Fall 2015

The West Virginia Autism Training Center @ Marshall University Magazine, Fall 2015

West Virginia Autism Training Center

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The West Virginia AUTISM Training Center
@ Marshall University

FALL 2015 ISSUE

Siblings
Growing Up with Autism
Sib Shop
Sibling Stress
Goodwill Graduation
Project AWARE

in this issue

Greetings

Trainings, Events, and News

Strengthening Supports

A Life of Quality

Creative Community

Autism State Updates

The West Virginia
Autism Training Center
at Marshall University

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

WVATC
@ Marshall University

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Greetings

From the Executive Director

Greetings, from the West Virginia Autism Training Center!

The WV ATC's mission – "to support individuals with ASD as they pursue a life of quality" – could not be carried out in full without focusing some aspect of our work on assisting individuals to develop and maintain *relationships*. In general, our lives are better when we feel connected to other people. Regardless of ability, an important part of the human experience is an expression to others that we care deeply about them, and to know that others care deeply about us. Relationships are integral to enhancing life quality for everyone.

Many of us have no greater – or longer – relationship than that which we develop with our siblings.

For the fall issue, editors of the WV ATC Magazine explored the theme of sibling relationships for individuals diagnosed with ASD. Luke Walker writes about sibling stress, and provides tips and resources that may be helpful to neurotypical siblings as they interact with brothers or sisters on the spectrum. Amy Kelly introduces us to the Sib Shop carried out each year at Camp Gizmo. Readers of this issue will be introduced to books and DVDs that discuss sibling relationships, which at times may be strengthened or complicated by ASD.

The manner in which sibling relationships can deeply influence life quality is illustrated by Cayton Carder's poignant essay "Growing up with Autism," and an interview editor Andrew Nelson conducted with siblings Amy and Brian Goodman. Professionals in the autism community often concentrate on enhancing life quality for individuals living with autism spectrum disorders; both articles, however, suggest that life quality for neurotypical siblings may be greatly enhanced by the relationship they develop with their siblings diagnosed with ASD.

Family and *community* are important themes at the WV ATC. That's why this issue also introduces readers to WV ATC staff, celebrates important milestones for West Virginians living with ASD, and provides you with the goings-on of state, regional, and local support and information groups.

We are, after all, a part of one large family.

Marc Ellison, Ed.D.
Executive Director
The WV Autism Training Center

Editor's Note:

Dear Readers and Friends,

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.

We are currently gathering content for our spring 2016 issue on the "history and future of autism services and supports in West Virginia." If you or someone you know has content such as interviews, photographs, stories, news articles etc. that you feel may be historically important and tell a story about the development of autism awareness or services in our state, please contact me at the above email address. We would love to hear about those artifacts.

Thank you for reading and please keep in touch.

Andrew Nelson

ASD Specific Trainings in West Virginia

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.

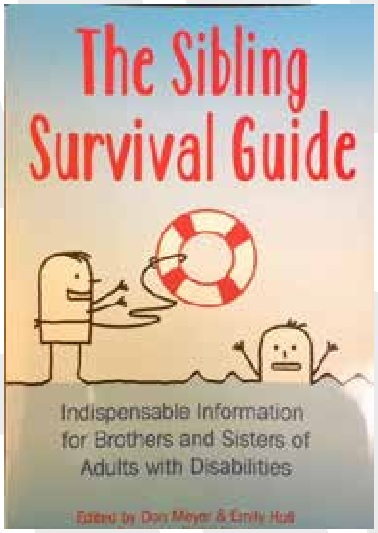
Berkeley County Transition Workshop 2015
When: Saturday, November 7, 2015 from 9:00 a.m. to Noon
Doors open at 8:30 a.m.
Where: James Rumsey Technical Institute
3274 Hedgesville Rd.
Martinsburg, WV 25403
Cost: The event is FREE. Continental breakfast will be provided.

Make & Take Series: Social Story Time
When: Tuesday, November 17, 6:30pm – 8:30pm
Where: First State Bank, 3754 Teays Valley Road
Hurricane, WV 25526, United States
Register here - http://www.marshall.edu/atc/make-take-series/
Open to the public - No fee

Preparing for Holidays and Gatherings
When: Tuesday, December 15, 6:00pm – 7:30pm
Where: Bank of Romney, 95 E Main St.
Romney, WV
Register by calling 304-698-4332 or emailing nelsona@marshall.edu
Open to the public - No fee

News from the
Autism Training Center Lending Library

IN OUR LIBRARY



The Sibling Survival Guide (2014),
edited by Don Meyer and Emily Holl

Meyer and Holl's Sibling Survival Guide, subtitled *Indispensable Information for Brothers and Sisters of Adults with Disabilities* provides just that – comprehensive information and practical advice for those who grow up in the culture of disability. The editors present lifespan advice designed to enhance the life quality of siblings as well as the life quality of their brothers or sisters who live with developmental disabilities. Check out The Sibling Survival Guide by contacting librarian Whitney Lawson at lawson81@marshall.edu, or by calling 304-696-2332

UPCOMING NATIONAL CONFERENCES

THE 13TH INTERNATIONAL CONFERENCE ON POSITIVE BEHAVIOR SUPPORT
San Francisco, California, March 23-26, 2016
The Expanding World of PBS: Science, Values & Vision
https://new.apbs.org/conference

NATIONAL AUTISM CONFERENCE
November 5-8, 2015 | St. Pete Beach, FL
http://nac.nationalautismassociation.org/

THE MATTHEW REARDON CENTER FOR AUTISM CONFERENCE
Thursday, February 11, 2016 at 7:30 AM - Friday, February 12, 2016 at 4:00 PM (EST)
Savannah, GA
https://www.facebook.com/2016autismconference

ASSOCIATION FOR BEHAVIOR ANALYSIS INTERNATIONAL
10th Annual Autism Conference: Translating Research Into Evidence-Based Practice
January 18-20, 2016
Hyatt Regency New Orleans; New Orleans, LA
https://www.abainternational.org/events/autism-2016.aspx

Meet the Autism Training Center Staff:
Cam Pulliam, Positive Behavior Support Trainer

Cam Pulliam

How long have you been an employee at WV ATC: Since August of 2008; working on my 8th year!

