

**The West Virginia Guide to
Accessing Services for
Individuals with Autism Spectrum Disorders**

**WV Team Autism
2014**

ABOUT WEST VIRGINIA TEAM AUTISM



Autism spectrum disorders (ASDs) are the fastest growing disability in our nation.

Approximately **1 in 88** children have an autism spectrum disorder (CDC, 2008).

Every state in the nation is asking - "how can we best serve these individuals and their families?" It is the belief of many key players in the area of ASDs in the state of West Virginia that the best way to make an impact on services in our state is through the collaboration of existing agencies, systems, and individuals who are dedicated to providing assistance, support and services for those with an autism spectrum disorder. We knew we could make a difference working together. Early on, WV Team Autism identified several critical areas of need in our state:

- 1) providing a system of seamless services for children from 0 to 21,
- 2) providing a continuum of services for adults,
- 3) building effective early intervention programs and
- 4) increasing our capacity for teacher training.

Another critical need identified was the need to help families find the appropriate supports and services they needed as soon after receiving the diagnosis as possible. This booklet is one outcome of the collaborative effort to address this critical need.

SPECIAL THANKS

Special thanks to the WV Team Autism committee that worked on the revisions and updates for this document. Your work serves as a testament to your dedication to WV children, teens, adults and families experiencing Autism Spectrum Disorder.

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ABOUT THIS GUIDE

We are pleased to offer you this booklet about services, resources and information for West Virginians with autism spectrum disorders and their families. The purpose of this booklet is to help you get started acquiring resources available to you and your child and to gain a better understanding of the educational system in West Virginia. West Virginia Team Autism members recognize, through personal and/or professional experience, the challenges facing families as they learn their child has an autism spectrum disorder (ASD). We know it can be overwhelming and frustrating to secure the supports and services your child needs. Our goal is to make sure every parent receives the support and guidance they need and that support and guidance are available right from the beginning.

This booklet is intended to be part of the file you have or will have developed to store information so that you can refer back to it as needed. We have included information that families have found helpful as they enter education and other service systems. You will be provided with specific information related to your individual needs and also be given the names of specific contact people in your area. We hope you find this booklet a useful tool now and for the future.

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Disclaimer: The purpose of this document is to offer helpful suggestions for families of children with autism spectrum disorders as they navigate the service delivery system in West Virginia. It is not the intent of West Virginia Team Autism to recommend any specific service or treatment over any other. This guide aims to provide information on state and other resources and is not intended as a comprehensive guide to all available service providers in all service delivery areas.

Where do I Start?

Whether families have just received a diagnosis of an autism spectrum disorder (ASD) for their child or they have had the diagnosis for several years, there is one thing most families have in common; they are on a journey with different twists and turns, challenges and celebrations. If you are at the beginning of this journey, the amount of information you are receiving is probably overwhelming. It is important to remember that most people cannot absorb everything all at once, nor should they. Every family has different dynamics. Some have multiple children, multiple jobs and may be engaged in a variety of activities outside of the home. Time may be limited. It is OK to access new information related to your child's diagnosis and service options a little at a time. As one parent put it " It's a marathon, not a sprint."

It is also important to know that while individuals with ASDs share some common overall characteristics, each individual is completely different from the next. What is effective for one individual may not work at all for another. Each individual has different strengths, abilities, interests and challenges. If there were one prescription for individuals with ASDs, we would all be using it. As you begin to investigate service options for your child, never hesitate to reach out to professionals and other parents for their input. Ask questions! Establishing positive relationships with others who understand ASDs can make all the difference in the world. But always remember, you are the expert on your child. No one knows your child like you do.

And finally, as you get started on this journey, remember that success IS a journey. There are many tools and resources contained in this guide that we hope will make your journey to success just a little bit easier.

Family Contact Information

Parents/Guardian _____

Child's Name _____ Date of Birth _____

Address _____

Phone – Home _____ Cell _____ Work _____

Email _____

Is your child and family receiving WV Birth to Three Services? Yes No

Team Member	Role on the Team	Email	Phone
	Service Coordinator		

Is your child receiving public school services? Yes No

Home School _____

Team Member	Role	Email	Phone
	Teacher		

Is your child or family receiving any other services? Yes No

Agency	Service	Email	Phone

This information should be shared with your WV Birth to Three Team and/or County Director of Special Education and the School Based Team. This information would also be beneficial to share with other community agencies supporting your child and family.

Step One:

Learn About Autism Spectrum Disorder

Prior to May, 2013, “autism” was the term commonly used when talking about autism spectrum disorders. “Autistic disorder” was one of five disorders characterized under the heading “Pervasive Developmental Disorders”. The other four disorders were “Asperger’s disorder”, “childhood disintegrative disorder”, “Rett syndrome” and “pervasive developmental disorder not otherwise specified”. With the revision of the Diagnostic Statistical Manual of Mental Disorders -V or DSM V (American Psychiatric Association, 2013), the heading “pervasive developmental disorders” was removed . The disorders listed above no longer exist as separate diagnoses on the autism spectrum. Instead, with the exception of Rett's Syndrome, they have been merged into the diagnosis of "Autism Spectrum Disorder." Rett's Syndrome has become its own entity and is no longer a part of the autism spectrum. While the new appropriate term is “autism spectrum disorder”, you will still hear the term “autism” and “Asperger’s disorder” or “Asperger’s syndrome” used frequently.

The more you know about autism spectrum disorder, the better equipped you will be to make informed decisions for your child. Educate yourself about treatment options, ask questions and participate in treatment decisions.

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a complex developmental disability that is the result of a neurological disorder effecting the functioning of the brain. ASD can profoundly impact how the person interacts with the world. Typically appearing during the first three years of life, ASD affects the person's ability to communicate and interact with others. ASD is often referred to as a "spectrum disorder" because the defining set of behaviors affect individuals differently and with varying degrees of severity.

Every person with ASD is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals who are mildly affected may exhibit only slight delays in language and have greater challenges with social interaction. Others, more severely affected, may exhibit significant problems in their ability to communicate with others and to tolerate the world around them.

ASD impacts . . .

- the frequency and way the person communicates with others
- how the person interacts with others
- how the person takes in and responds to sensory information
- the number and type of activities the person engages in.

Common characteristics include:

- Lack of or a delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g. hand flapping or twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make believe play
- Persistent fixation on parts of objects.

Although we do not have all the answers on the different causes of the Autism Spectrum Disorders, we do know they are treatable. Research studies have shown that early diagnosis and intervention can lead to significantly improved outcomes.

Where can I find more information?

Autism Speaks - www.autismspeaks.org

Autism Internet Modules - <http://www.autisminternetmodules.org/>

The Autism Society – www.autism-society.org

Also see Resources Section beginning on page 77.

Step Two:

Become the Expert on Your Child!

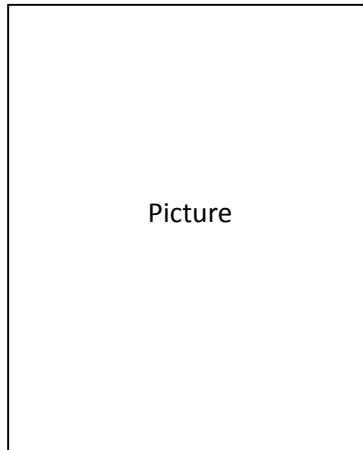
You have a source of knowledge regarding your child that no professional can ever have. You know your child best and communicating this wealth of information within partnerships with professionals can help to ensure that your efforts to support the growth and development of your child are successful.

Figure out what might trigger “disruptive behavior” and what elicits a positive response. What does your child find stressful? What is calming to your child? What is uncomfortable for your child? What is enjoyable? If you understand what affects your child you will become better at solving problems and preventing situations that cause difficulties.

ALL ABOUT ME!

For young children, tweens and teens

Adapted from WV Birth to Three – All About Me



Hi! My Name is _____. I am a pretty big deal! My Parents and I thought you would like to know a little bit about me! If you have any questions, please feel free to ask them. I am sure that I will be busy playing with my favorite things!

My Full Name is: _____ (But my parents only use my full

name, when I am in trouble). You can call me: _____ and I am _____ years old.

My best time of day is: _____

My favorite toys are: _____

My favorite food is: _____

I am afraid of: _____

A Bit About My Family:

My Parents/Guardian: _____

My Brothers & Sisters: _____

My Other Family & Friends You Might Want To Know About: _____

My Pets: _____

Things I Love:

1. _____
2. _____
3. _____

Things I Dislike:

1. _____
2. _____
3. _____

Things That Are Challenging For Me:

1. _____
2. _____
3. _____

Things That Motivate Me:

1. _____
2. _____
3. _____

Things You Might See If I get Frustrated:

1. _____
2. _____
3. _____

Things That Calm Me Down When I Get Upset:

1. _____
2. _____
3. _____

How I Communicate:

1. _____
2. _____
3. _____

Important Health Information (Doctor, Allergies, Etc.):

1. _____
2. _____
3. _____

Doctor(s) and Phone(s)

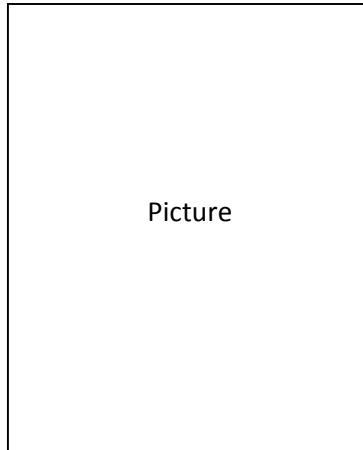
1. _____
2. _____
3. _____

Other Information That Might Be Nice to Know:

1. _____
2. _____
3. _____

A Bit About Me:

For older teens and adults



My name is: _____

I prefer to be called: _____

I usually communicate by: _____

Things I am interested in:

1. _____

2. _____

3. _____

Things that can be challenging for me:

1. _____

2. _____

3. _____

Things I sometimes do if I am upset or frustrated:

1. _____

2. _____

3. _____

Things that help to calm me down:

1. _____
2. _____
3. _____

Important health issues (Doctor, Allergies, Etc.):

1. _____
2. _____
3. _____

Other information that might be nice to know:

1. _____
2. _____
3. _____

My emergency contacts include:

1. _____
2. _____
3. _____

My Contact Information:

Home Phone: _____

Cell Phone(s): _____

Work Phone(s): _____

E-Mail: _____

Home Address: _____

Step Three:

Accept Your Child for Who They Are

Being told your child has Autism can be traumatizing and you may feel stunned by the news. You may also feel a variety of other emotions, like fear, shock, disbelief or despair. Accept those feelings as real and nurture yourself. You will also work to accept your child for who they are . . . the amazing, beautiful and loved being that you cannot imagine life without!

As you are honing your expert on your child skills, and learning more about Autism Spectrum Disorders you will want to begin to apply your knowledge. How does the information about ASD relate to the years of knowledge you have about your child? Taking your time to explore what Autism means to your child and family will begin to help you move forward in considering the most appropriate options.

When you understand how these sets of knowledge work together, you will be building a foundation for yourself as a strong advocate for your child. As you advocate with caring and understanding you will engage with professionals from a variety of service systems, all there under the premise of supporting your child and family. Approach these relationships the way you approach the relationship with your child - be kind, willing to listen and eager to problem solve together. If we do not emulate these positive attitudes then we cannot expect those from others. It is through these parent-professional partnerships that your child will learn and grow, gaining the skills necessary to be an active participant in all aspects of daily life.

The worksheet on the next page can begin to help you to identify specifics, such as:

- How ASD characteristics appear in my child
- Gifts and talents my child has
- Dreams our family has for our child and what they will be able to do.

Wrapping your brain around these concepts will assist you in your conversations with the variety of professionals with whom you will be developing partnerships in the care of your child. Remember they will never know the vast amounts of intimate knowledge you have regarding your child and their abilities and challenges. The professionals need you as much as your child does to ensure success in meeting their unique needs.

Remember – you are the expert on your child

How Does ASD Affect My Child?

Reflect upon the characteristics of autism and how they affect your child.

Characteristic	What this might look like	How does my child do this
Social Interactions	<ul style="list-style-type: none"> ▪ Have difficulty making eye contact with others ▪ Show little body language or facial expressions when interacting ▪ Have difficulty developing relationships with peers ▪ Seem uninterested in sharing experiences ▪ Engage less in give-and-take social interaction with caregivers, siblings and other close relations 	
Speech, Language and Communication	<ul style="list-style-type: none"> ▪ Have difficulty communicating with speech or with gestures ▪ Have difficulty understanding what others are saying to him ▪ Have difficulty using the language he has to interact with others ▪ Have difficulty starting or continuing a conversation ▪ Have difficulty using his own sentences, and instead, may repeat what others say (referred to as echolalia) ▪ Lack make-believe or pretend-play skills 	
Stereotypical or Repetitive Behaviors	<ul style="list-style-type: none"> ▪ Show interest in very few objects or activities and play with them in repetitive ways ▪ Perform repetitive routines and have difficulty with changes in these routines ▪ Spend time in repetitive movements (such as waving a hand in front of his face) 	

Remember to share these points with anyone involved with your child.

Step Four:

Enjoy Your Child and Celebrate Small Successes

If you show joy with your child and their accomplishments, facing the world openly with a smile your positive example can lead others to have a positive and joyful approach.

Milestones are an achievement, not just an item on a list

When you have a child with Autism, you learn to appreciate the milestones, both big and small. Some would say that we celebrate a little too much for such little accomplishments but I'd argue that we celebrate accordingly, it's other parents who take them for granted.

First words, learning to walk, swimming, riding a bike, reading, writing... all these things that make parents proud are far more than just steps along the way when your child has Autism... they're cause for celebration.

Take nothing for granted

Along the same lines, but very different from milestones, is taking nothing for granted. Unless you have a child with Autism (or another disability like it), you'll probably never know what it's like to be lucky enough to be hugged one time a year.

Does your child look you in the eye? If your child has Autism, maybe not. Does your child give you a hug or kiss sometimes? If your child has Autism, maybe not.

You will never ever realize just how much the tiniest little things can be so extremely important until they're not there.

Patience, more than you ever thought possible

The biggest problem with milestones is that everyone knows what they are and when they should happen so when your child is missing them, everyone says something. It's hard, it's oh so very hard.

After a while though, you develop a thicker skin... not just the patience required to take their "advice" a little better but also to have the patience and self-confidence in knowing that if you never give up on your children, the milestones will come.

The beauty that is around us

The world around us moves pretty fast and can be so filled with sights and sounds that it turns into a bit of a blurry mess. Our mind makes it that way to keep us from becoming overwhelmed, crazy and tired. We filter through a lot of everything that goes on in our daily lives without really realizing it.

Many people, especially the children, with Autism don't have the same filtering capabilities and often times do get overwhelmed by it all. This often results in meltdowns or even violence.

You, as the parent, become increasingly aware of the world around you because you have to, because you need to know what you are getting your child into. Loud restaurants, carnivals, movie theaters... many places can be far too difficult for your child to be able to process and you need to be aware of that before the fact.

As you develop this ability over time, it forces you to slow down and truly appreciate the sights and smells and sounds that surround us every single day.

You go outside and there isn't a car in the neighborhood... it's so very peaceful. Before you likely never would have noticed, much less enjoyed that feeling of peace, because your mind builds that filter in place before you ever go out and so you don't notice if there are cars or not.

Your child is perfect because of who they are

It isn't until others see your child as flawed, and worse, until you start to see your own child as flawed, that you can learn what is truly important... not a disability, not a disorder, not even a gift... a child is who they are inside and who they are inside is exactly who they are supposed to be... your child.

It's ok if no one will ever look at your child the same way you do, they're not supposed to. Our children are amazing human beings with unlimited potential.

The difference

Celebrate the differences, not just in your child, but in yourself. For better or worse, you've become a better person for it, you've become a better parent. Your child isn't like other children... and that seems hard to take but honestly, before your child was born, and you saw how "other children" are on the news or in movies... is that really what you wished for when you imagined having a child? For them to be like all the others?

