suffer from the consequences of poor credit ratings. Seniors on the Spectrum often live in conditions in which they are not getting many of their basic needs met.

continued on page 26

## At the Corner of Jimmy and Blaine: Life as an Adult with ASD with Jimmy Ward and Blaine Seitz

We sat down recently with our friends Jimmy Ward and Blaine Seitz at the Autism Training Center northern satellite office in Fairmont, WV to talk about their lives, hopes, challenges, and ideas for a better world for adults with ASD. Jimmy and Blaine are wonderful, colorful human beings. To hear the (mostly) unedited conversation in full audio please check out our WV Autism Training Center podcast at the following link: http://wvautismtrainingcenter. podbean.com

**WVATC:** Thanks for talking with us today. Who are you guys and what have you been

**Jimmy Ward:** Hey everyone! My name is James Ward. I technically live near the borders of Monongalia and Fairmont, WV and my family has a self-made business, a pet crematory. I am currently searching for a job right now and oftentimes I help out at our farm, either with the business or with the yard work.

Blaine Seitz: My name is Blaine Seitz. I am a long time resident of Morgantown, WV. I am currently unemployed but I do have an interview coming up this Friday so I am hopeful. I'm pretty sure it will probably be seasonal work, but when you have no job you look for whatever you can get. I am the oldest of three brothers. My mom of seventy years still manages to cook for me on occasion and I like dogs!

**WVATC:** How did you guys meet?

**Jimmy:** Sarah Kunkel (PBS Trainer at WV ATC) actually introduced us when she introduced me into this group (a monthly social group which meets at our ATC north office) and I was as nervous as an autumn leaf at this point. I wasn't sure about anyone but as time went on I finally did get a little more comfortable around him and I started to try and make conversation. I try my best to be as social as possible. So, I just asked Blaine simple questions and in the end I found out he was comic fan for example.



Jimmy Ward (left) and Blaine Seitz (right) passionately rap about life and shared interests.

**Blaine:** I'd like to think that the reason we met mostly is just because he and I have a lot of commonality between each other. We are both creative people. Morgantown has a small convention, WV Pop Con, that's been going on now for about 3-4 years and it's become a tradition between me, Jimmy, and Liz that we spend at least one day there going around and looking at art work. We each have different thing about what we love about pop culture and we can relate on that level because we are children of pop culture in some ways. We relate well because there are so many similarities between us.

**WVATC:** Excellent. It is pretty common knowledge that small transitions for individuals on the autism spectrum can be tough. For example, coming here from your home tonight, transitioning from one task to another, or changing classes throughout the school day can be a challenge. Is that true in your lives?

**Jimmy:** Not really. I mean, on a small level there may be little U turns or detours as I would like to say. But I've learned to adapt to it. There have been times I have been bothered like nuts over situations. Like when I was a kid we had a teacher that

always shifted around our desks to a different spot in the room. There was a time when I was in first or second grade and that happened and I just went off the wall. She got the heads up from my mom to let me know before something like that happens but knowing where my desk is NOT the big issue right now. If something happens I try my best to just go along with it.

**Blaine:** I would say for me, I think it happens. I've noticed it where I will be like "that wasn't what I wanted to have happen". But at the same time I've kind of internalized it to the point where it's like "okay, what is the best response to this?" as opposed to just freaking out. And most of the time I manage to get through it. It's not something I think of as a major life issue

**WVATC:** So for the parents out there who are wondering how their young child may manage these smaller transition challenges later in life, do I hear you saying is that it gets better over time?

**Jimmy:** Better over time? It's a much longer process than you might think. I, for example, am still looking for a job at this point. I haven't had a girlfriend. I only had

one year of college. The change into an adult...it's not going to be easy. There will be times when your kid, and I'm talking to the parents here, your kid is going to have interests. And it is most likely that you will try to help them find a job that matches their interests at least. At the very least. If they want part time work, like doing stock at a grocery store, that is one thing. But in terms of a long term goal I am just not set. I don't have a plan. I have my own creative interests, but they are very specific, and it's just hard to find a job that matches that specific mental need.