How did you first become interested in supporting individuals with ASD or working for the WV ATC: Well, I have always been interested in working with children who have special needs, including but not limited to ASD. As an Interim Service Coordinator and then Regional Coordinator for WV Birth-to-Three Services I had the opportunity to be part of teams for children living with a wide range of medical disorders and/or developmental challenges. I longed for more hands-on work with these children but my position, although very rewarding and challenging, did not afford me that opportunity. One day, however, an unexpected meeting occurred in which we were informed several positions were being eliminated due to financial concerns. That door closed and during my search for a new and equitable challenge I came across the West Virginia Autism Training Center's notice of positions available. I took the plunge and applied. To my surprise and excitement I was contacted for an interview and was offered the position as Positive Behavior Support Trainer. A new door had opened!

What are your interests/passions regarding supporting people with ASD: Wow, that may be difficult to express… First off, I just love the ability to work hands-on with the children, teens, or adults living with ASD and their families. There is something so fulfilling about being party to positive change and growth especially for those who may have felt hopeless or unsupported. I have always been drawn towards working within the early intervention realm and after completing my bachelor's degree at Carolina Wesleyan I knew that would be my focus. And as each year passes I have become even more emphatic about the need for early diagnosis and intervention across environments using data-proven models such as Positive Behavior Support. I've witnessed the changes; improved ability to cope, academic skill development, the elimination of behaviors of concern, increased comfort levels in various environments, and understanding safe boundaries just to mention a few. Most importantly an over-all improvement in the life quality of individuals with ASD and their family. So rewarding!

What are a few things that you like most about working for the WV ATC: One aspect that I really enjoy is the opportunity to travel to so many different communities in the southern part of the state. As anyone who lives here will tell you, it is truly adventure driving… a real experience. And the center affords me the flexibility to set a schedule for meetings with families, school staff, etc. that accommodates their needs and busy schedules. Finally, I feel that one of the most beneficial advantages to working for the WV ATC is something that I experience at least once a day: I learn something new about the individuals that we serve. A creative variation of a strategy, a beneficial resource, a professional that offers a new perspective and insight, training opportunities that support our staff in maintaining our edge on advances in the field. For all of these reasons and more I enjoy this work.

Any future trainings, workshops, groups or initiatives in the works: Since I began working with the WV ATC over 7 years ago, one of my personal goals has been to do as much as time allows in order to share whatever I can with county community partners, schools, support groups, and families who express a need for knowledge, resources, and general support for those diagnosed with autism. In addition, to make others aware of all of the beneficial services offered through ATC by staff who live and work in many locations through-out the state. There are several trainings coming up. Please check the Training Calendar on our website to see which one is near you.

Project AWARE

In October 2014, the West Virginia Department of Education, Office of Special Programs in partnership with the WV Autism Training Center at Marshall University was awarded a $9.7 million dollar Substance Abuse and Mental Health Services Administration's (SAMHSA) grant to focus on mental health needs of children, families and communities through the public school system over the next 5 years. The "Now Is The Time" Project AWARE Grant is an outcome of the President of the United States' plan to protect children and communities. WV Project AWARE will 1) Address the mental health needs of children, youth, families and caregivers and 2) Assist communities with the implementation of Mental Health First Aid (MHFA) and Youth Mental Health First Aid programs. To date, WV Project AWARE has trained 316 school personnel and cross system community members in Youth MHFA. The Project will focus on students in PreK through grade 12, ages 3 to 21 years, in West Virginia schools and three Local Education Agencies; Berkeley, McDowell and Wood serve as the demonstration sites to guide the development of a statewide sustainable systems' approach to improve mental health services. WV Project AWARE will build and expand the capacity of schools to increase awareness of the mental health issues of school-aged youth, provide training for school personnel and other adults who interact with school-aged youth to detect and respond to mental health issues, and connect children, youth and families who may have behavioral health issues with appropriate services. This project promotes school-community partnerships to connect families to mental health services and

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Sibling Stress

by Luke Walker, Positive Behavior Support Trainer, WV Autism Training Center

The effects felt within a family when a child has been diagnosed with an Autism Spectrum Disorder (ASD) can be both challenging and strengthening but it will impact the whole family. A significant aspect of the family that is often overlooked is the effects on siblings to the child with autism. A study from 2010 found that siblings of individuals with ASD's displayed signs of developing hyperactivity, and supported the notion that "mothers of young autistic children experience more depression and stress than mothers of typically developing children." (Barlow, 2010). Previous studies have had mixed findings but many suggest that siblings also experience symptoms similar to ASD such as difficulties with social interactions, communication, and behavior. Furthermore, around 30 percent of siblings of children diagnosed with ASD have some associated difficulties in behavior, learning, or development.

One previous study looked specifically at sibling's depression, social adjustment and the level of child care and domestic responsibility, for siblings for young boys with autism. They reported a significantly higher rating of depression compared to siblings of children without autism, but not a difference with social adjustment. (Gold, 1993).

Siblings of children with a disability such as ASD have also been found to have higher rates of behavioral and functional problems. The findings of a recent study showed that the siblings of children who had a disability were more likely to have difficulty with interpersonal relationships, functioning at school, use of leisure time, and other problems. Sixteen percent to 24.2 percent of siblings of children with a disability were classified as having "significant functional impairment" compared to around 10 percent in siblings of typically developing children. (Seltzer, Orsmond, Esbensen, 2009) Other research has been less conclusive and also highlights the fact that some siblings of individuals with ASD are satisfied with their relationship and show admiration for their sibling. This study found that adolescents and adults with ASD in larger families and who had fewer behavior problems had better sibling relationships. Adult siblings who had greater support from their parents had a more positive relationship with a brother or sister with an ASD diagnosis. (Goudie, Havercamp, Jamieson, Sehr, 2013)

The Role of Parents

Parental attention can also play a factor in the amount of stress for a sibling. Some parents have less time and resources to dedicate to a sibling as typically most of their attention is focused on raising the child living with ASD. It can be a struggle to balance the needs of the child with autism versus the needs of the family and other children.