No, none of us want our children to have it harder than anyone else, and no we don't want our children to suffer... but many of us recognize that we can have these thoughts and these feelings while still being able to recognize and celebrate the differences.

Your child is amazing.

You are amazing.

Celebrate it ... you've earned it.

Duncan, S. (2011). *Let me tell you a little about celebrating autism*. Retrieved from <http://www.autismsupportnetwork.com/news/let-me-tell-you-little-about-celebrating-autism-33899232>

Step Five:

Don't Give Up!

Children with autism have an entire lifetime to grow and increase their abilities, just like every other child! Don't jump to conclusions that your child will not be able to do certain things! It may feel overwhelming when you think of everything your child needs to learn but every day individuals with autism show the world what they can overcome, compensate for and otherwise manage what is challenging for them. Use the partnerships you have with professionals and other families to equip yourself with information, strategies and connections to support your child on their journey toward independence.

Find Nonverbal Ways To Connect

Connecting with your child can be challenging, but you don't need to talk in order to communicate and bond. You communicate by the way you look at your child, the way you touch him/her, and by the tone of your voice and body language. Your child is also communicating with you, even if he/she never speaks. You just need to learn the language!

- **Look for cues** – If you are observant and aware you can learn to pick up on the nonverbal cues that children with autism use to communicate. Pay attention to the kinds of sounds they make, their facial expressions, and the gestures they use when they are hungry, tired, or want something.
- **Figure out the need behind the tantrum** - it's only natural to feel upset when you are misunderstood or ignored, and it's no different for children with autism. When children with autism act out, it's often because you're not picking up on their nonverbal cues. Throwing a tantrum is their way of communicating their frustration and getting your attention.
- **Make time for fun.** A child coping with autism is still a kid. For both children with autism and their parents, there needs to be more to life than therapy. Schedule playtime when your child is most alert and awake. Figure out ways to have fun together by thinking about the things that make your child smile, laugh, and come out of their shell. Your child is likely to enjoy these activities most if they don't seem therapeutic or educational. There are tremendous benefits that result from your enjoyment of your child's company and from your child's enjoyment of spending unpressured time with you. Play is an essential part of learning and shouldn't feel like work.
- **Pay attention to your child's sensory sensitivities.** Many children with autism are hypersensitive to light, sound, touch, taste, and smell. Other children with autism are "under-sensitive" to sensory stimuli. Figure out what sights, sounds, smells, movements, and tactile sensations trigger your kid's "bad" or disruptive behaviors and what elicits a positive response. If you understand what affects your child, you'll be better at troubleshooting problems, preventing situations that cause difficulties, and creating successful experiences.
 - What does your child find stressful or overwhelming? _____
 - What does your child find calming? _____
 - What does your child find enjoyable? _____

Use what you know about your child to think about other strategies that might help you and your child connect as well. Think about these:

- **When giving your child instructions/directions . . .**
 - Come to me,
 - Get my attention, and
 - Speak in plain, simple words (i.e., Wyatt put your car in the bucket, it's bath time.)
- **Speak in clear words** – I need you to be very specific when you are talking with me. Saying 'hold your horses' is confusing, tell me you need me to 'stop running'. Don't tell me something is 'easy as pie' when there is no pie in sight, tell me 'this will be easy for you'.

- **I'm visually oriented**
 - Show me how to do things rather than telling me and be prepared to show me many times.
 - Using visual supports will help me understand what comes next during the day and will relieve stress for both of us. That will make our days run much more smoothly!
 - Visual supports might include visual schedules, photos, and cue cards
 - Where you can go to learn more:
 - Visual Supports –
 - Autism Speaks - <http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/visual-supports>
 - Autism Internet Modules - <http://www.autisminternetmodules.org/>
 - National Professional Development Center on Autism Spectrum Disorders - <http://autismpdc.fpg.unc.edu/content/briefs>
 - Tips for Creating Visuals – Center on Social Emotional Foundations of Early Learning - <http://csefel.vanderbilt.edu/modules/module3b/handout2.pdf>
 - Visual schedules –
 - Hands in Autism Interdisciplinary Training and Resource Center - www.handsinautism.org
 - Document discussing development and use of visual schedules (provides a wide variety of photographed examples) - <http://www.setbc.org/download/public/vss.pdf>
 - Visual Cues
 - First/Then Board –
 - <http://www.autismclassroomnews.com/2013/05/visual-schedule-series-first-then.html>
 - <http://lessonpix.com/articles/9/35/First+Then+Boards>
 - Activity System –
 - <http://autismpdc.fpg.unc.edu/content/structured-work-systems>
 - <http://www.autisminternetmodules.org/>
 - <http://www.iidc.indiana.edu/?pageId=416>
- **I want to be successful!** Focus on what I can do rather than what I cannot do. Like anyone I will avoid doing things that make me feel inadequate or inept. Use my strengths to help me find a way to accomplish things in a different way.
- **I want to interact with family and peers!** I need you to teach me how to play and communicate with others.
 - I rely on you for support, guidance and love. You will help me be successful!
 - Encourage others to invite me to play along
 - Start with my favorite games and then teach me how to do new things
 - Focus on structured activities that have a clear beginning and end.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with autism: Autism treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Step Six:

Be Consistent

Children with autism have a hard time adapting what they learn the first time. Be consistent in your child's environment to reinforce learning. Find out what your child's teachers and therapists are doing and incorporate those into the home environment. Be consistent with the way you interact with your child and dealing with any challenging behaviors.

Provide Structure and Safety

Learning all you can about autism and getting involved in treatment will go a long way toward helping your child. Additionally, the following tips will make daily home life easier for both you and your autistic child:

Stick to a schedule:

Children with autism need structure and routine. Set up a schedule for your child, with regular meals, therapy time, bath time, bed time. Try to keep disruptions to a minimum. If there is a schedule change, try and prepare your child in advance for it. (See links and information on page 20 for visual supports)

Reward good behavior:

Positive reinforcement can go a long way. Praise your child when they have good behavior or learn a new skill. Be very specific about what behavior they are being rewarded for. Look for other ways to reward them by giving a favorite toy or a favorite item they like. Helpful links:

- Pyramid Model for Supporting Challenging Behavior
 - http://www.challengingbehavior.org/do/pyramid_model.htm
 - <http://www.challengingbehavior.org/communities/families.htm>
 - <http://csefel.vanderbilt.edu/resources/family.html>
- Autism Speaks Challenging Behavior Tool Kit - <http://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit>
- Prompting - <http://autismpdc.fpg.unc.edu/content/prompting>
- Reinforcement - <http://autismpdc.fpg.unc.edu/content/reinforcement>

Create a home safe zone:

Create a private space in your home where your child can go to relax, feel secure, and be safe. This will involve organization and setting boundaries in ways that your child can understand. You can use visual cues to help your child understand a safe zone for them; labeling items, using colored tape to mark off areas or visual schedules as a strategy to keep your child happy and safe. For some children you may need to safety proof the house, particularly if your child is prone to tantrums or other self-injurious behaviors. Helpful links:

- <http://www.autism-society.org/living-with-autism/how-we-can-help/safe-and-sound/safety-in-the-home.html>
- <http://www.autismspeaks.org/family-services/resource-library/safety-products>

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with autism: Autism treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Step Seven:

Plan for Intervention

Every child with autism is unique and no one treatment plan will work with every child

Create a Personalized Intervention Plan

With so many different intervention options available, it can be tough to figure out which approach is right for your child. Making things more complicated, you may hear different or even conflicting recommendations from professionals and from other families. When putting together an intervention plan for your child, keep in mind that there is no single treatment that will work for every individual with autism. Each person is unique, with different strengths and challenges.

Your child's intervention plan should be tailored to his/her individual needs. You know your child best, so make sure you are communicating his/her needs and advocate to ensure they are met. One way to do that is to ask yourself the following questions:

What are my child's strengths? _____

What are my child's weaknesses? _____

What behaviors are causing the most problems? _____

What important skills does my child lack? _____

How does my child learn best? _____

What does my child enjoy and how can those activities be used in his intervention plan? _____

A good intervention plan will do the following:

- Build on your child's interests
- Offer a predictable schedule
- Teach tasks as a series of simple steps
- Actively engage your child's attention in highly structured activities
- Provide regular reinforcement of behavior
- Involve the family

Finally, keep in mind that no matter what autism intervention plan is chosen, your involvement is vital to success. You can help your child get the most out of intervention by working hand-in-hand with the team of professionals and following through with the intervention activities at home.

For more information on educational resources see pages 83-87.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with autism: Autism treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Team Approach

Preparing a child with autism to live a satisfying, happy and productive life is tremendously challenging but incredibly rewarding. As countless families who have made this journey can attest, success requires a committed team that includes not only vigilant and loving family members but also therapists, educators and a host of other professionals and members of the community. Along the way, home based interventions, school services, community outings and social skills groups all have an important role to play.

A team approach to intervention offers the best outcome for a child with autism. A team may include differing members but should be based on the individualized needs of the your child. Each member of the team brings a unique perspective and set of observations and skills, all of which are helpful in assisting your child with complex and variable needs.

You are an equal member of the team. You can offer a valuable and longitudinal view, contributing information and a history of successful (and unsuccessful) strategies. You will also benefit from information on strategies and successes at school that can help to extend learning into the home and community settings. A positive and collaborative relationship is beneficial to everyone.

Your child's team might include:

- a primary care physician who prescribes medication;
- an educator to help you learn to teach your child how to learn;
- an occupational therapist to help with activities of daily living;
- a physical therapist to assist with motor skill development; and
- a speech language pathologist to assist with communication and language skill development;
- a behavioral analyst to assist in understanding challenging behavior and ways to support development of positive social emotional skills;
- and others based on the needs of the child.

Many children with autism require various treatments to address all of their symptoms and needs. Common autism therapy includes:

- Behavior Therapy - www.autismspeaks.org
- Speech-Language Therapy - www.healingthresholds.com
- Play-based Therapy - www.autismspeaks.org
- Physical Therapy - www.cincinnatichildrens.org/services/ot-pt
- Occupational Therapy - <http://www.cincinnatichildrens.org/service/k/autism/default/>
- Nutritional Therapy - www.healing-arts.org (vitamin B, Magnesium, Omega)
- You can also review information on treatments and therapies at <http://www.autismspeaks.org/family-services/tool-kits/100-day-kit/treatments-therapies>

Step Eight:

Think Inclusion

Inclusion is part of a much larger picture than just placement in the regular class within school. It is being included in life and participating using one's abilities in day to day activities as a member of the community. Inclusion is being a part of what everyone else is, and being welcomed and embraced as a member who belongs.

Inclusion is about all of us

Inclusion is about living full lives – about learning how to live together

Inclusion makes the world our classroom for a full life

Inclusion treasures diversity and builds community

Inclusion is about our ‘abilities’ – our gifts and how to share them

Inclusion is not just a ‘disability’ issue

What is Inclusion?

In 1955 the story of a brave and tired woman named Rosa Parks was put in front of this country's awareness. They say this woman had gotten tired, in fact, historically tired of being denied equality. She wanted to be included in society in a full way, something which was denied people labeled as "black" people! So Rosa Parks sat down on a bus in a section reserved for "white" people. When Rosa was told to go to "her place" at the back of the bus, she refused to move, was arrested, and history was challenged and changed. All of this happened because Rosa Parks was tired, historically tired of being excluded. She had sat down and thereby stood up for inclusion!

Another powerful cry for "inclusion" is being heard today. This new cry is being raised by people with unrecognized abilities, (the so-called "disabled"). Many people whose abilities are regularly denied or ignored feel that society is not honoring the right to participate in society in a full way. Part of the call is for better accessibility, such as more wheelchair ramps, more signs and materials in braille, community living, etc. The Americans with Disabilities Act represents an attempt to hear the "inclusion" cry. However, much more needs to be done including a search for an acceptable definition and practice of inclusion.

Across this country a definition of inclusion is offered. It is generally accepted that "Inclusion" means inviting those who have been historically locked out to "come in". This well-intentioned meaning must be strengthened. A weakness of this definition is evident. Who has the authority or right to "invite" others in? And how did the "inviters" get in? Finally, who is doing the excluding? It is time we both recognize and accept that we are all born "in"! No one has the right to invite others in! It definitely becomes our responsibility as a society to remove all barriers which uphold exclusion since none of us have the authority to "invite" others "in"!

So what is inclusion? Inclusion is recognizing our universal "oneness" and interdependence. Inclusion is recognizing that we are "one" even though we are not the "same". The act of inclusion means fighting against exclusion and all of the social diseases exclusion gives birth to - i.e. racism, sexism, handicapism, etc. Fighting for inclusion also involves assuring that all support systems are available to those who need such support. Providing and maintaining support systems is a civic responsibility, not a favor. We were all born "in". Society will immediately improve at the point we honor this truth!!

Ashante, S. (1995). *What is inclusion*. Retrieved from <http://www.inclusion.com/inclusion.html>.

What are the pros and cons of including children with special needs in regular classrooms.

Inclusion is a popular approach for educating children with disabilities such as autism. Inclusion is another term for 'mainstreaming' or merging special education with regular education classes. The goal of inclusion is for all children with disabilities to attend "typical" schools and classrooms and receive the support they need to be successful.

The approach has a lot of appeal. It gives children with special needs the opportunity to learn in natural, stimulating environments. Inclusion makes it possible for friendships to occur with non-handicapped peers, provides positive role models, and may lead to greater acceptance in the community. In addition, children without disabilities may benefit by learning about differences between people and by having the opportunity to assist others. Teachers may benefit by achieving a broader application of differences and by learning new teaching techniques for instruction.

The approach is also in line with state and federal requirements for a child to be educated in what is called the "least restrictive environment". Finally, inclusion combats a long held history of segregation in the field of special education and disabilities. For decades, people with disabilities did not have access to public schools, facilities, housing and health care.

Many children have benefited from being included in their public schools. However, after more than 10 years of implementation, inclusion has not fully met its promise. Because inclusion is a philosophy about how children should be educated, it is sometimes recommended without prioritizing the needs of the individual child or preferences of the family. The place where a child is educated does not make instruction effective. Rather, it is the content and method of instruction that are most likely to result in improvement in the child's language, social skills and other behaviors.

Public schools are sometimes unable to provide the specialized education required for children with autism, especially those with the most severe language and behavioral disorders. It is unrealistic to expect that regular education teachers will always have the specific training required for this population, be aware of the latest research, or be able to readily adapt the school's curriculum. In addition, children with special needs are sometimes assigned one-to-one aides who have little training or experience with autism or other developmental disabilities.

Even with consultation from specialists, a regular school setting cannot always provide the intensive, focused, constant instruction these children require throughout the school day. Although schools may have a mandate to include all children, it is not uncommon that some eventually re-create special classrooms because the children did not receive the appropriate education or their behavior problems could not be addressed within the regular classroom.

What should parents do when considering different options for their child? First, inclusion should be considered on a case-by-case basis. Parents need to consider the needs of their own child, the capacity of the school to meet these needs and their own preferences.

Parents should find out whether the program they are considering includes these components:

- A language based curriculum

- A curriculum that progresses in an orderly manner throughout the day and addresses multiple skill development;
- Effective instructional techniques based upon research, including a strong focus on positive reinforcement, shaping, prompting and fading of prompts;
- Frequent opportunities for your child to respond to instruction;
- Little time when the child is not engaged in instruction;
- Daily recording of academic work and behavior problems; and
- Frequent review of progress and timely changes in procedures (i.e., interventions) if progress is not occurring.

Harchik, A. (2013). *What are the pros and cons of including children with special needs in regular classrooms*. Retrieved from <http://www.nationalautismcenter.org/learning/inclusion.php>.

Some other things to consider for the inclusive classroom:

- Inclusive Schooling - <http://www.paulakluth.com/readings/inclusive-schooling/>
- Getting Comfortable in the Inclusive Classroom - <http://www.paulakluth.com/readings/autism/getting-comfortable-in-the-inclusive-classroom/>

Step Nine:

Find Help and Support

Parent can share information, get advice or support from other parents. Just being around other parents sharing experiences can be helpful and reduce the isolation you may feel

Find Help And Support

Caring for a child with an autism spectrum disorder can demand a lot of energy and time. There may be days when you feel overwhelmed, stressed, or discouraged. Parenting isn't ever easy, and raising a child with special needs is even more challenging. In order to be the best parent you can be, it's essential that you take care of yourself.