**Blaine:** I would totally agree with Jimmy about everything he just said. I have gotten myself an Associate's Degree in health information management. And while I have a degree and I have a certification it has been very difficult, I find, because a lot of the jobs in health information management require you to have actual work experience. And it is really hard. This is what the marketplace has become unfortunately. Like Jimmy, I have never quite focused on a plan that I've had for my life. It's always been about drifting to interests or things that I wanted to do with my life. For me, I think what is most important for the parents to understand is your child will develop into an adult. It's not a question! What the question becomes is what they develop into, who they are, and what society will accept them as. And that is sort of the problem we've had as people with autism is that we've had these other expectations, some of them might be correct, some of them might not be.

#### **Jimmy:** (on the subject of creativity)

You can't have a job trying to express yourself. It's always expressing someone else's ideas and creation. It's kind of like Lego®. They're making sets, but most of them are not their sets. It always has to be Star Wars, Ghostbusters, Batman, DC, Marvel, or Disney. Someone else's idea and not your own!

Blaine: When you look at your child, and you look at what he can do, just remember that you as a parent have to be as much of an advocate for them as they are going to be for themselves. We are not always willing to speak up. Jimmy and I are not the confrontational types. We need people that are willing to advocate for us.

**Jimmy:** There is at least one more tough thing about the transition into adulthood. This is something that I have realized recently. It's the fact that when you have Aspergers (or ASD) you realize that you have to be an adult but in the end you still feel comfortable being that innocent child you try so hard to preserve. But in the end you are going to have to be one or the other. That's something I've been thinking about recently. You either going to have to grow up and give up all of your dreams and just accept that the world is going to be a tough, harsh place. And you are going to have to live or die or stay at home with your parents until they expire...and neither path sounds really good. But really...what can you choose? You either grow up or try to keep that happy-go-lucky personality that you know you have to leave behind but at the same time you don't want to leave behind. It's a difficult transition.

**WVATC:** Who or what has helped guide you through these difficult changes?

**Jimmy:** I can definitely say a lot of therapy helps. I've had counseling with my own doctor. I've been taking medications at times. I've been trying to find a job and am doing some job shadowing. What about you, Blaine?

Blaine: I was diagnosed at age 29 with autism. And it wasn't until then that I realized what it was I had problems with because before that I had been diagnosed with ADHD, schizophrenic disorder, mood disorders, you know. It made me realize that all of the diagnoses I had before, and even the one I have now, don't guite define exactly who I am. It is just a qualifier for a part of my self. I would say my family helped some and having therapy sessions helped. But I would say that the three people who have been the biggest help for me to get further along in my life are Peggy Hovatter (PBS Trainer at WV ATC) for one, Jimmy who has definitely helped, and I would probably say Sarah Kunkel.

**Jimmy:** Definitely Sarah!

**Blaine:** They have all managed to help me make sense of things. When I first starting learning about autism, Peggy had me start talking to a bunch of teachers. That was sort of the gateway to opening me

up about who and what I am. It was an aspect of me that was missing in the ingredients of who Blaine Seitz is. I started meeting more people. I started understanding my socialization issues. That started help me make more sense not just of my personality but the whole world around me. I qualified for me that I have this diagnosis and it is not a death sentence it is just a condition where we process the universe through our senses differently. We are unique but still the same!

**WVATC:** What is something in your life that is going well and that you are really proud of?

**Jimmy:** There is at least one thing that I have been proud of and that's just my getting back into the creative spirit. It's a long process, to be sure, and it takes time. Recently, I've gotten back into painting with my grandma. My most accomplished work that I have done, which I have posted online right now...I am happy with how it turned out! I am looking forward to actually working with her again, to learn more from her, and get to the point where I will at least do it as a pastime. I will find the time and use that skill to continue learning from my mistakes and pass those lessons I have learned from her on to someone else. That's the one thing that I am proud of, my creativity. The one trait that I can take away from Aspergers is that my creativity gives up so many ideas. It's scatter brained but that's what I like about it, I jump from one idea to the next. It keeps my mind busy. I just love creation. The joy of creation. It's like one of the things we inherited from god. As his children we inherited his love and likeness, why not his creativity? That is one of my better characteristics. My creativity.