Types of Stress on Neurotypical Siblings

Family life for siblings of children with ASD can be potentially stressful. The Autism Society of America describes the types of stress commonly faced by siblings:

- Jealousy over the time parents spend with the diagnosed sibling
- Embarrassment over any public displays of behavior and routines that make the family stand out from typical peers
- Frustration over social interaction difficulties with the sibling diagnosed with ASD
- Stressed about being the target of aggressive behavior
- Worry about parents being stressed
- May feel a need to overcompensate and overachieve in order to please parents and get more attention
- Fear of serving a future caregiver role to sibling with ASD

Positive Influence of ASD on Siblings

A large number of siblings of children with ASD have also exhibited the following positive characteristics: (from autism.lovetoknow.com)

- Admiration for sibling with autism
- Proud to help diagnosed sibling
- According to a Time.com article, "Autistic Kids: The Sibling Problem", a significant number of siblings of people with ASD go into autism support service careers.

The Needs of Siblings

The Autism Society of America provides an excellent PDF guide for parents to outline the needs of siblings. (See link in reference section that follows.)

Some examples of the needs of siblings include:

- Siblings need communication that is open, honest, developmentally appropriate, and ongoing.
- Siblings need developmentally appropriate and ongoing information about their siblings diagnosed with ASD
- Siblings need to learn interaction skills with their brother or sister with ASD

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Sibling Stress *continued from page 8*

Siblings need time to work through their feelings with patience, understanding, and guidance from their parent(s) and/or a professional, if appropriate

The WVATC Sibling Program

With these needs in mind, the WV ATC has designed a program to support siblings which addresses needs and provides information to the sibling. The program highlights the sibling's goals and dreams using an individualized approach that can involve further education about autism, how to interact with their siblings, increase time and attention from parents or provide an opportunity to discuss their feelings.

Contact the West Virginia Autism Training Center to find out more information about supporting siblings.

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Sib Shop-Where Nothing is for Sale!

by Amy Kelly, SchoolWide PBIS Coordinator, WV Autism Training Center

Camp Gizmo is a five-day hands-on camp where parents, professionals, and students learn how assistive technology can help young children (birth - 8 years) with significant and multiple developmental needs. The camp experience is based on the individual needs of the family and child. Gizmo offers multiple opportunities to receive evaluations, review possible adaptations or updates to current equipment, participate in new activities and experiences that may not be possible in their typical lives, time to network with other families that are facing similar situations and much more.

Unique to this camp is the focus on the whole family, not just the child with special needs. One example of how this is applied within the camp is "Sib Shop." Sib Shop was created by an individual who has a sibling with special needs. The idea is to offer typical developing siblings an opportunity to talk about their siblings and how they feel about their disabilities in a safe and nonjudgmental environment.

Jenny DeStefano has been the coordinator of Sib Shop for the past 10 years. Each year Sib Shop has around 5-7 kids that participate. They do activities such as crafts, take a tour of the campus, visit the *Make and Take* lab while all the time having focused conversations. When I asked Jenny about the types of conversations that take place she replied *"Everything that is said about feelings, worries or concerns of each participant in Sib-Shop is kept confidential. When parents have questions, I keep my answers honest but also maintain the confidentiality*

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Sib Shop *continued from page 9*

Pictured above from left to right Jenny DeStefano (coordinator of Sib Shop), Cameron Thomas, Devlin Daugherty, Dennis (Ethan) Thomas, Madeline Osburn, Lauren Rasberry and Megan Moreno (assistant)

promised to the kids. If they ask how their kids did I may reply with "they did fine."

Cameron is a 10 year boy whose brother has Cerebral Palsy with seizures, aspirations, hip dysplasia and microcephaly. When I asked him how Sib Shop went he replied "Pretty good, we did crafts and I like it." He attend last year as well, "I went last year before this year and I thought it was a shop where I could buy stuff but once I was there we talked about our sibs, their weaknesses and strengths stuff like that". I asked if he was planning on coming back next year and he said "I am definitely going back next year even if Jenny is not going to be there."

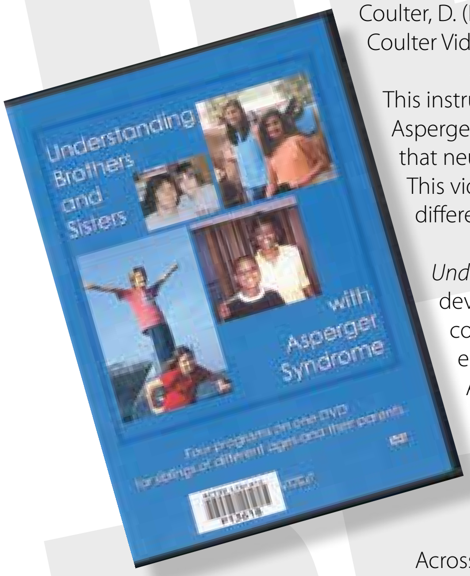
While Jenny has been part of Camp Gizmo as a focus family and then as the coordinator of Sib Shop for many years, she is taking a different direction in her career and will no longer be able to attend camp. She hopes Sib Shop will continue to grow and offer the typical developing siblings an opportunity to meet with other kids that have a sib with special needs. "The kids have a chance to meet other kids that are facing some of the same issues having a sibling with special needs. The kids have a lot in common and a lot to share with one another. They need to have a safe place to be able to talk about how they feel."