Don't try to do everything on your own. You don't have to! There are many places that families of autistic kids can turn to for advice, a helping hand, advocacy, and support:

- **Autism support groups** – Joining an autism support group is a great way to meet other families dealing with the same challenges you are. Parents can share information, get advice, and lean on each other for emotional support. Just being around others in the same boat and sharing their experience can go a long way toward reducing the isolation many parents feel after receiving a child's autism diagnosis.
 - Autism Society / National Resources and Support for families - www.autism-society.org
 - Autism Society of WV / State Society of support for families - <http://autismwv.blogspot.com>
- **Respite care** – Every parent needs a break now and again. And for parents coping with the added stress of autism, this is especially true. In respite care, another caregiver takes over temporarily, giving you a break for a few hours, days, or even weeks. Respite can be provided through the I/DD Waiver program/targeted case management/private pay.
- **Individual, marital, or family counseling** – If stress, anxiety, or depression is getting to you, you may want to see a therapist of your own. Therapy is a safe place where you can talk honestly about everything you're feeling—the good, the bad, and the ugly. Marriage or family therapy can also help you work out problems that the challenges of life with an autistic child are causing in your spousal relationship or with other family members.

Adapted from Smith, M., Segal, J., Hutman, T (2013). *Helping children with autism: Autism treatment strategies and parenting tips*. Retrieved from http://www.helpguide.org/mental/autism_help.htm.

Know Your Rights

Knowing your rights can help you to feel more in control. Your infant or toddler has a right to appropriate early intervention services if they are eligible for WV Birth to Three supports. Your preschooler to adult child has the right to a free and appropriate public school education. Getting involved in his or her education is among the most important things you can do as your child's advocate. As you'll see below, you have a right to be a part of every decision regarding your child's education, including the process of finding out if your child needs special services. You know your child best, and your input should be considered at every opportunity.

In order to make sure that your child gets the help he or she needs throughout his or her school career, you should familiarize yourself with the rights you have as your child's advocate. These rights are federally mandated by the Individuals with Disabilities Education Act (IDEA).

Your Child's Rights Determining Eligibility for Special Education and Related Services

- You have the right to request in writing that your child be evaluated to determine if he or she is eligible for special education and related services. This evaluation is more than just a single test. The school

must gather information from you, your child's teacher and others who would be helpful. An assessment of your child must then be conducted in all the areas that may be affected by the suspected disability.

- If the public school agrees that your child may have a learning disability and may need special help, the school must evaluate your child at no cost to you.
- Teachers or other professionals can recommend that your child be evaluated, but the school must get your explicit written consent before any part of the evaluation is started.
- If the public school system refuses to give your child an evaluation, they must explain in writing the reasons for refusal, and must also provide information about how you can challenge their decision.
- All tests and interviews must be conducted in your child's native language. The evaluation process cannot discriminate against your child because he or she is not a native English speaker, has a disability or is from a different racial or cultural background.
- Your child cannot be determined eligible for special education services only because of limited English proficiency or because of lack of instruction in reading or math.
- You have the right to be a part of the evaluation team that decides what information is needed to determine whether your child is eligible.
- You have the right to a copy of all evaluation reports and paperwork related to your child.
- You have the right to obtain an Independent Education Evaluation from a qualified professional and challenge the findings of the school evaluation team.
- You have the right for your child's evaluation to be completed within a specific timeframe. Some states have set a limit. For states who had no limit, as of July 1, 2005, the evaluation must be completed within 60 days of your written consent.

Your Child's Rights Once Determined Eligible for Special Education and Related Services

- You and your child have the right to attend and participate in a meeting to design an Individualized Education Program (IEP) which must be held within 30 days of your child being found eligible for special education services. An IEP should set reasonable learning goals for your child and state the services that the school district will provide.
- You and your child have the right to participate in the development of the IEP, along with a team that will include: your child's teachers, a representative from the school administration who is qualified to recommend and supervise special programs and services as well as representatives from other agencies that may be involved in your child's transition services (if your child is age 16 or older). You can also request an advisor to help you better understand your rights and responsibilities as a parent, and request that this person be present.
- Your child has a right to the least restrictive environment possible. Unless members of the IEP team can justify removal from the general education classroom, your child should receive instruction and support with classmates that do not have disabilities. Also be sure that special education services or supports are available to help your child participate in extracurricular activities such as clubs and sports.
- During an IEP meeting, the IEP team will develop goals for any related services, such as occupational therapy, which could help your child. Be sure the team specifies how often and for how long these services will be provided as well as in what setting the services will be provided. This team will also identify behavioral strategies to support your child's learning in school and at home.
- Be sure to discuss what kind of assistive technology devices-such as speech recognition software, electronic organizers or books on tape-could help your child. Assistive technology services include evaluating your child for specific devices, providing the device and training your child to use the device.
- You have the right to challenge the school's decisions concerning your child. If you disagree with a decision that's been made, discuss it with the school and see if an agreement can be reached. If all efforts don't work, IDEA provides other means of protection for parents and children under the law. These other ways of settling your dispute allow parents and school personnel to resolve

disagreements. Options include mediation with an impartial third person, a due process hearing or a formal hearing in a court of law.

- An IEP meeting must be held once a year and comprehensive re-evaluation must be done every three years, unless the IEP team agrees that it is not necessary. However, you may request an IEP meeting at any time.

Adapted from the National Center on Learning Disabilities Editorial Team (n.d.). *Knowing your child's rights*. Retrieved from <http://www.nclد.org/parents-child-disabilities/ld-rights/knowng-your-childs-rights>

Helpful links:

- WV Birth to Three
 - Information for families – <http://www.wvdhhr.org/birth23/families.asp>
 - Procedural Safeguards - http://www.wvdhhr.org/birth23/sdform/sdforms_Procedural_Safeguards_051205.pdf
- WV Department of Education
 - Policy 2419 – <http://apps.sos.wv.gov/adlaw/csr/readfile.aspx?DocId=23475&Format=PDF>
 - Hand in Hand in Special Education - <http://wvde.state.wv.us/osp/handinhand.pdf>
 - Parent Educator Resource Centers - <http://wvde.state.wv.us/osp/perc.html>
- Building Partnerships Between Families, Schools and Communities - <http://www.bridges4kids.org/>
- Special Education website - <http://www.wrightslaw.com/>

Step Ten:

Think About Challenges in a New Way!

There may be times that you cannot come up with a solution. What to do? Think in a different way!

How To Think ‘Outside of the Box’

Throughout this publication we have discussed the importance of consistency and routine for individuals with autism spectrum disorder. However, you might find yourself in a situation where the routine ways you have addressed questions or challenges simply is not helping you to find a solution that is really effective. Maybe you have also considered or used one or more of the following:

- Write about the problem
- Back off and do nothing
- Consult with someone new
- Observe, is your child showing you a solution through his behavior?
- Take time to re-direct, ask your child’s doctor, teacher, therapist for assistance

If you have still you have not found something to work. Well, that’s when it’s time to step outside of the box.

No doubt you have heard the term to ‘think outside the box’. Perhaps you have wondered what that meant in actual fact, or maybe you know what it means but you’re so firmly “inside the box” that you don’t even notice that you’re in the box. We always need to be on the lookout for new ideas and it’s the ability to think differently, generate new ideas and spark your creativity. You do need to actively work on building and cultivating these skills – but it can be done!

Generate new ideas

Standard idea-generation techniques concentrate on combining or adapting existing ideas. This can certainly generate results. But our focus is on equipping you with tools that help you leap onto a totally different plane. These approaches push your mind to forge new connections, think differently and consider new perspectives.

These techniques are extremely effective, they will only succeed if they are backed by rich knowledge of the area you’re working on. This is where all the work you have completed to learn about autism and the connections you have made to professionals and other families will come into play.

Breaking thought patterns

All of us can tend to get stuck in certain thinking patterns. Breaking these thought patterns can help you get your mind unstuck and generate new ideas. There are several techniques you can use to break established thought patterns:

- **Challenge assumptions:** For every situation, you have a set of key assumptions. Challenging these assumptions gives you a whole new spin on possibilities.
- **Reword the problem:** Stating the problem differently often leads to different ideas. To reword the problem look at the issue from different angles. "Why do we need to solve the problem?", "What's the roadblock here?", "What will happen if we don't solve the problem?" These questions will give you new insights. You might come up with new ideas to solve your new problem.
- **Think in reverse:** If you feel you cannot think of anything new, try turning things upside-down. Instead of focusing on how you could solve a problem, consider how could you create the problem. The reverse ideas will come flowing in. Consider these ideas – once you've reversed them again – as possible solutions for the original challenge.
- **Express yourself through different media:** How about expressing the challenge through different media? Clay, music, word association games, paint, there are several ways you can express the challenge. Don't bother about solving the challenge at this point - just express it. Different

expression might spark off different thought patterns and these new thought patterns may yield new ideas.

Connect the unconnected

Some of the best ideas seem to occur just by chance. You see something or you hear someone, often totally unconnected to the situation you are trying to resolve, and the penny drops in place. Why does this happen? The random element provides a new stimulus and gets our brain cells ticking. You can capitalize on this knowledge by consciously trying to connect the unconnected.

Actively seek stimuli from unexpected places and then see if you can use these stimuli to build a connection with your situation. Some techniques you could use are:

- **Mind map possible ideas:** Put a key word or phrase in the middle of the page. Write whatever else comes in your mind on the same page. See if you can make any connections.
- **Pick up a picture.** Consider how you can relate it to your situation.
- **Take an item.** Ask yourself questions such as "How could this item help in addressing the challenge?", or "What attributes of this item could help us solve our challenge?"

Shift perspective

Over the years we all build a certain type of perspective and this perspective yields a certain type of idea. If you want different ideas, you will have to shift your perspective. To do so:

- **Get someone else's perspective:** Ask different people what they would do if faced with your challenge. You could approach friends engaged in different kind of work, your spouse, a nine-year old child, customers, suppliers, senior citizens, someone from a different culture; in essence anyone who might see things differently.
- **Play the "If I were" game:** Ask yourself "If I were ..." how would I address this challenge? You could be anyone: a millionaire, Tiger Woods, anyone. The idea is the person you decide to be has certain identifiable traits. And you have to use these traits to address the challenge. For instance, if you decide to play the millionaire, you might want to bring traits such as flamboyance, big thinking and risk-taking when formulating an idea. If you are Tiger Woods you would focus on things such as perfection, persistence and execution detail.

Employ enablers

Enablers are activities and actions that assist with, rather than directly provoke, idea generation. They create a positive atmosphere. Some of the enablers that can help you get your creative juices flowing are:

- **Belief in yourself:** Believe that you are creative, believe that ideas will come to you; positive reinforcement helps you perform better.
- **Creative loafing time:** Nap, go for a walk, listen to music, play with your child, take a break from formal idea-generating. Your mind needs the rest, and will often come up with connections precisely when it isn't trying to make them.
- **Change of environment:** Sometimes changing the setting changes your thought process. Go to a nearby coffee shop instead of the conference room in your office, or hold your discussion while walking together round a local park.
- **Shutting out distractions:** Keep your thinking space both literally and mentally clutter-free. Shut off the Blackberry, close the door, divert your phone calls and then think.
- **Fun and humor:** These are essential ingredients, especially in team settings.

Final Thoughts

The ability to generate new ideas is an essential skill.. You can acquire this skill by consciously practicing techniques that force your mind to forge new connections, break old thought patterns and consider new perspectives.

Along with practicing these techniques, you need to adopt enabling strategies too. These enabling strategies help in creating a positive atmosphere that boosts creativity.

- Be willing to explore things that are out of your comfort zone. It's refreshing and you can find new interests and meet new people.
- Read biographies to see how other people overcame ruts in their lives. Adapt their thinking solutions to your current situation.
- Read something that isn't your usual genre. For example, if you think you *hate* crime fiction, why not try reading one? You might be pleasantly surprised; even if not, you've challenged your thinking processes. Be sure to read to the end!
- Explore faiths beyond your own. Try to find the similarities and connections. And aim to accept each for what it is

Mediawiki, (2013). *How to think outside of the box*. Retrieved from <http://www.wikihow.com/Think-'Outside-of-the-Box'>.

MindTools.com, (n.d.). Generating new ideas: Think differently and spark creativity. Retrieved from http://www.mindtools.com/pages/article/newCT_88.htm.

Swyers, M. (2010). 5 steps to thinking outside of the box. Retrieved from <http://www.inc.com/matthew-swyers/5-steps-to-thinking-outside-of-the-box.html>.

Next Steps Checklist

Done	#	Action																								
	1	Call the WV Birth to Three Regional Coordinator or County Special Education Director for your County: Name: _____ Phone _____ Items for Discussion: A: _____ B: _____ C: _____																								
	2	Organize your documents: A. Begin a binder to store documentation – you may contact the Parent Network Specialists with the Center for Excellence in Disabilities for assistance with this, see page 61 B. Make copies of documents to share with others – never give away your originals C. Documents to have on hand: <ol style="list-style-type: none"> 1. Social Security Card/Number 2. WV Department of Vital Statistics Birth Certificate 3. Diagnostic Paperwork 4. Pertinent medical paperwork 5. Immunization records 																								
	3	Investigate services for which you and your child may be eligible <table border="1" style="width: 100%; margin-top: 5px;"> <thead> <tr> <th style="width: 33%;">Service</th> <th style="width: 33%;">Contact Person</th> <th style="width: 34%;">Contact Information</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table>	Service	Contact Person	Contact Information																					
Service	Contact Person	Contact Information																								
	4	Access the WV Team Autism Website – http://sites.google.com/site/wvteamautism																								
	5	Call your regional contact person to review roadblocks and successes of steps 1-4 <table border="1" style="width: 100%; margin-top: 5px;"> <tbody> <tr> <td style="width: 50%;">WV Birth to Three</td> <td style="width: 50%;">See page ____</td> </tr> <tr> <td>County Special Education Director</td> <td>See page ____</td> </tr> <tr> <td>Parent Educator Resource Center</td> <td>See page ____</td> </tr> <tr> <td> </td> <td> </td> </tr> </tbody> </table>	WV Birth to Three	See page ____	County Special Education Director	See page ____	Parent Educator Resource Center	See page ____																		
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Step Eleven:

Getting Organized

Organizing and keeping paperwork will provide you an opportunity to maintain all the information you have learned about autism, along with the educational records, medical records and information from other agencies in one place. This will make it easier for you to locate information when you need it!

Organizing Your Child's Special Education File: Do It Right!

The special education system generates mountains of paper. Some information is important so you are afraid to throw anything away. The mountain of paper grows higher every year. What do you do with it? How do you organize this information?

You need a simple, foolproof document management system. In this article, you will learn how to organize your child's file. After you organize the information about your child into a file, you will have a clearer understanding of your child's disability and needs.

Document Management Systems

Think about the last school meeting. Did the IEP team members have a complete copy of your child's file? Did you have a complete copy of your child's file? How can the IEP team make decisions about your child's special education program if they do not have complete, accurate information about your child? Schools keep records in different places. Information and reports are misplaced. When you organize your child's file, you will have all the information about your child in one place. With our document management system, you can track your child's educational history. When you use this parent-tested system, you can quickly locate any document in your child's file.

When you take your organized file to the next school meeting, you will understand the power of getting organized. You will gain a sense of control.

Gather Information About Your Child

Follow these steps to get information about your child.

1. **Make a Master Provider List**

Make a list of all individuals and agencies that may have information or records about your child. Your list should include the names and titles of all professionals who have provided medical or mental health treatment services, including doctors, therapists, and other health care providers. Include their addresses, telephone and fax numbers, and email addresses. You may want to develop your list by category of service rendered, e.g., medical, educational, psychological evaluations.