**Blaine:** I have a couple of things. There is one thing I would like to fix in terms of being more proud of and doing more of... that is going back to my writing, I've decided. I haven't done that in a while. I am proud of the fact that I managed to go back to college and I managed to get a degree. I am convinced, even more so now, that I can go back to school and finally get my Bachelor's. I would like to finish that one out. I'm proud of the fact that I have managed to make it to age 40 without totally screwing everything up (laughs). I'm proud of the fact that I have such good

continued on page 26

## So Many Strange Shapes in a Sea

by Steven Anthony George

a solitary journey sets sail from schooling to working to being.

There are so many strange shapes in a sea In the puzzling hallways and mystifying offices With smiling counselors who expect me to know now What is best for myself, when I was not aware Only a year ago, nor even yesterday. In an ocean of words and guffaws The campus is vastness on vastness. The buildings are a labyrinth. The students are noisy and they have their noisy friends. What is new is a monster And what is different is a storm. Yesterday there was the warmth of familiarity, Which took so long to form. A warm blanket, Difficult, but secure. I want to crawl back to when there was a firm hand to help at every shore. But now it is too hot and too cold, and alone. No mother to cling to, to rely upon My head is my own to keep above the water Or to sink and drown, to make grades, to write papers, to understand that I must be in the correct room at the right time.

And then there is again, the taunting,

Name-calling by coworkers, though not in the open,

They gossip and whisper, but do not care

That it takes too long to get accustomed,

To understand the processes

And again there is no mother to guide me.

They think that I am too smart, because I speak

Often and in detail like the IBM Watson.

They think that I am too stupid, because I fail

To follow simple directions like a new trainee

Though I was hired a year ago.

The scent of cleaning chemicals
That they use is sickening but I cannot leave
or else I lose my job.
Maybe he is just defiant, they say.
Maybe he is lazy.
Why does he make excuses to get out of work?
He talks too much. He thinks he is the boss.
Why does he not talk to anyone?
He does not trust.
He must be a spy.

And then further complications arise as I travel the sea-road, But there are shores I must sail to and anchors I cannot drop, And there is no longer a captain to lead me, Or none that comes Without the great embarrassment of appearing weakened and helpless. So I complete journeys without others, Though dinner out with mates would be nice, but they do not drift even near me. No dinner parties, no birthdays No weddings, but the phone still rings and there are unexpected knocks on the door-They do not understand that those are not wanted. That there is cleaning, but the clothes pile up. There are appointments and meetings, disturbing and confusing. There are bills to pay, but which first, and when?

> there is no realization from anyone that there is anything wrong I seem to be doing okay, so I am okay.

#### At the Corner of Jimmy and Blaine continued from page 23

people in my life. I am happy and proud of the fact that I have Jimmy in my life, because with him around, a lot of the times I am reminded of myself.

**WVATC:** Imagine a young man or woman in high school about to graduate next spring is reading this and they are thinking they would like to meet friends and make new friends. What is something you could tell that young person to help them make that happen?

**Blaine:** You find friends in the places where you find the most commonality. I would say what you do to build relationships is to look for the things you feel most strongly about and what you think you can build on with other people. I think that's the most important thing.

**Jimmy:** Socializing is by far the most important to try to accomplish. There have been times, there have been clubs and social gatherings going on in college that I wanted to join but I was just so nervous. I chickened out at the last second. If you are interested in a group don't make the mistake I did. Just try. Just try. Even if you are just sitting there listening just try to be part of that group. Possibly make some small talk and maybe, eventually if you feel confident enough, go back there again and try to talk a little bit more. Build up that connection with people. In the end, you are eventually going to have someone that's going to stick around with you that you can

lean on. I know it is a cliché to say that but really just having someone around to help be that support is definitely going to be a big factor in the long run of your life. It doesn't matter what your job you get, what your relationship is, as long as you have someone who is trusting and loyal to you that is all you really need.