"Sib Shop is only one of the many labs at Camp Gizmo. Families can easily become overwhelmed with all that is offered and lose focus of why they are here. As a camp leader my role is to support the family with coordinating their labs, evaluations, meetings and everyday needs, to answer questions and offer a lending hand if needed. My main focus, is of course the assigned families but I take full advantage of talking with other professionals, team leaders and other families that come from all areas of West Virginia. I have had the pleasure of attending camp as a team leader since 2012 and will continue to do so as long as they will accept me. While the past years have been a wonderful experience I must say "this was the best camp ever".

***Camp Gizmo is held in the month of July** at the West Virginia School for the Deaf and Blind. It is funded by the WV Department of Ed/Office of Special Programs, WVDHHR/Bureau for Public Health/Office of Maternal, Child and Family Health/ WV Birth to Three, and WVDHHR/Bureau for Children and Families/Division of Early Care and Education and in-kind support is provided by WVATS, WVU Center of Excellence in Disabilities, National Seating and Mobility, Assistive Technology Works, Inc. and Appalachian Center for Independent Living. Support and coordination provided by WV Early Childhood Training Connections and Resources.*

Understanding Brothers and Sisters with Asperger Syndrome: a DVD Review

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



Coulter, D. (Director). (2007). *Understanding Brothers and Sisters with Asperger Syndrome* [DVD]. United States: Coulter Video.

This instructive video was developed as a resource for siblings and parents of individuals diagnosed with Asperger's Syndrome (i.e., identified by the DSM-V as Autism Spectrum Disorder Level 1). Research supports that neurotypical siblings of individuals with disabilities are typically more mature, patient, and independent. This video emphasizes the importance of celebrating the strengths and understanding the unique differences of siblings with ASD in child-friendly language.

Understanding Brothers and Sisters with Asperger Syndrome includes four separate segments for varied developmental age levels. For children ranging from approximately ages 4 to 7, the program includes colorful, friendly puppets discussing Asperger Syndrome. The pre-teen program (i.e., ages 7 to 12) entails interviews of real-life siblings discussing unique facets of having a brother or sister with an Autism Spectrum Disorder. Similarly, the program for ages 12 to adult includes commentary from a narrator, coupled with sibling interviews. Finally, the parent segment includes interviews of "real-life" mothers and fathers of individuals with ASD. This program provides parents with pertinent information on meeting the needs of neurotypical siblings, while ensuring that their child with ASD receives the appropriate attention and care.

Across each developmentally appropriate program, the narrators and siblings interviewed exhibit precocious levels of insight and maturity. However, some of the segments are slightly dated, and the video may overall be more appropriate for primary-age children. Overall, this video is an impeccable resource to foster awareness of Asperger's Syndrome and reduce feelings of isolation in siblings of individuals with ASD.

WV ATC FACTS

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 guardians 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.

NCWV Parent Support Group

by Danelle Conaway

Seeing a Need:

South Ridge Church is a non-denominational Christian community founded in 2005. Though we have had many children with special needs come through our doors over the years, we had never ventured into forming a special needs ministry. That all changed in the summer of 2014 when we received an email from Andrea, a single mom of a 7-year old daughter profoundly affected by ASD. Andrea was looking for a place to worship where her daughter, Mae, would be welcomed, cared for and accepted. It had been over 5 years since this family had been part of a church community.

Creating a Plan:

We felt this was the time to begin the process of creating a special needs ministry. We agree with Amy Fenton Lee (2013) when she writes in *Leading a Special Needs Ministry*, "It is the Church's responsibility to thoughtfully, intentionally, and respectfully engage everyone-because God loves them all." (p. 40). After many conversations with Andrea, we decided to hold a meeting with her and anyone else interested in forming a special needs ministry for children.

Several women from our church attended who had personal experience with children who had special needs, some of us with special needs children ourselves. We decided to move forward with a two-front plan. We would begin creating a special needs buddy program during our services, but we would also create a support group for parents of children with special needs and for any parent who needed encouragement, community and resources. We called this group "Parenting Outside the Box".

Tapping our Resources:

Our first meeting in the fall of 2014 of the Parenting Outside the Box support group was only minimally attended, but it was a great time of sharing and we quickly realized the huge need for supportive community for parents, but especially for parents with special needs children. Not long after, we were contacted by the West Virginia Autism Training Center at Marshall University about our group and how we might partner with them to reach more families. After some planning, what followed was a supportive partnership and a relaunch of our group in the winter of 2015 under the new name of the North Central West Virginia (NCWV) Parent Support Group.

In December of 2014, Andrea brought Mae to our Family Ministry area for the first time. Mae has been with us nearly every Sunday since. We have been able to put together a team of 4 buddies who are experienced with children with special needs. These buddies spend the morning with Mae the same Sunday each month and provide Andrea her own time to build relationships with other adults, enjoy worship and be spiritually fed while our buddies engage in play, worship and fun with Mae.

Navigating the Journey:

Creating a special needs ministry has not been easy to say the least, but we are so grateful for Andrea and Mae and all that they have brought to our lives and to our church. We have learned so much about autism, inclusion, special needs and supporting families through our special needs buddy program. The West Virginia Autism Training Center has been a critical resource to us as we navigated the journey of a special needs ministry over the past several months. We are looking forward to expanding our program to better meet the needs of other families of special needs children and to better support those in the community looking for a place where their child can belong.

Creating a Welcoming Community Environment:

The NCWV Parent Support Group has had several meetings this past Spring that included topics such as parental self-care, how to empower siblings of children with special needs, community resources, healthy eating and essential oils. We have also been fortunate to partner with several community agencies as we work on expanding our group and being able to serve even more families in our area. The NCWV Parent Support Group is not a faith-based group. It is strictly a community support group where we have light refreshments, engage in fun conversation and games, have educational time but also time for sharing, exchange of ideas and support. We meet the 2nd Monday of each month and will kick off September 14th with the West Virginia Parent Training and Information non-profit organization as they help us understand and prepare for Individualized Education Programs (IEPs) and 504 plans. All are welcome, and child care is available upon request. The NCWV Parent Group meets the second Monday of each month at 1659 Fairmont Avenue, Fairmont, WV and can be found on Facebook by searching for NCWV Parent Support Group.