Master Provider List - <http://www.wrightslaw.com/info/format.master.prov.list.pdf>

2. **Request Your Child's Records**

Send a letter to all individuals and agencies on your list and request a copy of your child's records. Explain that your request relates to a school issue and the need to secure an appropriate education for your child. Ask if you should expect to pay a photocopying fee and what this fee will be. Your letters should be neat and convey a professional image.

- **Tip:** See Chapter 23 in *Wrightslaw: From Emotions to Advocacy* (<http://www.wrightslaw.com/store/feta.html>) for sample letters to request information and records - If you do not receive a response within ten days, send a short letter explaining that you requested information ten days ago and have not received a response. Attach a copy of your original letter to the second request letter. Ask if you can do anything to help expedite the request. Offer to visit the office to help copy the information. Be polite.
- **Tip:** Make photocopies of all letters for your file.

3. **Request Your Child's Educational Records**

Write a letter to the school and request a complete copy of your child's entire cumulative file and confidential file, omitting nothing. You want copies of all evaluations, records, correspondence, and

other documents the school has about your child. Use a word processor for your letter. Expect to pay a reasonable photocopying fee.

- **Tip:** See more sample letters at the end of Chapters 23 and 24 in *Wrightslaw: From Emotions to Advocacy*. - <http://www.wrightslaw.com/store/feta.html>
- Send one letter to the principal of your child's school and one letter to the director of special education. If you do not know the director's name and address, call the main office of the school district and request this information. If your child does not attend a public school, send the letter to the principal of the last public school your child attended.
- Before you mail these letters, sign them and make copies of the signed letters for your Master File. Log the letters into your contact log.

4. Organize the Master File

You will organize and file all information about your child in a large binder. Gather all documents that relate to your child. Bring all paper in boxes, file folders, and bags together in one place. Begin by organizing the documents by year.

Step 1: Date All Documents

- With a pencil, lightly write the date of each document in the lower right corner of the first page (Example: 05/09/12).
- **Tip:** Use a soft lead pencil when you date the documents. You may need to erase your notations later.
- Before long, mail will roll in from your requests. Using a pencil, lightly date each document in the lower right hand corner. Date everything- evaluations, reports, correspondence, report cards, and medical reports.
- When you find duplicate documents, compare the duplicates, decide which document has the best photocopy quality, and use this as your master. Put the duplicates in a box. You will not need them for your notebook. Do not throw them away. You may need to provide copies to other people later.
- **Tip:** Do not write on original documents. You may need these documents later.
- *Do not stop to read the documents.* Many parents say that when they organize documents, they begin to read and are sidetracked. Force yourself to stick with this job until you finish. Just date and organize! Lightly pencil the date on the bottom right corner of the first page.
- **Tip:** Work samples provide useful information about your child's skills. Include a few samples of your child's schoolwork.

Step 2: File All Documents in a large Binder

- File all dated documents in a large binder. Sometimes you might have two or three binders. When documents are formatted horizontally, date and place them in a portrait vertical style.
- File all documents in chronological order, oldest document on top and newest document at the end. Some parents use the child's birth certificate as the first document in the file. The last document is the most recent piece of information. This may be a report card, IEP, or letter from the school.
- **Tip:** Do not put documents in clear plastic envelopes. If you are in a meeting and need to find a document in the file, removing documents from plastic envelopes takes too long.
- Do not file documents by category (i.e., IEPs, psychological evaluations, correspondence, etc.). If you file documents by category, your system will fail. Assume you have a comprehensive letter written by a child psychologist three years ago. The Eligibility Committee and the IEP team used the psychologist's letter. Is this document a letter? A report? An evaluation?

- *If your system is confusing and difficult, it will fail.* Trying to figure out categories is confusing and time-consuming. Use our parent-tested system. You have better things to do with your time!

Step 3: Read the Master File for the "Big Picture"

- After you complete Step 2, read your child's Master File from beginning to end. When you read the information chronologically, you will see the big picture
- At the beginning of this article, I mentioned the mountains of paper generated by the special education system. After reports are written, they are filed away. Few people will read or review this information again.
- Because there is no master plan, no one looks at the big picture.
- Instead of looking at the forest, parents and school staff focus on the bark of the trees. When you organize your child's file, you will see the forest. You will understand. Many parents say that making a neat, organized, chronological Master File is a powerful educational experience.

Create Your Document List

You have dated the documents and filed them in chronological order, oldest document on top, most recent on the bottom. Now you need to create your Master Document List. When you organize documents chronologically and generate your Master Document List, you can compress your child's history into a few pages. You can locate any document in seconds.

To create your Master Document List, make a table with four columns. If you are using a word processing program, insert a four-column table.

- **Tip:** If you use a word processing program, the program can sort the list by date, author, or type of document. If you are not using a computer, draw a table with four columns on several sheets of paper.
- Label the columns: Date, Author, Type, and Significance.
- Enter each document by date, author, and type. You can leave the "Significance" column blank for now. When you use a word processing program, you can change the font to highlight test data and other important information. This makes it easier to find important information.
- **Tip:** When you use a word processing program, you can change the font to highlight test data and other important information. You make it easier to find important information. For a sample document list - <http://www.fetaweb.com/03/format.doc.list.pdf>
- **Tip:** If you want to make a note on a document in your Master File, write on a sticky note that you attach to the document.
- Attach sticky notes to all pages in your Master File that have test scores (i.e., the Wechsler Intelligence Test and Woodcock Johnson Tests.) Sample master documentation list - <http://www.fetaweb.com/03/sample.doc.list.pdf>
- When you organize your child's file, you will learn about your child's disability and educational history. This is an important step in becoming an expert. When you finish this job, you will have a clearer understanding of your child's educational needs.
- You do not need to complete the "Significance" column yet. When you learn more about evaluations and test scores, you will recognize important information in documents.
- **Tip:** See how a Master Document List is used to create an Exhibit List (sample - <http://www.fetaweb.com/03/exhibit.list.pdf>) for a due process hearing.
- As you organize your child's file, you will learn about your child's disability and educational history. You will have a clearer understanding of your child's academic and functional needs.

After you create your Master Document List, you will be able to find a specific document quickly and easily. These are important steps in becoming an effective advocate for your child.

More Articles About Documents and Organizing Information

- **The Paper Chase: Managing Your Child's Documents Under the IDEA** by Bob Crabtree, Esq. If you have kids with special educational needs, you can be overwhelmed by paperwork in no time. This article teaches you about the importance of different documents and how to organize them. You learn about documents that are keepers; education records; documents you should create and how; tips for consulting with an attorney. - <http://www.fetaweb.com/03/paperchase.crabtree.htm>
- **Paper Trails: Documents, Exhibit Lists and Due Process Hearings** by Pete Wright. This is one of several articles about documents that was published in the - <http://www.harborhouselaw.com/articles/docs.prepare.wright.htm>
- **Paper Trails, Letter Writing and Documentation.** When you advocate for a child, you use logs, calendars, and journals to create paper trails. - <http://www.wrightslaw.com/info/ltrs.index.htm>

For assistance in developing an organization or record keeping system, see the Center for Excellence in Disabilities – Parent Network Specialists on page 61.

Adapted from Wright, P. (2013). *Organizing your child's special education file: Do it right*. Retrieved from <http://www.wrightslaw.com/info/organize.file.htm>.

History of Autism Services in West Virginia

A Brief History of Autism Services in West Virginia

Many people may not know that West Virginia has a rich history grounded in providing services for individuals with autism spectrum disorders and their families. Autism pioneer Dr. Ruth Sullivan came to Huntington, West Virginia in the 1970's and initiated several "firsts" in the field. She was active in working with Congress to establish the first legislation that mandated ALL children are entitled to a free appropriate public education in the least restrictive environment (PL 94-142). Prior to that, there was no mandate that stated children with special needs should attend public school. Dr. Sullivan also recognized that autism was a misunderstood condition and that the public, including educators, knew little about it. It was common for people to ask her about her "artistic" son.

Prior to coming to Huntington, Dr. Sullivan and several other parents formed the National Society for Autistic Children, now known as the Autism Society of America. She operated the only Autism Hotline in the nation from her home. In the late 1970's and early 1980's, when the de-institutional movement was occurring, she recognized the need for families to receive appropriate supports and education in order to keep their children in their natural home. Dr. Sullivan conducted a needs assessment related to services available for families of children with autism and also assessed educator's knowledge about appropriate education for students with autism. The lack of availability of services and the lack of educator's knowledge about autism was evident. In 1983, Dr Sullivan presented the findings to West Virginia legislature, and along with several other parents, lobbied for the creation of the West Virginia Autism Training Center to be housed at Marshall University. Today, this statewide center has served over 2,700 families and their children and has provided education and training to thousands of educators.

At the same, Dr. Sullivan established the Autism Services Center (ASC), a behavioral health center for developmental disabilities including autism. The ASC became a pioneer in providing quality group home living and now has many group homes in the Huntington area. In 1988, Dr. Sullivan's son, Joseph, became one of the individuals that Dustin Hoffman studied for his movie character, Rainman. Dr. Sullivan became a consultant on the film. Rainman premiered in Huntington, West Virginia at the historic Keith Albee Theater. The premier was attended by Hoffman and director Barry Levinson. Rainman became a critically acclaimed film and brought the term "autism" to the public.

Another first in autism in the nation occurred in 1999 when West Virginia became the first state in the nation to join the CDC's surveillance of autism study through a grant awarded to the WV Autism Training Center. Subsequently, West Virginia became the first state to establish autism spectrum disorders as a reportable condition of childhood. In 2002, The WV Autism Training Center established its College Program for Students with Asperger Syndrome making it the first of its type in the nation. This program supports college degree seeking students with Asperger syndrome as they navigate the social and academic aspects of college life. Beginning with one student in 2002, the program has grown to support 46 students from all across the nation.

In 2011 West Virginia became the 25th state in the nation to enact autism insurance legislation. Through the hard work of parents and professionals, and after several years of lobbying for the law, the legislation passed. Work continued in 2012 to improve and correct some of the language in the law.

As every state in the nation struggles to provide appropriate and vitally needed services for individuals with ASDs and their families and educators, it is important to remember that West Virginia has been a pioneer in so many areas. The work continues through the efforts of the agencies listed in this guide and through the collaborative efforts of WV Team Autism. The overarching goal of every state is to provide a seamless and coordinated system of service delivery that will increase the quality of life for those living with ASDs and their families. Our work in West Virginia diligently continues as we strive to achieve that goal.

Service Options

Finding services that work best for your family and child can seem like a full time job. However, having the supports that work for you, meet your child's needs, as well as support your dreams for their future can be is the best of all worlds.

Finding those services with the best fit for you can be challenging but not impossible. It takes doing your homework, networking with other families and professionals, and always seeking out the answers to the questions you have.

This section of our guide provides you with some general information on service options in West Virginia.

West Virginia Autism Training Center

In 1983, The West Virginia Legislature approved a bill to establish a state-wide center that would focus on providing education and training to parents, educators and others significant in the lives of West Virginians with a primary diagnosis of autism. It was determined that the center would be housed at Marshall University. The West Virginia Autism Training (WV ATC) offers a variety of educational and resource services and provides these services in the local community where the individual resides.

Who is eligible for services? Any West Virginia resident with a primary diagnosis of autism, pervasive developmental disorder (PDD-NOS), or Asperger Syndrome can register for the services of the WV ATC.

What do I do to apply? Registering for services is easy. Just call 1-800-344-5115 (toll free in WV) or 304-696-2332 and ask to speak to the intake coordinator. The in-take coordinator will get some basic information from you and will send you an application packet. You will complete the application forms and submit a copy of the diagnostic report that shows your child has a diagnosis of autism, PDD-NOS or Asperger Syndrome. Soon thereafter, you will receive a packet of information which will include your registry card. You will also receive a call from the intake/family resource coordinator to review the information contained in the packet and to answer any questions. She will explain how you can use your registry card.

What services can I receive as a registered family? The following training and resource services are among those available at no cost to registered families:

- A lending library of books and DVDs related to autism spectrum disorders
- Participation in WV ATC workshops and in-service training at no cost
- Coaching sessions on a variety of topics (conducted by our family resource coordinator by phone)
- Information about national, state, and local community resources
- The Family Focus Positive Behavior Support process

Who can I contact for more information about the WV ATC? Call 1-800-344-5115 or 304-696-2332 for more information. Ask for the intake/family resource coordinator, they will be able to answer any questions or if you have a very specific question, they will connect you with the appropriate individuals.

Please visit the WV Autism Training Center website at
<http://www.marshall.edu/atc>

WV Birth to Three

WV Birth to Three is the state early intervention program. Early intervention services are described in the Individuals with Disabilities Education Act, which provides states with federal grants to support the activities of states in supporting it's youngest citizens. The intent of WV Birth to Three services is to enhance the capacity of families to meet the needs of their children and to minimize the impact of a child's disabilities on their ability to participate in the daily life of the family.

The WV Birth to Three system provides home and community based education opportunities for families with young children, aged birth through age 2, who are experiencing one of the following:

- Developmental delay, or
- A physical or medical condition that is likely to result in a developmental delay, or
- Biological and/or environmental risk factors that may contribute to developmental delays.

Services and supports from WV Birth to Three are focused on the priorities and concerns of families and should address the unique needs of each individual child. When a child is referred to the WV Birth to Three system a comprehensive evaluation and assessment of the child's strengths, challenges and needs for support across the everyday activities and routines of the child and family. If the child is determined eligible for the WV Birth to Three system an Individualized Family Service Plan (IFSP) is developed which will spell out the outcomes the family and team will be working toward as well as the services and supports that will be provided in collaboration with the family.

WV Birth to Three Contacts

Updated 8-2013

Region	Address	Phone/Email	Counties Served
State	WV Birth to Three State Office 350 Capitol St, Rm 427 Charleston, WV 25301-3714	304-558-5388 Fax 304-558-2183 Toll Free 1-800-642-9704 dhhrwbtt@wv.gov	
1	Wendy Miller, Coordinator Catholic Charities WV 2000 Main Street, Ste 121 Wheeling, WV 26003	304-214-5775 Fax 304-214-5792 Toll Free: 1-800-619-5697 wmiller@ccwva.org	Brooke, Hancock, Marion, Marshall, Monongalia, Ohio, Tyler, Wetzel
2	Helen Wilson, Coordinator The Arc of Mid-Ohio Valley 912 Market Street Parkersburg, WV 26101	304-485-2000 Fax 304-865-2072 Toll Free: 1-866-401-8919 Birthto3@arcwd.org	Calhoun, Doddridge, Gilmer, Harrison, Pleasants, Ritchie, Wirt, Wood
3	Barbara Tucker, Coordinator River Valley Child Development 1701 5 th Ave, Box 14 Charleston, WV 25312	304-414-4460 Fax 304-414-4461 Toll Free: 1-866-402-2094 RAURegion4@aol.com	Clay, Jackson, Kanawha, Roane
4	Barbara Tucker, Coordinator River Valley Child Development 432 – 2 nd Street Huntington, WV 25701	304-523-5444 Fax 304-523-5556 Toll Free: 1-866-982-8855 RAURegion4@aol.com	Boone, Cabell, Lincoln, Logan, Mason, Mingo, Putnam, Wayne
5	Rachel Hamner, Coordinator Mountain Heart Community Services 1200 Harrison Avenue, Suite 220 Elkins, WV 26241	304-637-2844 Fax 304-637-2845 Toll Free: 1-800-449-7790 rachel.t.hamner@wv.gov	Barbour, Lewis, Preston, Randolph, Taylor, Tucker, Upshur
6	Rachel Hamner, Coordinator Mountain Heart Community Services Work 4 WV Center PO Box 1610 Lewisburg, WV 24901	304-647-3810 Fax 304-647-5521 Toll Free: 1-866-229-0461 rachel.t.hamner@wv.gov	Braxton, Greenbrier, Monroe, Nicholas, Pocahontas, Summers, Webster
7	Melissa Saddler, Coordinator Mountain Heart Community Services Post Office Box 5650 Princeton, WV 24740	304-425-2926 Fax 304-425-7367 Toll Free: 1-866-207-6198 melissa.k.saddler@wv.gov	Fayette, McDowell, Mercer, Raleigh, Wyoming
8	Elizabeth M. Loy, Coordinator RESA VIII Child Development Services 109 S. College Street Martinsburg, WV 25401	304-267-3595 Fax 304-267-3599 Toll Free: 1-866-681-4957 eloy@access.k12.wv.us	Berkeley, Grant, Hampshire, Hardy, Jefferson, Mineral, Morgan, Pendleton

Public Education

Special education services pick up where early intervention services leave off, at age 3. Your county school district provides these services through their special education department. The focus of special education is different from that of early intervention. While early intervention addresses your child's overall development, special education focuses on providing your child with an education, regardless of disabilities or special needs. The document that spells out your child's needs and how these needs will be met is the **Individualized Education Program (IEP)**. Like the IFSP, the IEP describes your child's strengths and weaknesses, sets goals and objectives, and details how these can be met. Unlike the IFSP that focuses on supporting the child and family in home and community settings, the IEP is almost entirely related to how the school district will support your child in learning and functioning within the school environment.