**WVATC:** : In closing, let's say we had this magical power tonight where we could teleport the leaders from all of the agencies in our state that create supports for adults with autism here...what is one thing you would beg and plead for to make your life better?

**Jimmy:** One of the bigger problems, like I said, is the job aspect. Trying to find that career that you really really want. I'm not trying to sound like someone who gets everything they want because they feel entitled to it...but good grief! Could you kindly make some exceptions to the jobs that we really want and dream of? For example, I have grown up with Legos® for the longest time and I have been working with Technic pieces making my own figures, my own stories behind them, and I feel like what if I went to Lego® and actually gave them some of these ideas? Be like a counselor of ideas with story boards! However, what do you need? An Engineering Degree. I took one year of college, people! Guess how far away that dream looks! What I'm saying is, could you kindly just give us some assistance or



exceptions for some of us that might not be able to get through the education system but are still more than talented enough to fit your job? That's what I want. That's what some of us need. Help the guy that is looking and wants that job, who wants that lifestyle, to have that future. Give them the assistance because they can't do it by themselves. They need help.

Blaine: When you become a support structure in someone's life, regardless of what your relationship is, they may not always listen and sometimes you have to push a little. At the same time, it is one of those balancing acts in life where you have a relationship with a person and there are certain things you can help them with and that's when you should do it. Then, when you don't think you can help them or they don't want your help you don't need to give it. I just think that's one of the things that needed to be said.

**WVATC:** We can't thank you guys enough...this was awesome.

#### Transitions to Adulthood and Self-Sufficiency continued from page 21



Unless we are at severely disabled, there is usually no assistance available with basic living. I don't know what resources are available to me or how to access them if there are - and I work in human services. Once we are out on our own, we are indeed on our own. Services for autistic children and their parents are everywhere, and as well as for those who are greatly debilitated by their disorder. For the rest of us, depression, loneliness, and crippling anxiety will very often result in hospitalizations, substance abuse, and in the worst cases, suicide - all of which could be avoided with services that follow autistic teens to adulthood so that they could transition not only from childhood to adulthood, but from adulthood to selfsufficiency as well. That is something that must exist because of our disability. Society cannot merely assume that at a certain age we learn and fully outgrow that disability, because that simply does not happen.

### Autism State Update

## **EXAUTISM SOCIETY**



Dr. Brenda Smith Miles presents to a full house at the ASA-WV Conference

A standing ovation from audience members concluded the West Virginia Autism Society Conference for "Supporting Individuals with ASD: A Day with Dr. Brenda Smith Myles," held at the Bridgeport Conference Center, in Bridgeport, on Saturday, September 24, 2016.

"Everyone has something to contribute," explained Dr. Myles, the guest speaker. "The potential of individuals with autism is limitless. To help them, we need to think differently. We need multiple ways to reach our goals."

Dr. Myles' presentation centered around behavior interventions and simple strategies for learners with Autism Spectrum Disorder. She covered the anatomy of meltdowns, and ways to teach problemsolving, time strategies, a balanced agenda, structured flexibility, predictability, and provided a practical IEP template.

"These are strategies that allow our kids to be successful," Dr. Myles stated. She suggested challenging behavior often occurs because students with Autism Spectrum Disorder (ASD) don't have the skills to problem solve, recognize their feelings, and calm themselves.

Over 95 participants from 23 West Virginia counties attended the conference. Parents, educators, autism mentors, aides, and therapists supporting individuals with ASD were given tools to work with that included the latest research information, useful resources, practical applications, and a mix of examples including videos and other media usable in supporting ASD individuals.

Dr. Myles has made over 1,000 presentations world-wide and written more than 250 articles and books on autism spectrum disorders, including Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns (with Southwick), and Asperger Syndrome and Adolescence: Practical Solutions for School Success (with Adreon), the winner of the Autism Society of America's Outstanding Literary Work.

Dr. Myles is a consultant with the Ohio Center for Autism and Low Incidence (OCALI) and the Ziggurat Group. She is also the recipient of the Autism Society of America's Outstanding Professional Award and the Princeton Fellowship Award, as well as numerous other honors.