A Life of Quality
Growing up with Autism

by Cayton Carder

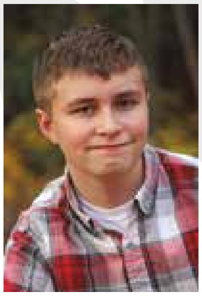
Growing up with a sibling on the autism spectrum is all I have ever known. My brother, Ben, was diagnosed with autism when he was 3 years old. I was age two. Being so young, I didn't understand why there were so many people coming to visit us. There were ABA therapists, Birth to Three staff, and psychologists coming almost daily to work with Ben. Looking back, I now understand why there was such an urgent push to "fix" my brother. He wasn't talking, wasn't making eye contact, and he would line up his toys, always according to size, shape, and color. He needed help and our family was desperate to utilize any means to make that happen.

By the time we started kindergarten together, Ben was talking and making improvements every day. But social interactions were slow to improve. Sometimes other kids would ask me why Ben talked to himself. Sometimes they would laugh and sometimes they would walk away. I had to learn to educate and advocate for my brother, explain autism to our peers, and help Ben to navigate the outside world at this very young age. I would openly explain autism, why Ben sometimes needed space, and a few times, I had to step in and address a few older bullies. As we progressed through school, however, many of our classmates began to understand and help Ben if he was having trouble with an assignment, participating in an activity, or having difficulty with a teacher or another student. It became sort of a team effort, which has continued to today, where we are now freshmen at Preston High School. Ben and I even did our 5th grade social studies project on "Living with Autism" and we made it all the way to the WV state social studies fair where we placed 3rd. Ben would talk about what it feels like to be a person on the autism spectrum and how he tries to deal with things that he sometimes does not know how to handle. During the presentation in front of the state judges, Ben got upset due to the pressure and walked away. I carried on with the presentation and explained *"Ladies and gentlemen, THAT is autism…sometimes he just needs some time to decompress and take a timeout."*

Although embarrassing, it was a perfect opportunity for me to educate those people on "Living with Autism".

Being a sibling of someone on the autism spectrum isn't always easy. But, I have learned to accept and love my brother's quirky sense of humor, his addiction to all things electronic, and his ever-growing collections of many things including Lego masterpieces, paperclips, Ninja Turtle paraphernalia and video games!

Oh, and did I mention that the kid has a killer memory when it comes to Pokémon characters? Let me tell you…he can identify any character EVER imagined in the Pokémon world and knows every tiny factual tidbit about each and every one of them! Sometimes I wish I could have just a tad of that ability for my school exams!



Sure, it's easy to point out how my brother is different… although he looks like a typical teenager and acts like one in many different ways. But my goal in life as a sibling of autism is to focus on the positive and amazing attributes that Ben and many kids like him have and encourage and educate as many people as I can about autism.

Miss West Virginia and Miss West Virginia's Outstanding Teen.

I have competed in pageants since I was 8. It started out as an activity that my mom and I enjoyed so that we could spend time together. As the years progressed, I decided that competing in the Miss America system was the direction that I wanted to pursue. Most recently, I won the title of Miss Discovery Trail's Outstanding Teen and competed at Miss West Virginia/Miss West Virginia's Outstanding Teen this past June in Morgantown. I was the youngest contestant in the entire pageant and placed in the top 8! Unlike some of the other systems, Miss America requires that each contestant promote her "platform". Mine was a no-brainer….of course it would be Autism Awareness! I have lived this "platform" all of my life. In fact, Autism Awareness IS my life.

The Miss America crown has four (4) points. Each point has an underlying meaning: Scholarship, Success, Style, and Service. Not only do I think that the points are wonderful for every pageant queen, but they are also applicable to anyone, even kids on the autism spectrum:

Scholarship- Make goals and stick to them. For me, I would like to go to graduate school and become a biological oceanographer so that I can study the effects of pollution on our waterways. (Yes, pageant queens can also throw on a wetsuit and clomp through the marshy mud!) I also would like to see my brother succeed in school and maybe someday be able to earn a college degree. The kid is a whiz when it comes to video games and computers. Who knows? Maybe he will someday be able to design the next best game? Sometimes he struggles with homework, studying for tests, and paying attention in his classes. It isn't something that comes easy to Ben, but I have found that consistency with study

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habits, several days' notification prior to exams so that he doesn't have to "cram", and modified (shortened) assignments help to alleviate the stresses of his schoolwork. My ***scholarship*** goal for Ben is that nothing is impossible. It may take a little longer, and it may need to take a different path, but we will keep trying.

Success- I work very hard in school to maintain a 4.0 GPA and I strive to succeed in my academics as well as juggle friends and practicing for the next big pageant. But I also work hard to ensure that my Brother will have the skills to someday be successful. We have had many small successes over the years with Ben that many people not familiar with autism might take for granted. My parents were told many years ago that he might never speak. He now talks, jokes, complains about homework, and is forever arguing about getting haircuts. (For some reason, he truly thinks that growing a mullet like Shaggy from Scooby Doo is totally cool, although he currently is not winning the mullet debate). I guess you can say that each success is measured by hard work, dedication, and the importance of each goal, no matter how small or insignificant. My brother is living proof that successes happen every day.