Special Education Services – For Children Ages 3 - 22

The Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446, (IDEA 2004) and the IDEA regulations (34 CFR Part 300), require that States set forth policies and procedures to demonstrate that the a goal has been established providing full educational opportunity to all students with disabilities who are residents, aged birth through twenty-one years of age and a detailed timetable for accomplishing that goal. West Virginia is diligently working to ensure full educational opportunities for all students with disabilities, aged birth through twenty-one years of age. The State works toward the realization of this goal through the implementation of, and compliance with, IDEA 2004 and any subsequent reauthorization, state policies and procedures and the implementation of the West Virginia Continuous Improvement and Focused Monitoring System (CIFMS).

Accessing Services: Your Child's Rights for Public Education

Every child has the right to a free appropriate education. The Individuals with Disabilities Education Act (IDEA), enacted in 1975, mandates a public education for *all* children and makes the schools responsible for providing the supports and services that will allow this to happen. The law mandates that the state provide children with a free appropriate public education that meets his or her unique individual needs. In addition, the IDEA legislation has established an important team approach and a role for parents as equal partners in the planning for an individual child, and promotes an education in the least restrictive environment. In addition to IDEA, there are other laws that provide guidance to schools and protections for students, these include:

- Americans with Disabilities Act of 1990 (ADA) sets forth, as a civil right, protections and provisions for equal access to education for anyone with a disability
- Section 504 of the Rehabilitation Act of 1973 is another civil rights law that prohibits discrimination on the basis of disability in programs and activities, public and private that receive federal financial assistance.

What is a “Free and Appropriate Public Education” (FAPE)?

A free appropriate public education (FAPE) must be available to all students residing in WV between the ages of three and twenty-one, inclusive, who are eligible for special education services. Each word in this phrase is important, but “appropriate” is the one that relates specifically to your child with special needs. FAPE is individually determined for each student, based upon their unique needs that will allow them to make educational progress. Although you and your child's teachers or therapists may want to provide your child with the best and optimal programs and services, the school district is simply required to provide an appropriate education. FAPE must include special education services in the least restrictive environment (LRE) and may include related services, transition services, supplementary aids and services, and/or assistive technology devices and services. Districts must also ensure that students have available to them the variety of education programs and services available to students without

exceptionalities including art, music, industrial arts, consumer and homemaking education and vocational education. One of the challenges here is working with the school district to determine what is appropriate and, therefore, what will be provided for your child. This is a collaborative process, and may require considerable negotiation in order to secure the appropriate services from the school.

What is “Least Restrictive Environment” (LRE)?

IDEA also provides that children with disabilities are entitled to experience the “least restrictive environment” in schools. This means that eligible students must be educated with general education students in the general education classroom, in their home school, to the maximum extent appropriate. Removal from the general education environment occurs only when the nature or severity of the exceptionality is such that education in general classes and other settings with general education students cannot be achieved satisfactorily even with the use of supplementary aids and services. This does not mean that every student has to be in a general education classroom, but the objective is to place the student in as natural a learning environment as possible, within his home community.

The participation of children with disabilities in the general education environment is often referred to as “mainstreaming” or “inclusion.” Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations, and to successfully situating a child with a disability in the least restrictive setting. In determining an appropriate placement in the LRE, the IEP Team begins with the general education environment with supplementary aids and services. If the student’s IEP cannot be implemented in that environment with an expectation of reasonable progress on and achievement of IEP goals, a placement on the continuum of placement options providing less education with students without disabilities may be considered. An eligible student is not to be removed from age-appropriate general education classrooms solely because of needed accommodations and modifications to the general education curriculum. The IEP must explain the extent, if any, to which the student will not participate in the general education classroom, the general education curriculum, or extracurricular or other nonacademic activities and indicate the percentage of time in general and special education.

Participation in Nonacademic and Extracurricular Services and Activities: The IEP Team determines the supplementary aids and services appropriate and necessary for the student to participate with students without disabilities in nonacademic and extracurricular services and activities to the maximum extent appropriate. These services and activities may include, but are not limited to, meals, recess, field trips, counseling services, athletics, transportation, health services, recreational activities, special interest groups or clubs sponsored by the district, referrals to community agencies, career development and assistance in making outside employment available.

Parent involvement in education has proven to be a key factor in the success children achieve in school, but not every parent knows how to be involved and not every teacher or school administrator knows how to encourage participation from families. Connecting the dots of communication between home and school has become an important focus for the WV Department of Education, Office of Special Programs.

Information in this section is adapted from the following:

- Autism Speaks (2013). 100 day kit. Retrieved from <http://www.autismspeaks.org/family-services/tool-kits/100-day-kit>.
- WV Department of Education (2012). Education for students with exceptionalities. Retrieved from <http://apps.sos.wv.gov/adlaw/csr/readfile.aspx?DocId=23475&Format=PDF>.

County Special Education Directors & Parent Educator Resource Center Staff

Updated 8-2013

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State Department of Education	Office of Special Programs Building 6, Rm 304 1900 Kanawha Blvd Charleston, WV 25305	304-558-2696 Fax: 304-558-3741 Toll Free: 800-642-8541	Betsy Peterson	bpeterso@access.k12.wv.us
Barbour	Jana Miller 105 S Railroad St Philippi, WV 26416	304-457-3030 Fax: 304-457-3559 janmille@access.k12.wv.us	Mary McCartney & Lisa Lepsch Belington Middle Rt 2 Box 343 Belington, WV 26250	304-823-1245 Mary – bswdpe@yahoo.com Lisa – llepsch@access.k12.wv.us
Berkeley	Hal Van Metre 515 W Martin St Martinsburg, WV 25401-3285	304-264-5055 ext 303 Fax: 304-264-5058 hvanmetr@access.k12.wv.us	Lynn Reichard 515 W Martin St Martinsburg, WV 25401-3285	304-263-5717 Fax- 304-263-5767 lreichar@access.k12.wv.us
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Clay	Bev Nichols PO Box 120 Clay, WV 25043-0120	304-587-2077 Fax: 304-587-4181 bnichols@access.k12.wv.us		

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Jackson	Lisa Martin P.O. Box 770 Ripley, WV 25271-0770	304-372-7309 Fax: 304-372-7312 ldmartin@access.k12.wv.us	Brandi Randolph & Cathy Stout P.O. Box 770 Ripley, WV 25271	304-273-3545 Brandirandolph@hotmail.com ccstout@access.k12.wv.us

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Kanawha	Sandra Boggs 200 Elizabeth Street Charleston, WV 25311-2119	304-348-7740 Fax: 304-348-6671 sboggs@kcs.kana.k12.wv.us	Sheila Harper, Marilyn Nichols, Samantha Perna, & Jane Pierce 157 2 nd Avenue South Charleston, WV 25303	304-348-7715 Fax: 304-205- 6048 perc@kcs.kana.k12.wv.us
Lewis	Dr. Carol Williams 239 Court Avenue Weston, WV 26452-2002	304-269-8300, Ext. 120 Fax: 304-269-8342 cgwillia@access.k12.wv.us		
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Logan	Leah Perry 66 School Street Logan, WV 25601	304-792-2076 Fax: 304-752-7471 lperry@access.k12.wv.us	Debbie Willis P.O. Box 477 Logan, WV 25601	304-792-2075 Fax: 304-752-7471 dwillis@access.k12.wv.us
Marion	Gia Deasy 200 Gaston Avenue Fairmont, WV 26554-2778	304-367-2120 Fax: 304-367-8976 gdeasy@access.k12.wv.us		
Marshall	Shelby Haines 2700 4 th St PO Box 578 Moundsville, WV 26041-0578	304-843-4400 ext 138 shaines@access.k12.wv.us	Cathy Givens & Susie Baker 162 Middle Grave Creek Road Moundsville, WV 26041	304-843-4457 Fax: 304-843-4461 cjgivens@access.k12.wv.us psbaker@access.k12.wv.us
Mercer	Todd Browning 1403 Honaker Avenue Princeton, WV 24740-3048	304-487-1551 ext 290 Fax: 304-4821840 tbrowning@access.k12.wv.us		
Mineral	Susan Vance One Baker Place Keyser, WV 26726-2898	304-788-4218 Fax: 304-788-4204 svance@access.k12.wv.us		
Mingo	Janet Varney Rt 1 Box 310 Williamson, WV 25661-9746	304-235-7110 Fax: 304-235-3705 jvarney@access.k12.wv.us	DeAnna New, Teria Keathley & Christie Tilley Rt 2 Box 310 Williamson, WV 25661	304-235-3333 ext 7113 Fax: 304-235-5191 dnew@access.k12.wv.us tkeathle@access.k12.wv.us ctilley@access.k12.wv.us

County	Address	Contact Information	PERC Address	PERC Contact Information
Monongalia	Tiffany Barnette 13 South High Street Morgantown, WV	304-291-9210 ext 512 Fax: 304-296-1379 tbarnet@access.k12.wv.us	Julie Parsons & Pat Stemple 200 W Park Ave Westover, WV 26501	304-291-9288 ext 238 Fax 304-291-9311 jparson@access.k12.wv.us
Monroe	Brian Baker PO Box 330 Union, WV 24983-0330	304-772-3094 Fax: 304-772-5020 bkbaker@access.k12.wv.us		
Morgan	Terry Riley 247 Harrison Avenue Berkeley Springs ,WV 25411-1909	304-258-2014 ext 21 Fax: 304-258-9146 tjriley@access.k12.wv.us		
Nicholas	Kathy Sibbett 400 Old Main Drive Summersville, WV 26651-1388	304-872-3611 ext 143 Fax: 304-872-5012 ksibbett@access.k12.wv.us		
Ohio	Leah Stout 2203 National Road Wheeling, WV 26003	304-243-0314 Fax: 304-243-0347 lmstout@access.k12.wv.us		
Pendleton	Donald Bucher PO Box 888 Franklin, WV 26807-2207	304-358-2207 Fax: 304-358-2936 dbucher@access.k12.wv.us	Sarah Boggs & Diana Smith PO Box 888 Franklin, WV 26807	304-358-7072 Fax: 304-358-32936 Tirzahjoy03@yahoo.com dsmith@access.k12.wv.us
Pleasants	Kim Kehrer 202 Fairview Drive St. Marys, WV 26170	3304-684-2215 Fax: 304-684-3569 kkehrer@access.k12.wv.us	Sherri West & Helen Wells PO Box 308 St Marys, WV 26170	Teresa Knight Phone: 304-684-7643 Knight1004@frontier.com
Pocahontas	Ruth Bland 926 Fifth Avenue Marlinton, WV 24954-1298	304-799-4505 Fax: 304-799-4499 rbland@access.k12.wv.us		
Preston	Angie Varner 300 Preston Drive Kingwood, WV 26537-0566	304-329-0580 ext 223 Fax: 304-329-0720 arharris@access.k12.wv.us		
Putnam	Annette Pratt 9 Court House Drive Winfield, WV 25213-9348	304-586-0500 ext 1111 Fax: 304-586-0555 anpratt@access.k12.wv.us		
Raleigh	Cynthia Corley-Hicks 136 Sullivan Road Glen Morgan, WV 25847	304-256-4559 Fax: 304-256-4715 Cyhicks@access.k12.wv.us	Ruth Baker, Ann Darby & Lori Thompson 301 Park Avenue Beckley, WV 25801	304-256-4667 Fax: 304-256-4563 Rbaker1018@aol.com adarby@access.k12.wv.us llthomps@access.k12.wv.us

County	Address	Contact Information	PERC Address	PERC Contact Information
Randolph	Donna Simmons 40 – 11 th Street Elkins, WV 26241	304-636-9150 ext 153 Fax: 304-6367-2516 dnsimmon@access.k12.wv.us		
Ritchie	Deborah Bever 134 South Penn Street Harrisville, WV 26362-0216	304-643-2991 ext 226 Fax: 304-643-2994 dbever@access.k12.wv.us		
Roane	Melissa O'Brien PO Box 609 Spencer, WV 25276-0609	304-927-6405 Fax: 304-927-6440 mobrien@access.k12.wv.us		
Summers	Kim Rodes 116 Main Street Hinton, WV 25951-2439	304-466-6006 Fax: 304-466-6008 krodes@access.k12.wv.us		
Taylor	Suzanne Viski RR 2 Box 157 Grafton, WV 26354	304-265-2497 ext 21 Fax: 304-265-2508 sviski@access.k12.wv.us		
Tucker	Kim Lipscomb 501 Chestnut Street Parsons, WV 26287-1005	304-478-2771 Fax: 304-478-3422 knorman@access.k12.wv.us	Cindy Simmons & Angie Davis 501 Chestnut Street Parsons, WV 26287-1005	304-478-3827 Fax: 304-478-966 cindyrobson@hotmail.com foreverdavis@hotmail.com
Tyler	Melinda Walton PO Box 25 Middlebourne, WV 26149-0025	304-758-2145 Fax: 304-758-4566 mwalton@access.k12.wv.us		
Upshur	Tina Lou Edwards 102 Smithfield Street Buckhannon, WV 26201-4309	304-472-5480 ext 1016 Fax: 304-472-0258 tnedward@access.k12.wv.us		
Wayne	Kim Adkins 212 North Court Street PO Box 70 Wayne, WV 25570-0070	304-272-5116 ext 348 Fax: 304-272-5993 kkadkins@access.k12.wv.us	Patricia Cline & Mary Lynne Smith PO Box 70 Wayne, WV 25570-0070	304-272-5993 ext 345 Fax: 304-272-5993 plcline@access.k12.wv.us mrysmith@access.k12.wv.us
Webster	Mike Bonnett 315 South Main Street Webster Springs, WV 26288-1123	304-847-5638 ext 120 Fax: 304-847-2538 mbonnett@access.k12.wv.us	Vicki Hamrick 315 South Main Street Webster Springs, WV 26288-1123	304-847-5638 ext 120 Fax: 304-847-2538 vhamrick@access.k12.wv.us
Wetzel	Deborah Novotny 333 Founddry Street New Martinsville, WV 26155-1110	304-455-2441 ext 23 Fax: 304-455-3446 dnovotny@access.k12.wv.us	Anita Estel WCCCF RR 2 Box 107 New Martinsville, WV 26155	304-455-3014 anitaestel@yahoo.com

County	Address	Contact Information	PERC Address	PERC Contact Information
Wirt	Angie Cox PO Box 189 Elizabeth, WV 26143-0189	304-275-4279 Fax: 304-275-4581 amcox@access.k12.wv.us	Mary Beth McCloy & Ashley Gunnoe PO Box 699 Elizabeth, WV 26143	304-275-3977 ext 30 perc.wirt@gmail.com agunnoe@access.k12.wv.us
Wood	Holly Yoke 1210 Thirteenth Street Parkersburg, WV 26101-4198	304-420-9655 Fax: 304-420-9689 ysantin@access.k12.wv.us	Beverly Shelton, Suzy Howell & Janet Memel 1210 Thirteenth Street Parkersburg, WV 26101-4198	304-420-9590 Fax: 304-420-9689 (Call 1 st) bshelton@access.k12.wv.us sahowell@access.k12.wv.us jmemel@access.k12.wv.us
Wyoming	Karolyn Stump PO Box 69 Pineville, WV 24874-0069	304-732-6262 ext 203 knstump@access.k12.wv.us		
WV Schools for the Deaf and the Blind	Russell Conrad 301 East Main Street Romney, WV 26757	304-822-4863 ext 863 Fax: 304-822-4849 reconrad@access.k12.wv.us		

Center For Excellence in Disabilities

Established in 1978, the Center for Excellence in Disabilities (CED) is located in Morgantown, West Virginia and has a satellite office in Big Chimney, West Virginia with staff located in offices across the state to better serve clients in their communities. The CED is a unit within West Virginia University (WVU), Health Sciences, and because of the placement within the University, has access and alignment within the Schools of Pharmacy, Public Health, Nursing, Medicine and Dentistry. Reporting authority with WVU tacitly supports the opportunity for collaboration, education and training needed to support and strengthen the state's capacity to meet the needs of persons with disabilities. - See more at: <http://cedwvu.org>

Positive Behavior Support Project

Positive Behavior Support (PBS) is an inclusive approach for developing effective behavior supports. Positive Behavior Support utilizes functional behavioral assessments to develop supports for individuals. Work is done with an interdisciplinary team and starts with participants' personal goals and desires. The emphasis is on modifying the environment so that individuals can lead fulfilling and productive lives in community settings.