In her current role with OCALI, Dr. Myles works to develop new programs and identify policies to ensure people with autism meet their potential. She works to identify current and future trends and necessary resources. As part of her trip to West Virginia, prior to the conference, she made a stop at the West Virginia Autism Training Center, located at Marshall University in Huntington, West Virginia, to learn about the center's College Program for Students with ASD.

"Ohio does not yet have a program similar to Marshall's. The Marshall program is amazing. It's the missing link. It provides a real college experience with same age mentors, developing relationships and giving guidance. I was surprised how comprehensive the program is," she said. "Programs like this across the country have the potential to change the landscape of employment and independent living for individuals with ASD."



Dr. Brenda Smith Miles and WV ATC Advisory Board member Dr. Vijay Shah at the conslusion of the annual state conference.

### West Virginia Team Autism Update



West Virginia Team Autism was formed in 2007 in an effort to build and maintain a statewide collaborative network to fully and appropriately support West Virginians with autism spectrum disorders (ASDs) and their families. Realizing the importance of bringing together parents and professionals to strengthen services across the state, the team committed to meeting quarterly to engage in a variety of activities. Those activities include 1) updates on existing and new services available 2) identifying

gaps in services and 3) working together in groups targeting specific activities that address needs. One of the great advantages of the team is the opportunity it creates for members to become informed about what services each agency or group offers. The tendency to work in "silos" when providing supports to families and people with ASDs is often a reality. WV Team Autism aims to work together to develop a seamless system of services across the state. Members include representatives from West Virginia Birth to Three, the WV State Department of Education – Office of Special Programs, Regional Education Service Agencies, The WV Autism Training Center at Marshall University, The West Virginia University Center for Excellence and Disabilities and their Intensive Autism Service Clinic, the Mountaineer Autism Project, Bright Futures Learning Services, Autism Society of West Virginia affiliate chapter in the Northern Panhandle, and family members.

Most Recent Efforts: The group most recently updated the West Virginia Guide to Accessing ASD Services. This comprehensive, free resource booklet can be found online at the WV ATC website, www.marshall.edu/atc under the tab "External Resources."

#### WV PBIS



The West Virginia Department of Education Office of Special Education and the West Virginia Autism Training Center at Marshall University are collaborating with Regional Education Services (RESA) and Local agencies (LEA'S) to implement Positive Behavioral Interventions and Supports. The project is funded through IDEA Part B Discretionary monies from the United States Department of Education's Office of Special Education Programs.

WV PBIS Initiative partners include: The National Technical Assistance on PBIS, Don Kincaid (University of South

Florida), the West Virginia Autism Training Center, West Virginia Regional Education Service Agencies (RESA), County Board of Education personnel, Office of Special Education, Office of Student and Community Support and Office of Accountability and School Effectiveness.

The mission of PBIS is to support school teams via training and technical assistance as they take a proactive systems approach for creating and maintaining a safe and positive school environment. The goal of PBIS is to makes schools effective and efficient and provide equitable learning environments for all students. Decreasing aggressive conduct and bullying can occur through improving culture and climate, building relationships with students and staff, changing academic outcomes and increasing prosocial behaviors.

Most recent efforts include: the development and implementation of a coach training in the northern and southern regions of West Virginia, the launch of the new www.wvpbis.org website, fall PBIS Academies in RESA 4, 5 and 8 have all completed day 1 with days 2 and 3 coming up in October and November, and 33 new school teams registered for the Fall Academy

Peggy Hovatter, PBS Trainer at WV ATC. recently asked friends at a social group meeting for adults to share what their thoughts were when they transitioned from high school to adulthood. Here are their answers...

- 1. Find out jobs that actually make money after college.
- 2. Transition to getting up earlier without parental help.
- 3. Lack of skills..."Everything was done for me before. I had to learn HOW to be independent"
- 5. Not really knowing what I wanted to do.
- 6. Teach life skills in high school (finances, daily responsibilities, etc)
- 7. Mandatory counseling that starts in 10th grade (The comment was also made that they feel the counselors don't want to get involved...??)
- 8. Add counseling to the IEP.
- 9. We are very unique. Interpersonal relationships with people like us have been very
- 10. Society neglects, undervalues or misunderstand who we are.
- 11. Society does not understand what we need. 10 million people and we are an island of our own.