Style- As all pageant girls know, you need to find the right gown. You need to practice your talent (I love musical theater… I have sung "Popular" from the Broadway musical, *Wicked*, and I am currently working on "Roxie" from *Chicago* and I love it!) You also need to sharpen your current events knowledge and of course, practice your interviewing and public speaking skills. I love to shop for bargains and one of my responsibilities is making sure that my brother looks like the typical teenager. (This is where the "Shaggy mullet argument" comes into play…NOT a good look for him!) He has reluctantly agreed to accept my fashion advice for school. I enjoy coordinating his outfits and keep my mom updated on the latest guy fashion trends. He doesn't seem to care now…but maybe someday he will thank me for making sure he goes to school in style.

But the single most important element of the Miss America crown, in my opinion, is **service**.

Service- As I mentioned previously, autism advocacy and autism awareness has been ingrained into my life since I was a baby. I have lived through the meltdowns. I have had to diffuse Ben's frustrations at school and I have had to learn to explain and teach our peers about autism and why Ben sometimes acts differently. Therefore, I have a firsthand perspective on living with autism and I feel as if I have a duty to educate and advocate for all of those living on the spectrum. I have participated in many local "Autism Walks", rallies, and hey, I am now writing this article…ALL to bring much needed public attention to understanding and accepting people with autism. Community service is such an integral part of the Miss WV system and during the last 2 years I have had the opportunity and the pleasure to take my platform, "Until All the Pieces Fit" and present it to schools and classrooms all over North central West Virginia. As we all know by now, the symbol for autism research and awareness is a puzzle piece. That's why I call it, "Until all the pieces fit". I am hopeful that someday, with enough focus on finding the cause, there will be a cure. But until then, it is my responsibility as a sister and advocate to "use my crown as a microphone" and educate as many kids as possible about what it means to be autistic and how to understand and be friends with all kids, regardless of their disability.

I designed my school presentation for elementary and middle school aged kids in the form of a game show. We have contestants, a computerized "game show", buzzers and, of course, PRIZES for the correct answers. I have found that kids are very willing to listen and participate for a small pencil or beach ball! The kids love it! And teachers? Well, let's just say that they love the time I am taking with their students but they are probably glad to see the autism awareness beach balls and mini-footballs go home at the end of the day! Seeing my message getting through to the kids is such a great feeling. I talk about my brother, show them pictures of us together, and tell them about how we are different and how we are the same. Competing in pageants is a lot of fun, but my single most favorite aspect of being a titleholder is having the opportunity to yell my message to the world, "Be nice to everyone, regardless of their abilities or disabilities and if you know a kid at school that needs a little extra help or encouragement, then help them out!"

As the pageant season gears up this fall, I will undoubtedly be brushing up on my singing, speaking skills, and my fitness. But most importantly, I will be heading out to the West Virginia schools in hopes of educating more and more kids to always do the right thing. I want to use my crown and sash to advocate for kids on the autism spectrum, just like my brother, until we find the missing puzzle piece, or "Until All the Pieces Fit".

Cayton is 14 years old and a freshman at Preston High School in Kingwood, WV. If you are interested in learning how to promote Autism Awareness in your school or would like for Cayton to present at your elementary or middle school, please contact Andrew Nelson at the WV Autism Training Center.

Autumn's Goodwill Graduation

by Barbara Hunt, Positive Behavior Support Trainer, WV Autism Training Center

In the summer of 2015 Autumn graduated from the Goodwill Industries Training Center Life Skills program. The summer program includes training in money management, house-keeping, educational planning, transportation, work-readiness and knowledge of community resources.

Autumn excelled in the program and greatly improved her meal preparation skills. She was the main chef for the lunch prepared for the graduation luncheon. Autumn's parents, brother and aunts attended the luncheon as well!

Autumn and her family look forward to continuing involvement in programs at Goodwill Industries. Her brother Darien will participate in the Life Skills program next summer and Autumn will likely participate in the Work Readiness program.

Patience, Love, and the Unintended Consequences: an interview with Brian and Amy Goodman

Brian and Amy Goodman are siblings living in the Harpers Ferry area. Amy was the very first graduate of WV ATC's College Program for Students with Autism Spectrum Disorder and is now the Director of Autism Now at The ARC of the U.S. I caught up with them at Amy and her husband Leonard's new home to talk about growing up as siblings, the recent passing of their parents, and ideas for increasing the quality of life for individuals on the autism spectrum and their siblings.
– Andrew Nelson, Program Coordinator
- Eastern Panhandle Region, WV Autism Training Center


Brian and Amy Goodman

Where did you grow up?

BG: Colorado, for ten years while my father was a professor at Colorado State University. Then he got a National Science Foundation Grant to study science education among Indians so we spent six months in the middle of the Navajo reservation in northern Arizona. As a result of that he got a job running an area health and education center that was headquartered in Window Rock, Arizona, which is the capital of the Navajo Nation. We spent three years there and then moved to Tempe, Arizona so my mother could go back to graduate school at Arizona State.

What did she study?

BG: She was getting her Masters in Community Health Nursing. At some point my father got a job with the National Science Foundation out here (West Virginia) and mom followed. At that point, I was in the Army and Amy was at home.

AG: You forgot one important part, we went to Montana first!

BG: Oh yes, that's right we did some time in Montana as well! That's the best place I have ever lived…the quality of life was so high.

AG: For you!

BG: It was gorgeous. A little university town, what's not to like! *(laughs)*

Amy, you said "for you", it wasn't so good for you?

AG: No. I was in high school and I didn't like it.

BG: Yeah, that was tough.

Were you guys in high school at the same time? Did you see each other in the hallway or anything?

Both: No! No!

AG: We are five years apart.

BG: It was right when I had come out of the service, so that would have been '86. Then we moved to Rockville, I went back to Arizona for a while and then came out here.

When is the first time you remember the word autism entering your life?