The Positive Behavior Support process utilizes a team approach to create support plans by asking, "Why is this person behaving this way?" Positive Behavior Support is a long-term approach that focuses on teaching participants new behaviors to replace challenging ones. It requires an initial investment of time and resources from a variety of people to create real and lasting change. Positive Behavior Support is positive and proactive and focuses on preventing problems before they occur.

The Crisis Services (in the Positive Behavior Support project) are time-limited consultations designed to assist interdisciplinary teams in stabilizing the behavior of individuals who are in crisis. After stabilization, Positive Behavior Support services and trainings are available to assist the team in supporting the individual.

The Positive Behavior Support Project is designed to strengthen, develop, or combine community resources through the provision of a comprehensive and intensive consultation service to staff, parents, professionals, and individuals with challenging behavior in West Virginia. Positive Behavior Support consultants operate from a person-centered values base and will apply state-of-the-art teaching, assessment, and management technologies to develop support providers' capacities. See more at: <http://pbs.cedwvu.org> or call 304-293-4692.

Training and Resources for Autism Insurance Navigation in WV Project

Our goal at TRAIN is to provide information and access to those parents, autism professionals, and insurance providers who are navigating West Virginia's recently-passed insurance coverage for children with autism. Passing this legislation was a major milestone in making effective services available to the public. The success we have achieved so far is due in large part to the collaborative effort of our stakeholder's, however; the task is not yet complete. Questions and concerns regarding the implementation of the legislation create obstacles that delay access to much needed services. TRAIN was established to help navigate these obstacles more efficiently. Rather than tackling each problem on an individual basis our goal is provide a united front where all stakeholders have equal access to resources and information to aid in successful implementation. Parents can sign up for the TRAIN Newsletter or locate providers at: <http://trainwv.cedwvu.org>

A Summary of the Autism Insurance Legislation -

The new autism insurance legislation requires coverage for autism spectrum disorders for policies renewed after January 1, 2012. Coverage includes treatments that are medically necessary including Applied Behavior Analysis (ABA). This coverage applies to any individual between 18 months and 18 years of age diagnosed with an autism spectrum disorder before the age of 8. For more information about services and eligibility please visit: <http://trainwv.cedwvu.org> or call 304-293-4692.

Parent Network Specialists Project

PNS primarily assists children and families enrolled in the CSHCN program with educational, vocational and transitional services. This statewide project features five Specialists who are parents of children of varying ages who have a disability and are located in geographically strategic areas of West Virginia. These Parent Network Specialists provide one-on-one information and referral services and follow-up to families who have a child with a disability. Parent Network Specialists receive on-going training in pertinent areas such as Title XIX MR/DD Waiver and Medicaid processes, HIPAA regulations, the roles of other agencies, and the availability of resources.

The Parent Network Project has produced a Care Notebook for parents and other family members caring for a child with a disability. The Care Notebook is a case management tool and a resource guide, which can be used as a single depository of information (e.g., medical, emergency contacts, and care provider contact information) that parents can have available to take to appointments or to leave at home as a reference for care providers. The annotated resource guide section provides contact information for disability-related agencies and services. See more at: <http://pns.cedwvu.org>

Parent Network Specialist	Contact Information Updated 8-2013	Counties Served
Sandra Buchanan	CED – 959 Hartman Run Rd, Morgantown, WV 26505 304-293-4692, Fax 304-293-7294 sbuchanan@hsc.wvu.edu	Brooke, Hancock, Harrison, Marion, Marshall, Monongalia, Ohio
Connie Dulaney	Wood County DHHR – 400 5 th Street, Parkersburg, WV 26102 304-420-2560, Fax 304-420-4886 connie.l.dulaney@wv.gov	Calhoun, Doddridge, Gilmer, Pleasants, Ritchie, Tyler, Wetzel, Wirt, Wood
Kelly Miller	Charleston PNS – 350 Capitol Street, Rm 427, Charleston, WV 25301 304-356-4359, Fax 304-558-2866 kelly.n.miller@wv.gov	Boone, Cabell, Kanawha, Lincoln, Logan, Mingo, Wayne
Susanne Taylor	CED – 4510 Pennsylvania Ave, STE B, Charleston, WV 25302 304-720-3200, Fax 304-720-3204 sutaylor@hsc.wvu.edu	Jackson, Mason, McDowell, Mercer, Putnam, Roane, Wyoming
Terry Vankirk	Braxton County DHHR – 1920 Sutton Ln, Sutton, WV 26601 304-765-7344, Fax 304-765-3694 terry.l.vankirk@wv.gov	Braxton, Clay, Fayette, Greenbrier, Lewis, Monroe, Nicholas, Pocahontas, Raleigh, Summers, Upshur, Webster
Wanda Hedrick	Pendleton County DHHR – 100 Thorn Creek Rd, Ste 200, Franklin, WV 26807 304-358-2305, Fax 304-358-7163 wanda.j.hedrick@wv.gov	Barbour, Berkeley, Grant, Hampshire, Hardy, Jefferson, Mineral, Morgan, Pendleton, Preston, Randolph, Taylor, Tucker

WV Assistive Technology Clinic

Assistive Technology (AT) is any device used to perform tasks that would otherwise be difficult or impossible. These devices can be as complex as computers with screen reading software or as simple as Velcro used in place of buttons or shoe laces.

Examples of assistive technology:

- People who are blind or have low vision can use assistive technology ranging from a magnifier to a screen reader for a computer.
- People with physical disabilities can use assistive technology ranging from a cane to a power wheelchair.

The AT Clinic assessment team is led by a nationally certified Assistive Technology Practitioner, Jamie Hayhurst. The team is designed to help individuals identify and use assistive technology to support independence and enhance their quality of life.

Clinic staff works with clients, families, providers, vendors and insurers to determine the type of assistive technology that best meets the needs of the individual, and to identify possible funding sources.

Assistive Technology Clinic Services

Interdisciplinary clinical assessments can include:

- Computer access
- Environmental controls
- Adaptations to living and work environments
- Activities of daily living
- Recreational activities

Where are services offered? Assistive Technology Clinic services are offered in Morgantown at the Center for Excellence in Disabilities.

Who provides these services? An interdisciplinary team is brought together around the needs of each client. A team can include a physical therapist, occupational therapist, neurologist and an assistive technology practitioner.

How much do these services cost? There is **no** charge for individuals.

Clinic fees for agencies and organizations:

- Comprehensive assistive technology assessments - \$850
- Computer access assessments - \$300

Who is eligible for services? Any individual, or agency/organization representing an individual, who may need assistive technology devices or services.

How do I make an appointment or make a referral for services? Call 800-841-8436.

What other help is available? After the assessment, staff will follow up with each client to ensure that the recommended assistive technology is received, that it functions properly, fulfills the recommendations made by the assessment team and meets the individual's needs to the greatest extent possible. See more at:

<http://clinics.cedwvu.org/atclinic>

Feeding and Swallowing Clinic

The Feeding and Swallowing Clinic provides interdisciplinary assessments of infants, children and adolescents who have feeding, eating, or swallowing problems. Assessments are completed by a team of professionals in the areas of nutrition, occupational therapy, behavioral psychology, speech-language pathology, and social work.

The Objectives Of The Clinic Are:

- Improve eating skills and behaviors
- Improve physical growth and development
- Improve the nutritional status of children

The Clinic Assists Families In:

- Promoting self-feeding
- Increasing acceptance of food types and textures
- Transitioning from tube feeding to eating by mouth
- Improving sucking, chewing, biting and/or swallowing skills
- Improving meal-time behaviors
- Improving the quality of the diet

Appointments And Clinic Visits

- Call 304-293-4692, fax 304-293-4692 or e-mail the clinic coordinator (mandis@hsc.wvu.edu) to make an appointment. Once scheduled, a packet of information is sent to the family.
- Families are welcome to bring caregivers and professionals who work with their children to the clinic. Visits usually take between one and two hours.
- The Feeding Clinic has family friendly clinic rooms. The Feeding Team is present for each visit, with the team members usually taking turns going into the clinic to interact with and evaluate each child. Family members typically stay with their children in the clinic room for the entire visit.
- Techniques in feeding and positioning may be demonstrated; behavioral strategies, assistive technology, nutrition and other issues may be discussed. Families receive written reports several weeks after their visit. See more at: <http://clinics.cedwvu.org/feeding>

Intensive Autism Service Clinic

Autism is a lifelong neurobiological disorder that impairs a person's ability to communicate and relate to others. The CDC estimates that 1 in 88 children have an autism spectrum disorder. Boys are four times more likely than girls to be affected by autism. Autism is the fastest growing developmental disability with a growth rate of 10% to 17% annually.

The intensive Autism Service Delivery Clinic (iASD) sees children with a diagnosis of autism spectrum disorder from the ages of two to six. One of the main goals is to help the child "learn to learn" through intensive, individualized one-to-one intervention. Having an impact on these skills at this young age has been shown to have a profound positive impact for children with autism through their lifetimes.

What Services Are Offered? The Clinic is currently providing very successful one-to-one behavioral services to a limited number of children, ages 2 to 6 years, who have been diagnosed with an autism spectrum disorder. All treatment is based on the science of applied behavior analysis, combining discrete trial training with naturalistic and incidental teaching. Young children served by the clinic receive between 7 and 35 hours of free services per week. They each have an individualized curriculum updated weekly and are taught by at least two different therapists (which helps the skills to generalize) throughout each day.

The Clinic Helps Children To: "Learn how to learn" through evidence-based behavioral interventions. Learning assessments are completed on each child and individualized curriculum is developed and implemented to assist in skill building in all areas of development.

Where Are Services Offered? The Intensive Autism Service Delivery Clinic takes place in Morgantown at the Center for Excellence in Disabilities.

How Much Do These Services Cost? There is **no** charge for these services at the time.

Who Provides These Services? All programming is supervised and overseen by a Board Certified Behavior Analyst (BCBA) who has experience in working with young children with autism, and is implemented by trained students or volunteers who are seeking experience in this field. Many of our student volunteers are from the Behavioral Intervention Program in the Department of Psychology-the only such program in the state-that requires 70+ hours of supervised hands-on experience in order to sit for their BCBA licensing exam.

Who Is Eligible For These Services? Children with a diagnosis of autism from of the two to six. The Clinic is currently limited to five children on rotating schedules due to space requirement and the availability of trained therapists.

Who provides these services? Our knowledgeable staff!

How do I make an appointment or make a referral for services? Call toll free at **888-829-9426** to be put on the waiting list. See more at: <http://clinics.cedwvu.org/autism>

Early Childhood Lending Library

The Early Childhood Lending Library contains numerous resources for parents, educators, students, service providers and the general public. Resource topics include:

- Pregnancy/Parenting
- Early childhood development
- Family health
- Disabilities across the lifespan
- Team building
- Assistive technology

To see what resources are available, visit the Virtual Loan Library at <http://vll.cedwvu.org>.

Items may be borrowed from the Library for a period of 30 days. A loan agreement outlines the terms of the lending policy and is available by calling 800-642-9704. Items available for loan include:

- Books
- Video (VHS)
- Training Curricula
- Assistive Technology Devices
- Toys
- Journals/Magazines

Items can be mailed to you at no cost. However, you are responsible for paying mailing costs to return items you have borrowed. See more at <http://cedwvu.org/resources/library.php>.

Intellectual/Developmental Disability Waiver

WV I/DD Waiver is a Federal/State funded program designed to deliver services to individuals with intellectual disabilities or related developmental disabilities in their homes and communities. The I/DD Waiver program reimburses for services to instruct/train, support and assist eligible individuals to achieve the highest level of independence possible.

Eligibility Requirements

- Person must have a diagnosis of mental retardation and/or related conditions
- Person must require the same level or type of care provided in an ICF/MR facility
- Person must have substantially limited functioning in 3 of the following areas:
 - ✓ Self-care
 - ✓ Receptive/Expressive Language
 - ✓ Learning
 - ✓ Mobility
 - ✓ Self-Direction
 - ✓ Capacity for Independent Living
- Person's income must be less than three times the maximum monthly SSI benefit rate
- Person must have less than \$2000 in assets (minus any allowable exclusions)

How Do I Apply?

- Receive an application (WVBMS I/DD-01) information packet from one of the following locations:
 - ✓ Local Behavioral Health Center
 - ✓ County DHHR Office
 - ✓ APS Healthcare
- The applicant and/or legal representative must complete the application and submit it to APS Healthcare
- Any location sit can assist the applicant to complete the application at no cost
- The applicant will be contacted to select a psychologist within WV's Independent Psychologist Network to complete the assessments required to apply
- The assessments are completed and submitted within 60 days of initial application
- A final eligibility determination will be made by WV's Medical Eligibility Contract Agent within 30 days of receipt based on medical, physical, psychological and social evaluations of the applicant

For More Information Contact

APS Healthcare – I/DD Waiver Program
100 Capitol Street, STE 600, Charleston, WV, 25301
866-385-8920, Fax 866-521-6882
wvddwaiver@apshealthcate.com

WV Department of Vocational Rehabilitation

The Division of Rehabilitation Services is West Virginia's primary vocational rehabilitation resource for people with disabilities who want to work. DRS helps many West Virginians prepare for careers consistent with their interests, needs and abilities. DRS helps many more to maintain their current employment if a disability is making it difficult to continue working.

Vocational rehabilitation provides direct, personalized services. During the vocational rehabilitation process, a counselor will work with you one-on-one to plan an individualized program that leads to paid employment. You will actively participate in planning your services, and how those services will be delivered. Services may include evaluation, restoration, vocational training, occupational tools and equipment, assistive technology and job placement assistance. Work-related counseling is the most essential service offered by DRS. A trained counselor will be available throughout the rehabilitation process to answer questions, help with problems and offer guidance toward achievement of your rehabilitation goals. A successful rehabilitation may take anywhere from several months to several years.

Are You Eligible?

Eligibility is based on three factors:

- you have a physical or mental condition that interferes with your ability to get or keep a job;
- you can benefit from services in terms of an employment outcome; and
- you need vocational rehabilitation services to get or keep a job.

To determine your eligibility for vocational rehabilitation services, an initial interview is set up between you and a rehabilitation counselor. If you wish, a friend or family member may accompany you. Your counselor will talk with you about your career plans and the services you feel are necessary to reach an employment goal. The counselor will ask about your work history, education, and disability.

If possible, bring any reports (medical, psychological, etc.) from people who have previously provided services to you. You should also bring your work history. This will help your counselor more quickly determine your eligibility for DRS services.

DRS is required by law to maintain your confidentiality. All personal information provided by you or any other source is strictly confidential and won't be released to anyone (other than your legal guardian, if applicable) without your written consent.

Making A Plan

After you have been determined eligible for services, the next step will be to develop an Individualized Plan for Employment (IPE) with your counselor. The IPE is an agreement between you and DRS that describes the services that will be provided for you to meet your employment goal.