The mission of the Autism Training Center is to provide support to individuals with autism spectrum disorders as they pursue a life of quality. This is done through appropriate education, training and support for professional personnel, family members or quardians and others important in the life of the person with autism.

**WV ATC serves** the entire state of WV.

**WV ATC serves** individuals of all ages.

**WV ATC provides** training in autism for approximately 1500 people annually.

**WV ATC services** are at no cost to registered families.

**WV ATC provides Autism Mentor** training for paraprofessionals working in classrooms.

**WV ATC sponsors** The College **Program for Students** with Autism Spectrum Disorder.

**WV ATC** collaborates with the WV Department of Education Office of Special **Programs and** WV Birth to Three.

### WV Association of Positive Behavior Support Network Update



The WV Association of Positive Behavior Support (WVAPBS) Network is a nonprofit organization committed to collaborating statewide to promote the philosophy, core values and evidence-based practices of positive behavior support. Participants represent a wide variety of systems and interests, promoting PBS within their area of expertise. The WV Autism Training Center has been actively involved in the WV APBS Network since its inception in 2003.

During this last year, the WVAPBS Network finalized a PBS Endorsement process for WV professionals across a variety of fields and 14 individuals have become endorsed as Positive Behavior Support Professionals since January 2016. To find out more about the endorsement process, read about the benefits of endorsement to consumers, service

providers and service systems, and download an application, please go to the WVAPBS website at http://www.wvapbs.com/index.html. You will also find a Registry of Endorsed Professionals with each person's contact information and the counties in which they serve. This is a valuable resource for consumers who are looking for an endorsed professional in their area. This Registry will grow as more individuals become endorsed throughout the state.

Some other goals that sub-committees of the Network are working on include a number of marketing/informational goals to educate consumers about positive behavior support. Plans are underway to provide PSA's on PBS and a parent Tip Sheet about What is PBS?

The Training committee is working on increasing the number of training/professional development workshops offered around PBS.

Efforts are also underway to expand involvement with the Network through increased access to monthly leadership and committee meetings by identifying a more reliable and accessible conference call platform. The National Association for Positive Behavior Support has offered assistance in finding a platform that will serve the WV APBS Network's needs. The WV APBS Network encourages interested persons to attend our monthly Leadership Team meetings held at MUGC in Charleston or volunteer to serve on a committee. Information about meeting times and dates may be found on our website (listed above) and our Facebook page: https://www.facebook.com/WVAPBS.

Gloria Sage WV APBS Network Leadership Team





Autism is a disorder of the brain. Symptoms of autism occur during the first three years of life, although an individual might not receive a diagnosis until much later. Individuals with autism have problems with communication and socializing with others. In young children, autism affects the development of "typical" play behaviors. Autism is considered a developmental disorder in that some normal developmental milestones, such as when a child says their first words, are absent or abnormal. Autism is considered a pervasive developmental disorder in that these developmental differences affect many aspects of life and may last throughout a person's lifetime. Currently, there is no one specifically known cause of autism and no one treatment. Early special education programs using behavioral methods have proven to be the most helpful treatment for persons with autism.

#### A person with ASD might:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

#### **Examples of social issues related to ASD:**

- Does not respond to name by 12 months of age
- Avoids eye-contact
- · Prefers to play alone
- Does not share interests with others
- · Only interacts to achieve a desired goal
- Has flat or inappropriate facial expressions
- Does not understand personal space boundaries
- Avoids or resists physical contact
- Is not comforted by others during distress
- Has trouble understanding other people's feelings or talking about own feelings

For more information on autism, please also visit: www.marshall.edu/atc

## **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.

## GIVE NOW!

Donations to support the Autism Training Center can be made on-line at: www.marshall.edu/atc





www.marshall.edu

The West Virginia Autism Training Center One John Marshall Drive Huntington, WV 25755

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