AG: Well, after we lived in Rockville, then we moved here to West Virginia in Harpers Ferry, and Brian had met Kent (Moreno) online, through the Grateful Dead so I will let him tell you all about that. *(laughs)*

BG: There is a Grateful Dead forum that Robert Hunter, who is a lyricist, supports/runs/owns. We both (Kent and Brian) posted on this forum. I knew he (Kent) was a behavior analyst and dad had a lot of questions, because he was big into the brain and wanted to know about different behaviors and what caused them. We set up a meeting for lunch and Kent came down for lunch. We went for lunch and Amy went with us and when we got back Kent looked at us and said "do you know what Asperger Syndrome is?" We said no, and he said "it's on the autism spectrum, and I'm not qualified to diagnose but I will tell you I'm 99% sure Amy has Aspergers." Dad immediately started diving in and researching it and click-click-click-click… everything was falling into place, and it started to make sense…things that we didn't understand for a lot of years.

How old were you then Amy?

AG: That was when I was 33. Mom and dad, after they had discussed it, after they looked it up, decided yep, I fit the bill. They told me and then decided to get a diagnosis…maybe about 13 years ago.

Were there any supports for siblings at that time?

BG: None that I ran across, but I was also out doing my own thing.

What was West Virginia like at that time, as far as the state of autism supports and awareness?

BG: I didn't think they were really "up on it" until we ran into the Autism Training Center at Marshall, that was the first time we ran into something that was really good support. And Kent was invaluable in terms of hooking us up there!

AG: He knew that they (WV ATC at Marshall) had started a program for undergraduates and he said "well, why don't you contact them"…Kim Ramsey or whoever was in charge of it. I did and she said it was for undergraduates and I said I was going to go to graduate school and she said to call her back. A couple of months later, I called her back and she said

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to go ahead and get accepted into grad school and then they would let me in the pilot program. I was one of eight. I was the first female, the first graduate student, and the first one to graduate from their program. That was 2004-2006. It was a two year grad program.

Let's go back to growing up. Were you guys pretty tight?

AG: No.

BG: No, I've got another sister and she and I…it was a big sibling rivalry thing but we tended to be closer than, say, Amy and I. We didn't connect that way at that time. Now we know what's going on and understand the "why's" of some things it makes a big difference.

Tell me more about that.

BG: Well, behaviors that you might find odd in a neurotypical person, if you don't have an understanding of it, the first reaction is "what is wrong with you?" As opposed to just looking at it, or coming at it from a different direction, or a different way of arriving at the same place. It's just much easier to deal with once you understand that that is what's going on and that they are going to find their way…the way that works for them! It's not necessarily going to be what you are used to.

Amy, you had two siblings. What is it like growing up with two neurotypical siblings?

AG: Well, there was a time when my sister was like "why don't you get a job, why don't you move out, how come you are not doing what other people do at your age? Now you graduated from college, why aren't you getting out, why aren't you living on your own?" I couldn't explain it.

So there was pressure?

AG: Oh, yeah.

BG: I think we all put pressure on her because of not understanding "what was the driving force here".

How long did it take to wrap your head around it?

AG: Once we knew.

BG: Once we knew it started coming around pretty quick. The attitudes change real quickly from bewilderment or even anger sometimes at why things aren't going the way you think they should to trying to be supportive and finding a way to accomplish what you want to accomplish. I think that makes a big difference. Things still aren't always hunky-dory but we work on it. I work on it. I think Amy works on it too. It's evolving and it continues to evolve.

Amy, if you could look back and give your 30 year old self a piece of advice now that you are where you are, is there anything you would tell yourself?

AG: Just to love yourself for who you are. Because if you can't love yourself, you can't love anybody else and you can't have relationships if you don't know how. So, basically chill out and do what it takes to make relationships work…

BG: I like that!

AG: (continues) and do what it takes to get going on your life.

What are some things you would tell a 14 year old sibling reading or listening to this interview who is scratching their head wondering what it all means? Can each of you give 3-5 things that would go into any "Sibling Survival Guide"?

BG: Patience. Be loving. You've got another person here, they're still a person. They may be different from you but they are still a person.

AG: I would say listen.

BG: Yes, listen for what someone is trying to tell you and not what you want to hear. Which is a good skill to have all the way across the board, of course, but really helps here.

AG: Don't be judgmental. See them for what they are good at.

BG: Yeah support them as best you can in what they are good at. When they are running into problems that are tough to handle, then maybe it is time to step in and lend a hand. Or to support them as they go through whatever trial it is that they are dealing with in their personal life at that point.

Do you think it is the job of a sibling to help peers understand autism? Is it the role of the neurotypical sibling to be a defender?

BG: Yes, if things are getting out of hand I think somebody needs to step in and somebody who is a sibling will be more qualified than most people to make that decision whether or not things have escalated to that point. How you do that is going to vary by the individual, I think, in terms of explaining what the differences are, and that their brain works differently from yours and how to find a way to mesh with that so that things work. And that takes two sides and people need to understand that and that's what your role is. Help them understand that here is a good person if you take the time and effort, and it does take some effort sometimes to break through the shells that have built up because of years of being degraded or put down or treated differently. That extends from school situations often into the adult world that is supposed to be protecting people because "they're the different one" and they don't get it either.

Amy, you are in a new role and job, can you give a quick overview of what you are doing?

AG: I am the director of Autism Now at The ARC of the U.S. and we work with people with intellectual and developmental disabilities. I oversee our website and I answer emails and all of the telephone calls, but I also give good advice and people follow me on Facebook and Twitter.

Amy reminiscing about wedding day

BG: And you're doing webinars and public speaking!

AG: Yes, it's been four years now. I'm on the self-advocate council where I work with lots of people who like to speak up for themselves.

I'd like to honor your mom and dad. Recently, you donated autism related books to the Autism Training Center on their behalf. Can you talk a little bit about that?

BG: They were incredible people. Education has always been a priority in our house and we grew up with books. Lots of them. You need to learn, that's where you start. Let's find something related to this and

Amy remembering mom

start there and work our way around until we have enough information to wrap our minds around it and start making some decisions or coming to some conclusions about what it is we are dealing with.