Evaluation, counseling, job development, and placement services are provided at no cost to you. You may be required to share the cost of some services, but your rehabilitation counselor will talk to you about any costs before services start.

Basic services may include:

- Work-related counseling and guidance
- Evaluation services may include vocational, medical, psychological or educational evaluations
- Information and referral services

- Accessibility and worksite evaluations and accommodations
- Assistive technology
- Restoration services may include treatment of medical or psychological conditions; orthotic and prosthetic devices; or physical, occupational, speech, or hearing therapy
- Vocational training may include vocational school, college, technical or business school or on-the-job or supported employment training
- Employment services may include resumé writing and interview skills development, job search and placement

Your Right To Appeal

Your rehabilitation counselor will explain your rights at various times during the vocational rehabilitation process. If you have been denied services and you disagree with that decision, you can file an appeal. If you need help preparing the appeal, you can call the Client Assistance Program (CAP) operated by West Virginia Advocates, Inc. You may contact a CAP representative directly through the West Virginia Advocates at 1-800-950-5250. This is a toll-free call within West Virginia.

Apply For Services

If you are interested in applying for services, you may contact a DRS office near you or submit a request online at www.wvdrs.org.

WV Division of Rehabilitation Services Contacts

Updated 8-2013

District	Counties Served	Office Contact Information
1 – Charleston	Boone, Calhoun, Clay, Jackson, Kanawha, Mason, Putnam, Roane	<ul style="list-style-type: none"> • Charleston District & Branch Office – 304-356-2371 • Point Pleasant Branch Office – 304-675-0867 • Ripley Branch Office – 304-373-0313 • Spencer Branch Office – 304-927-0954 • Teays Valley Branch Office – 304-760-7082
2 – Clarksburg	Barbour, Gilmer, Harrison, Lewis, Marion, Monongalia, Preston, Randolph, Taylor, Tyler, Tucker, Upshur	<ul style="list-style-type: none"> • Clarksburg District & Branch Office – 304-842-2951 • Elkins Branch Office – 304-637-0205 • Fairmont Branch Office – 304-367-2714 • Morgantown Branch Office – 304-285-3155 • Weston Branch Office – 204-269-0547
3 – Wheeling	Brooke, Doddridge, Hancock, Marshall, Ohio, Pleasants, Ritchie, Tyler, Wetzell, Wirt, Wood	<ul style="list-style-type: none"> • Wheeling District & Branch Office – 304-238-1092 • Parkersburg Branch Office – 304-420-4580 • Parkersburg South High School – 304-420-4916 • Sistersville Branch Office – 304-652-2354 • Weirton Branch Office – 304-723-5311
4 – Beckley	Braxton, Fayette, Greenbrier, Mercer, Monroe, Nicholas, Pocahontas, Raleigh, Summers, Webster	<ul style="list-style-type: none"> • Beckley District & Branch Office – 304-256-6900 • Lewisburg Branch Office – 304-647-7515 • Oak Hill Branch Office – 304-465-3025 • Princeton Branch Office – 304-425-1256
5 – Huntington	Cabell, Lincoln, Logan, McDowell, Mingo, Wayne, Wyoming	<ul style="list-style-type: none"> • Huntington District & Branch Office – 304-528-5585 • Cabell Midland High School – 304-743-8496 • Huntington High School – 304-528-6511 • Logan Branch Office – 304-792-7060 • Marshall University – 304-696-2394 • Mullens Branch Office – 304-294-5653 • Prester Center – 304-399-7768 • Welch Branch Office – 304-436-3175
6 – Martinsburg	Berkeley, Grant, Hampshire, Hardy, Jefferson, Mineral, Morgan, Pendleton	<ul style="list-style-type: none"> • Martinsburg District & Branch Office – 304-267-0005 • Keyser Branch Office – 304-788-2313 • Moorefield Branch Office – 304-538-2701 • Romney Branch Office – 304-822-3957

Financial Resources

Adequate financial resources are key to a family accessing supports and services to maximize the health, educational, and independence of their children with Autism Spectrum Disorders.

West Virginia Children's Health Insurance Plan (WVCHIP)

What is WVCHIP? WVCHIP was created to help working families who do not have health insurance for their children.

Your children are eligible if they:

- Live in West Virginia
- Are 18 or younger
- Don't have health insurance now and haven't had it in the past six months (for the Basic CHIP Plans) or the past twelve months for the CHIP Premium Plan (some exceptions apply, go to <http://www.wvchip.org/insurance.shtml> for more information)
- Are not eligible for the West Virginia State Employee Health Insurance – PEIA
- Are not eligible for West Virginia Medicaid
- Live in families meeting WVCHIP Income Guidelines
- Are United States citizens or qualified aliens (Children who are not U.S. citizens must provide verification of their alien status.)

To apply: Go to the following website - <http://www.wvchip.org> or call 1-877-WVA-CHIP. TDD and translation services are available.

The CHIP Helpline operation hours are
Monday - Friday 8:00 AM to 8:00 PM and Saturday 8:00 AM to 4:00 PM

WV MEDICAID PROGRAM

Medicaid provides medical care to individuals who otherwise may not be able to afford the care. A variety of services are provided, according to state and federal guidelines, depending upon the individual or family circumstances. Recipients of Supplemental Security Income (SSI) automatically qualify for Medicaid. There are many ways to qualify to receive Medicaid.

HOW TO QUALIFY FOR MEDICAID

MEDICAID CITIZENSHIP AND IDENTITY REQUIREMENTS

All Medicaid applicants or recipients will be asked to provide documents to verify U.S. citizenship and identity. The following documents listed are some of those you may use to prove citizenship and/or identity.

Proof of Citizenship and Identity (No other proof required):

- U.S. Passport

Proof of Citizenship (Separate Proof of Identity Required):

- A U.S. public birth record
- A final adoption decree; evidence of civil service employment

Proof of Identity:

- School Identification Card with a photograph

Intellectual/Developmental Disability – I/DD Waiver

I/DD Waiver Program (formerly the MR/DD Waiver Program) provides services that instruct, train, support, supervise, and assist individuals who have intellectual disabilities and/or developmental disabilities in achieving the highest level of independence and self-sufficiency possible in their lives. The I/DD Waiver Program provides services in natural settings, homes and communities where the member resides, works, and shops instead of ICF/MR facilities.

Children With Disabilities Community Services Program – Cdcsp

CDCSP is a West Virginia optional program that provides Medicaid benefits to severely disabled children who meet the program's eligibility requirements. It is administered by the Bureau for Medical Services (BMS) and approved by the Centers for Medicare and Medicaid Services (CMS), the federal agency responsible for I/DD Waiver. The CDCSP is an alternative to institutionalization and provides medically necessary services that are community-based and costs less than institutional services.

HOW TO APPLY FOR MEDICAID

Contact the local DHHR office that serves your county and/or You can apply online by going to <https://www.wvinroads.org/inroads/PGM/ASP/SC001.asp>

Social Security Disability Income for Children

This provides information for the parents, caregivers or representatives of children under age 18 who have disabilities that might make them eligible for Supplemental Security Income (SSI) payments.

Supplemental Security Income (SSI) Payments For Children With Disabilities

SSI makes monthly payments to people with low income and limited resources. Your child under age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. The amount of the SSI payment is different from one state to another because some states add to the SSI payment. Your local Social Security office can tell you more about your state's total SSI payment.

SSI Rules About Income And Resources

When the Social Security Administration (SSA) decides if your child can get SSI, they consider your child's income and resources. They also consider the income and resources of family members living in the child's household. These rules apply if your child lives at home.

If your child's income and resources, or the income and resources of family members living in the child's household, are more than the amount allowed, the SSA will deny the child's application for SSI payments.

SSI Rules About Disability

Your child must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must not be working and earning more than \$1040 a month in 2013. (This earnings amount changes every year.) If he or she is working and earning that much money, we will find that your child is not disabled.
- The child must have a physical or mental condition, or a combination of conditions, that results in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.

If your child's condition(s) results in "marked and severe functional limitations" for at least 12 continuous months, we will find that your child is disabled. But if it does not result in those limitations, or does not last for at least 12 months, the SSA will find that your child is not disabled.

Providing Information About Your Child's Condition

When you apply for benefits for your child, the SSA will ask you for detailed information about the child's medical condition and how it affects his or her ability to function on a daily basis. They also will ask you to give permission for the doctors, teachers, therapists and other professionals who have information about your child's condition to send the information to us. If you have any of your child's medical or school records, please bring them with you. This will help speed up the decision on your application.

What Happens Next?

The SSA sends all of the information you give us to the Disability Determination Services in your state. Doctors and other trained staff in that state agency will review the information, and will request your child's medical and school records, and any other information needed to decide if your child is disabled.

If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask you to take your child for a medical examination or test. We will pay for the exam or test.

Immediate SSI Payments To The Child

It can take three to five months for the state agency to decide if your child is disabled. However, we consider certain medical conditions so limiting that we expect any one of them to disable a child. In these cases, we make SSI payments right away and for up to six months while the state agency decides if your child is disabled.

If your child has one of the limiting conditions that is expected to disable a child, he or she will get SSI payments right away. However, the state agency may finally decide that your child's disability is not severe enough for SSI. If that happens, you will not have to pay back the SSI payments that your child got.

How To Contact Social Security Administration

You may contact SSA directly by the website www.ssa.gov/onlineservices. In addition to using the website, you can call toll-free at **1-800-772-1213** to get specific questions answered from 7 a.m. to 7 p.m., Monday through Friday.

WV Insurance Legislation

The autism insurance mandate went into effect on July 1, 2011 and requires companies to cover autism treatments on plans issued or renewed after January 1, 2012. Any treatment that is medically necessary and prescribed by a licensed physician or licensed psychologist is covered. Applied Behavioral Analysis (ABA) services are expressly covered by the mandate.

The mandate applies to all individuals diagnosed with an autism spectrum disorder by age eight or younger who are currently 18 months to 18 years of age. According to the mandate, autism spectrum disorder includes "any pervasive developmental disorder, including autistic disorder, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder, or pervasive developmental disorder as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association."

This mandate does not apply to Medicaid/medical cards, self-funded plans, federal employees, insurance plans that originate outside of WV or companies with 25 or fewer employees. Many policies, such as those for coal mines and medical facilities, are self-funded. Asking if a policy is self-funded should be one of the first questions families ask when calling to access the autism benefit. For more information about West Virginia's insurance mandate visit <http://trainwv.cedwvu.org>.

Family Support

Family Support is a statewide service to assist families in accessing childcare, home modifications, transportation and other needed supports and services, this funding source is available through your local behavioral health center. A Family Support application can be obtained by calling your service coordinator/case manager or Family Support Coordinator of your behavioral health center. The funding is based on need and is mainly used to fund respite but other requests will be considered.

Family Support does have a policy that you cannot prepay for items and receive Family Support funds. Each agency establishes their application policies so they may differ across the state. In addition, each agency does not receive the same amount of funding.

For additional information contact one of the following:

Name	Center - Updated 8-2013	Contact Info	Counties Served
Jason Deussenberry	Division of Developmental Disabilities 350 Capitol Street, Rm 350 Charleston, WV 25301	304-356-4784	Statewide
Jessica Adkins	Autism Services Center 929 4 th Ave / PO Box 507 Huntington, WV 25710	304-252-8014 ext 221 Fax 304-525-8026 jadkins@autismwv.org	Cabell, Lincoln, Mason, Wayne
Tonya Tripplett	Northern WV Center for Independent Living 1109 US Rt 33 E Elkins, WV 26241	304-636-0413 Fax 304-636-6508 ttripplett@nwvcil.org	Barbour, Randolph Tucker, Upshur
Brooke Connolly	Eastridge 235 S Water Street Martinsburg, WV 25404	304-263-8954 ext 127 Fax 304-263-8954 bconnolly@eastridgehs.org	Berkeley, Jefferson, Morgan
Elizabeth Gray	FMRS 101 S Eisenhower Drive Beckley, WV 25801	304-256-7100 Fax 304-256-7111 egray@fmrs.org	Fayette, Monroe, Raleigh, Summers
Michelle Duprey-Anderson	Healthways, Inc. 501 Colliers Way Weirton, WV 26062	304-723-5440 Fax 304-723-0665 mduprey-anderson@healthwaysinc.com	Brooke, Hancock
Georgette Hensley	Logan Mingo Area Mental Health, Inc PO Box 176 Logan, WV 25601	304-792-7130 Fax 304-792-7146 ghensley@suddenlink.net	Logan, Mingo
Patty Bolen	Southern Highlands Mental Health Center 200 12 th Street Ext Princeton, WV 24740	304-425-0432 Fax 304-425-1332 judyakers@shcmhc.com	McDowell, Mercer, Wyoming
Tedi Ferrell	Northwood Health Systems Inc. PO Box 6400 Wheeling, WV 26003	304-234-500 ext 264 Fax 304-234-3511 tferrell@corp.northwoodhealth.com	Marshall, Ohio, Wetzel
Sharon Engle	Potomac Highlands Guild PO Box 1119 Petersburg, WV 26847	304-257-4687 Fax 304-257-1945 sharone@phgmail.net	Grant, Hampshire, Hardy, Mineral, Pendleton
Cyndi Lough	Seneca Health Services 804 Broad Street Summersville, WV 26651	304-872-2090 ext 122 Fax 304-872-2574 cynlough@shsinc.org	Greenbrier, Nicholas, Pocahontas, Webster

Name	Center - Updated 8-2013	Contact Info	Counties Served
Karen Sprouse	Prestera Center 911 Michael Ave Charleston, WV 25312	304-414-2065 ext 2810 karen.sprouse@prestera.org	Boone, Clay, Kanawha, Putnam
Misty Childers	United Summit Center 6 Hospital Plaza Clarksburg, WV 26301	800-786-6486 ext 318 Fax 304-623-2180 mchilders@uscwv.org	Braxton, Doddridge, Gilmer, Harrison, Lewis
Cheryl Perone	Valley Health Care 301 Scott Avenue Morgantown, WV 26505	304-396-1731 ext 207 Fax 304-225-2288 cperone@valleyhealthcare.org	Marion, Monongalia, Preston, Taylor
Molly Fielder	Westbrook Health Services, Inc. 2121 E 7 th St Parkersburg, WV 26101	304-485-1721 ext 519 Fax 304-485-6710 mfiedler@westbrookhealth.com	Calhoun, Jackson, Pleasants, Ritchie, Roane, Tyler, Wirt, Wood

Resources

A variety of resources have been included for you as you are beginning and/or continuing your journey to seek information, evidence based practices, and service options.

OVERVIEW OF RESOURCES FOR FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

AUTISM SOCIETY



The Autism Society, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy. <http://www.autism-society.org/>

STATE AFFILIATES OF THE AUTISM SOCIETY

Autism Society Of West Virginia - <http://autismwv.blogspot.com/>

Providing information, supporting research, and advocating for programs and services to enhance the lives of West Virginians living on the autism spectrum and those who support them

LOCAL AFFILIATES OF THE AUTISM SOCIETY

Autism Society River Cities - <http://www.autism-society.org/chapter192>

Counties served:

- Cabell
- Wayne
- Putnam
- Ashland, Kentucky
- Proctorville, Ohio

Organizers of the Annual Rally
Rally for Autism

Northern Community Autism Chapter - Karen Randolph, 304-670-8675, www.hancockasa.org

Counties served:

- Wetzel
- Brooke
- Hancock
- Marshall
- Ohio

Other Parent Supports

Autism Speaks

Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Their longtime friend Bernie Marcus donated \$25 million to help financially launch the organization. Since then, Autism Speaks has grown into the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. We are proud of what we've been able to accomplish and look forward to continued successes in the years ahead. <http://www.autismspeaks.org/>

WEST VIRGINIA STATE AGENCIES

West Virginia Autism Training Center - <http://www.marshall.edu/atc/>

The West Virginia Autism Training Center at Marshall University (WV-ATC) is a state funded, statewide center providing training, information and support to West Virginians with autism spectrum disorders of all ages, their families, educators, and other individuals involved in their lives. The main service delivery model is called Family Focus Positive Behavior Support (FFPBS). FFPBS includes person and family-centered planning, the development of a support team of individuals and the development and implementation of a comprehensive positive behavior support plan tailored specifically for the individual with an ASD. WV-ATC also offers a variety of other services including statewide training on topics related to ASDs, a lending library, family coaching sessions by phone and connections to state and national resources. To qualify, an individual must be a resident of West Virginia and have a diagnosis of an autism spectrum disorder. Services of the WV ATC are at no cost to families.