AG: That's what my dad did when he collected all of those books and all of those articles. He really got into it because I was his…I was his baby, I was his youngest, his good buddy and he just wanted to help me in any way he could…so he did.

Was there anything that you can put your finger on that they did as parents that you will always take with you?

BG: It didn't matter what we did, they never stopped loving us. They didn't always like us, well, speaking for myself anyway, but they never stopped loving us. And they have always been supportive of positive endeavors we've been involved with. That really goes a long way. They'd do anything they could to help us achieve what it was we were trying to achieve.

AG: Yep, they did. That's how I got through grad school.

Thinking about the future, what could be done in our state to make sibling supports stronger?

BG: I think the hardest thing you face is getting the information out to people that this is available to begin with. It is really a matter of getting the word out that this is there, this is where you find it, and making it easy to access.

AG: Especially for people with disabilities. A lot of them don't know.

BG: As a sibling, I wouldn't know that there is a sibling program around here if there was. I think working through the schools is really good. That is probably the easiest way to get information out so that kids recognize that it is going on, and parents can meet, and you can find some people that are dealing with the same things you are, and I can find some people that are dealing with the same things I am. And the sibling with Aspergers might meet someone like they are and realize that they are not alone. (To Amy) You must have felt very alone for a long time.

AG: If I had known in the 1980's it might have been different when I was in junior high or high school.

What is next for you two? What is the next chapter?

BG: I have no clue. I am wrapping up mom's estate. Trying to find some reasonable employment and hoping that a connection I have to a concert production company is going to come through for me because there is nothing I'd rather do.

AG: Actually, I've covered almost everything that I said I wanted to do. From buying a house to getting married. I want to keep my job and work hard to help people with disabilities. I work on a lot more projects now, I'm expanding my horizons and working on different projects at The Arc.

On behalf of our agency and state, thanks for what you both do and for sharing your story.

BG: Well, thank you to Robert Hunter for hooking me up with Kent. I dropped a note on him one time and I said "you really have no idea how much this has impacted my entire family in a positive way, so for every negative thing you see here that makes you want to stop doing this (Grateful Dead forum) please understand that there are unintended consequences. And the unintended consequences are just life changing in a positive way." And his answer was "unintended consequences, indeed…"

Amy and husband Leonard

The Autism Awareness Tree at Eagle Intermediate School

by Tiffani Kaczor

It was very important to us to raise autism awareness at Eagle School Intermediate. Each teacher was given a list of facts as well as links to videos to start the conversation to learn and raise awareness about autism. Some classes went above and beyond and researched their own facts. Each student wrote one fact they learned on a puzzle piece for the growing tree.

Editor's Suggestion:
please send any original art, poetry, photography, creative projects, or interesting community programs to nelsona@marshall.edu for consideration for publication in our magazine!

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.

The WVAPBS Network recently finalized a PBS Endorsement process for WV professionals across a variety of fields. An initial Endorsement Board was established with technical assistance from the state of Virginia and this Board is now accepting applications for an expedited endorsement process. Some of the benefits to consumers, service providers and service systems of PBS endorsement include the following:

- Enables consumers (individuals and family members) to discriminate between professionals who have advanced training/experience in positive behavior support and those who do not.
- PBS Endorsement can be obtained across fields in addition to other training and credentials
- Promotes best practices in Positive Behavior Support
- Provides consumers with the opportunity to select individuals with extensive knowledge to provide validated high quality services
- Builds capacities of skilled professionals and strengthens quality service delivery across service systems.
- Develops a community of committed practitioners who share resources, ideas, support and enhance the quality of service provision.
- Promotes a focus on meaningful outcomes and quality of life improvements for individuals who receive services
- Increases the fidelity of Positive Behavior Support services and supports in consistency in the quality of services by adhering to the APBS standards of practice.
- Provides organizations and agencies avenues for internal staff training and mentoring

WV ATC's Charlotte Hays and Sarah Kunkel are two members of the initial Endorsement Board. Information about the endorsement process and forms are available on the WVAPBS Network blogsite at: http://wvapbs.blogspot.com/

The APBS Network is also making plans for the fourth WV APBS Network conference to be held in 2016. Further details will be provided on the blog and FB page as plans are finalized. The Network is continuing to expand its digital presence through its blog and Facebook page: www.facebook.com/WVAPBS, with assistance from WV ATC's Luke Walker. Plans are underway to provide outreach activities and training for families and individuals about the key concepts of positive behavior support. Stay up to date on the Network's activities and projects and opportunities to get involved by accessing our blog and FaceBook page.

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.

THE WEST VIRGINIA GUIDE TO ACCESSING SERVICES
FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS
Go to www.marshall.edu/atc
and click on "external resources" to access the guide

Most Recent Efforts: (1) Revised WV Team Autism Resource Guide, and made it available on-line:
The revised West Virginia Guide to Accessing Services for Individuals with Autism Spectrum Disorder is now available on line. This guide is a collaborative effort among West Virginia Team Autism Spectrum Disorder (WV Team ASD) member agencies and individuals. Individuals with ASD of all ages, their families and anyone supporting them will find this guide a most valuable resource. It contains information related to services available specific to West Virginia as well as information for families who have just received a diagnosis for their child.

(2) A WV Team Autism Strategic Plan meeting, designed to establish future goals, will be held in early December, 2015

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provide evidence-based programs supporting safe and supportive school and community environments using the Community Schools' framework.

WV Positive Behavior Support in Schools (WV PBIS)
The WV PBIS project is a collaboration between the WVDE Office of Special Programs and the WV ATC. The mission of the project is to support schools via training and technical assistance to implement the critical elements of the PBIS framework. The framework is a data driven, evidence based approach to supporting the social emotional development of students. To date we have trained 52 schools in 29 counties. The futures is bright for the project as interest from schools and other stakeholders continues to

What is Autism?

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

source - www.cdc.gov

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