Our Mission: To provide support to individuals with Autism Spectrum Disorders as they pursue a life of quality.

Center For Excellence And Disabilities (CED) - <http://www.cedwvu.org/>

The Center for Excellence in Disabilities (CED) at West Virginia University (WVU) continues to work with consumers and state, local and federal agencies to realize opportunities and overcome challenges for people with developmental and other disabilities of all ages and their families. The Center, funded through the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Intellectual and Developmental Disabilities, has services for people with disabilities throughout the state of West Virginia.

West Virginia Developmental Disability Council - <http://www.ddc.wv.gov>

The WV Developmental Disabilities Council is a 32 member organization that was established by an Executive Order of the Governor on March 6, 1972. The Council is authorized and funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). It is administratively supported by the WV Department of Health and Human Resources.

The Council's mission is to assure that West Virginians with developmental disabilities receive the services, supports and opportunities they need to achieve independence, productivity, integration and inclusion into the community. It does this in four major ways:

- including people with developmental disabilities and their families in the development of policies and programs;
- analyzing needs and advocates for improvements to the human service system;
- providing training and technical assistance to build competent and inclusive communities; and
- providing grants to community organizations to demonstrate innovative services and practice

Division Of Rehabilitation In West Virginia - <http://www.wvdrs.org/> - **Get ready to work!**

The West Virginia Division of Rehabilitation Services (DRS) is a state agency that serves West Virginians with disabilities. The mission of DRS is to enable and empower individuals with disabilities to work and to live independently.

DRS operates two major programs. The vocational rehabilitation program helps people with disabilities get or keep a job. For those who are unable to work, the Disability Determination Section (DDS) determines eligibility for Social Security disability benefits or Supplemental Security Income.

West Virginia Parent Information And Training (WVPTI) - <http://www.wvpti.org/>

West Virginia Parent Training and Information, Inc. (WVPTI) is a non-profit agency that operates a statewide federally funded Parent Training and Information Center, Family to Family and is the Family Voices of State Affiliate Organization for West Virginia. The programs and services of WVPTI, Inc. are based on the concept of parents helping parents, in special education programs and other areas.

West Virginia Advocates - <http://wvadvocates.org/>

West Virginia Advocates, Inc. (WVA) is the federally mandated protection and advocacy system for people with disabilities in West Virginia. WVA is a private, nonprofit agency. Our services are confidential and free of charge. WV Advocates can provide technical assistance for special education.

West Virginia Arc - <http://www.thearc.org>

Services for individuals with Intellectual and Developmental Disabilities

Chapters In West Virginia

- The Arc of West Virginia
- The Arc of Harrison County
- The Arc of Mid-Ohio Valley
- The Arc of Ohio County
- The Arc of Three Rivers

Bureau For Behavioral Health And Health Facilities - <http://www.dhhr.wv.gov/bhhf>

Welcome to the Bureau for Behavioral Health and Health Facilities. Our mission is to ensure that positive meaningful opportunities are available for people with mental illness (children, adolescents, and adults), substance abuse, intellectual and developmental disabilities and those at risk. We provide support for individuals, families, and communities in assisting persons to achieve their potential and to gain greater control over the direction of their future. The Bureau recognizes the invaluable knowledge and experiences the consumers and families provide in helping to develop and improve services in West Virginia. The BBHFF operates under the auspices of the West Virginia Department of Health and Human Resources (WVDHHR). We envision a community that values and respects people and is responsive to their individual needs, wants and desires for the enrichment of their lives. We believe in integrity-based leadership that is flexible enough to respond to change that is guided by individuals, families, and communities.

Mountaineer Autism Project - <http://mountaineerautismproject.org>

Mountaineer Autism Project (MAP) is a nonprofit organization of WV parents and professionals whose goal is to support best practices while making positive changes in the state to enable West Virginia's children with autism to achieve their highest potential. We support a seamless, comprehensive plan for screening, early identification, and diagnosis of autism spectrum disorders and access for all families to scientifically validated best outcome treatment (Early Intensive Behavior Intervention).

MAP was formed by a group of West Virginians committed to helping families recognize, understand, and successfully manage the challenges of Autism Spectrum Disorder (ASD). At the founding of MAP, it was estimated that only about 1.6% of the state's children with autism were receiving intensive, evidence-based services, which is why MAP is dedicated to ensuring the early detection, diagnosis, and Early Intensive Behavior Intervention of every child with autism in West Virginia. We work to increase access to information and resources for parents, train physicians and other diagnosticians to detect and diagnose autism earlier, and increase the number of professionals who are qualified to deliver evidence-based services.

In our short history, we have led successful efforts to pass Legislation that would mandate autism insurance coverage for young children in WV, worked with the WV Legislature’s Government Organization committee to clarify oversight for Board Certified Behavior Analysts in WV, developed and implemented a program (TRAIN-WV) to help stakeholders implement autism insurance in WV, held town meetings for WV families to learn more about autism insurance, and provided information to families across the state interested in ABA services. We are working to expand autism coverage for all children in WV, and provide state-wide training for families on topics specific to autism, such as preparing for adolescence, wandering, and family stress. MAP is open to all parents and family members of children with autism and to professionals committed to supporting Early Intensive Behavior Intervention. If you are interested in attending a MAP meeting or becoming a Friend of MAP, please visit our web site

DIAGNOSIS AND ASSESSMENT INFORMATION



Screening and Diagnosis for autism: <http://www.cdc.gov/ncbddd/autism/screening.html>

Diagnosing autism spectrum disorders (ASDs) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child’s behavior and development to make a diagnosis.

ASDs can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.^[4] However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need.

Diagnosing an ASD takes two steps:

1. **Developmental Screening**

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.

All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:

- 9 months
- 18 months
- 24 or 30 months
- Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

In addition, all children should be screened specifically for ASDs during regular well-child doctor visits at:

- 18 months
- 24 months
- Additional screening might be needed if a child is at high risk for ASDs (e.g., having a sister, brother or other family member with an ASD) or if behaviors sometimes associated with ASDs are present

It is important for doctors to screen all children for developmental delays, but especially to monitor those who are at a higher risk for developmental problems due to preterm birth, low birth weight, or having a brother or sister with an ASD.

If your child's doctor does not routinely check your child with this type of developmental screening test, ask that it be done.

If the doctor sees any signs of a problem, a comprehensive diagnostic evaluation is needed.

2. Comprehensive Diagnostic Evaluation

The second step of diagnosis is a comprehensive evaluation. This thorough review may include looking at the child's behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.

In some cases, the primary care doctor might choose to refer the child and family to a specialist for further assessment and diagnosis. Specialists who can do this type of evaluation include:

- Developmental Pediatricians (doctors who have special training in child development and children with special needs)
- Child Neurologists (doctors who work on the brain, spine, and nerves)
- Child Psychologists or Psychiatrists (doctors who know about the human mind)

For More Information On Screening And Diagnosis Visit

Learn The Signs/Act Early

www.cdc.gov/ncbddd/autism/screening.html

Klingberg Neurodevelopmental Center

The Klingberg Neurodevelopmental Center helps children who are having difficulties in the areas of development, attention, and learning.

We offer multi-disciplinary diagnostic evaluations for children displaying difficulties in the areas of development, attention, learning, and sleep. Our core team includes a pediatric neurologist, an educational psychologist, a social worker, and a parent educator. Most of the children seen through the center are between the ages of one and eleven.

Our core team includes a pediatric neurologist, a licensed psychologist, a social worker, and a parent educator. Most of the children we see at the Center are under the age of 6.

Services

The Klingberg Neurodevelopmental Clinic sees children who have, or may be at risk of having, delays in any area of development. Our multi-disciplinary team includes our Klingberg staff plus a pediatric geneticist, an audiologist, and a neonatal pediatrician.

If your child is referred to our Clinic, we will need to review his or her medical, educational, and social records.

Evaluations

If we determine that we can help your child, evaluations at our Neurodevelopmental Clinic usually take at least 3 hours. During this time our team will:

- learn more about your child's medical, behavioral, and developmental history
- observe your child as he or she plays and interacts with others
- complete diagnostic and developmental assessments

The team will then provide you with feedback about what we've learned and make recommendations for further evaluation or treatment.

At the end of the appointment, you will be given an information sheet outlining our findings. You will receive a more extensive written report in about a month. Much of the report is devoted to recommendations for intervention and education.

Referrals

To make a referral to the Klingberg Neurodevelopmental Clinic, please call 304-293-7331 or toll free 800-842-3627 and ask for extension 293-7331. Referrals may be made by parents, physicians, or other care providers.

Depending on the needs of each child, referrals to other professionals, such as pediatric neurologists or geneticists, can be provided. If our team does not think your child can be well-served by our clinic, we can offer you information about more appropriate resources. While the Klingberg Neurodevelopmental Center does not offer intensive, ongoing treatment for pervasive developmental disorders at this time, we can make recommendations for that treatment.

For more information you can visit <http://medicine.hsc.wvu.edu/pediatrics/Home/Klingberg-Center>

AUTISM SPECIFIC TO AGE GROUPS

Early Intervention

WV Birth to Three - <http://www.wvdhhr.org/birth23/>

WV Birth to Three directs the coordination of the statewide system of early intervention services for families with children age birth to three that have developmental delays.

Education

Office of Special Programs - <http://wvde.state.wv.us/osp/>

The West Virginia Department of Education, Office of Special Education supports County Boards of Education in educating all students, aged three to 21. They have developed a guidance document for educating students with autism you might find helpful. You can locate this document at http://wvde.state.wv.us/osp/autisum_guidance_1-6-12.pdf.

Adults

- WV Bureau For Behavioral Health Services And Health Facilities - <http://www.dhhr.wv.gov/bhhf/Pages/default.aspx>
 - Other Behavioral Health Service Providers:

- Appalachian Community Health Center – <http://achc.inc>
- The Arc of the Three Rivers – <http://arcthreerivers.org>
- Autism Services Center – <http://autismservicescenter.org>
- EastRidge Health Systems- <http://eastridgehealthsystems.org>
- FMRS Health Systems - <http://fmrs.org>
- HealthWays - <http://healthwaysinc.com>
- Logan Mingo Area Mental Health - (304) 792-7130
- Northwood Health Systems - <http://www.northwoodhealth.com>
- The Potomac Center - <http://potomaccenter.com>
- Potomac Highlands Guild - <http://thephg.org>
- Pretera Center for Mental Health Services - <http://pretera.org>
- Seneca Health Services - <http://shsinc.org>
- Southern Highlands Community Mental Health Center - <http://shcmhc.com>
- United Summit Center - <http://uscwv.org>
- Valley Health Care - <http://valleyhealthcare.org>
- Westbrook Health Service - <http://www.westbrookhealth.com>
- College Program For Students With Autism Spectrum Disorder - <http://www.marshall.edu/collegeprogram/>
- Goodwill - <http://www.goodwill.org/>
- Housing And Urban Development (HUD) - <http://www.hud.gov/>
- Intellectual Developmental Disabilities Waiver - <http://www.dhhr.wv.gov/bms/hcbs/idd/Pages/default.aspx>
- Medicaid - <http://www.dhhr.wv.gov/bms/Pages/default.aspx>
- Oar/Organization For Autism Research - <http://www.researchautism.org/resources>
- Social Security - <http://www.ssa.gov/>
- Vivient Monitoring Systems - <http://www.vivint.com/en/>
- West Virginia Division Of Rehabilitation Services - <http://www.wvdrs.org/>
- WV Developmental Disabilities Council - <http://www.ddc.wv.gov/RESOURCES/Pages/default.aspx>

NATIONAL RESOURCES FOR ASPERGER SYNDROME

The College Support Program for Students with Asperger Syndrome -

<http://mucollegesupport.blogspot.com/>

The College Program for Students with Asperger Syndrome was developed in 2002, by the West Virginia Autism Training Center at Marshall University.

The program exists to offer appropriate academic, social and independent living skill supports to individuals with autism spectrum disorders, so that they may have a successful college experience and learn skills necessary to enter a competitive workforce.

Welcome to the OASIS @ MAAP web site! -

<http://www.aspergersyndrome.org/>
The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for Autism and Asperger Syndrome to create a single resource for families, individuals, and medical professionals who deal with the challenges of Asperger Syndrome, Autism, and Pervasive Developmental Disorder/ Not Otherwise Specified (PDD/NOS).

EDUCATIONAL APPROACHES TO AUTISM SPECTRUM DISORDER

There are many different opinions about how best to help children with autism. There are two general approaches to instruction: those based on [Applied Behavior Analysis \(ABA\)](#) and those that follow a [Developmental Approach](#).

In general, ABA approaches are more structured in terms of environmental arrangements and skill expectations. In ABA approaches, the adult will systematically encourage certain responses from the child and then respond in planned ways designed to either increase or decrease certain behaviors. Behavioral approaches also carefully measure progress and modify strategies based on the data collected (see the quality indicators of ABA programs on page 85). Developmental approaches are often more spontaneous in the way that adults will respond to the child, and the child's behavior. For children functioning at early stages of development, emphasis is put on encouraging the child to develop his own ideas and to engage in social interactions in reciprocal ways. In many of these approaches, the focus is on thinking about the 'whole child' including the child's regulatory and sensory challenges.

There are many educational models and strategies available to families and schools today. Families are encouraged to look at all of the approaches and, along with your child's teacher or other professionals, decide on what strategy, or combination of strategies best fit your child and family. While there are no conclusive studies showing that one approach is better than another, we do know that the most affective approaches are intensive and implemented as early as possible. Models that have been researched include, but are not limited to:

- Discrete Trial Instruction
- Developmental Intervention
- Activity Based (Naturalistic) Instruction
- Pivotal Response Training
- TEACCH Method

It is important that families and educators identify specific skills that they would like to work on, and continually monitor instruction to see if progress is being made. If progress is not being made, it is critical that the team seeks to understand why this may be, and how instruction might change to better address the child's needs.

Following are examples of the first three approaches listed above (discrete trial instruction; activity-based instruction; developmental intervention) to demonstrate that the same skill can be taught in a variety of ways. The skill that is exemplified below is "imitating an adult."

Discrete Trial Instruction (DTI)

The "Discrete Trial" strategy is a frequently used intervention based on Applied Behavior Analysis (ABA). Here, specific skills are taught to a child in a one-on-one structured learning setting. Usually, a child is given a specific instruction by his teacher, and the child responds. The child is either rewarded for a correct response, or provided with a correction for an incorrect response.

Developmental Intervention

In this approach, instead of directing the child to do something ("Jake, do this"), the teacher or therapist sets up a situation that encourages the child to initiate a desired behavior. Then, the focus of the intervention is to build on this initiation to develop further engagement, thinking, and communication.

Activity-Based (Naturalistic) Instruction

Activity-based instruction combines aspects of Discrete Trial Instruction and Developmental Intervention strategies described above. Here, the child is systematically taught a skill during ordinary activities throughout his school day or at home, making sure that many opportunities are given to repeat and learn the skill.

The three examples described above are just a few of the many types of interventions that have been used to successfully teach young children with autism. The important thing to remember is that, whatever approach is used, you should feel comfortable with it. To read about real life stories teaching skills using these different methods visit <http://www.pbs.org/parents/inclusivecommunities/autism4.html>.

The above information has been taken from <http://www.pbs.org/parents/inclusivecommunities/autism4.html>

Quality Indicators of an ABA Program

<http://www.behaviorbabe.com/qualityindicators.htm>

When a parent decides to seek ABA therapy for their child, it is important to make informed decisions about providers and the programs they offer. The 30-point criterion listed below is compiled from multiple sources, each of which focuses on determining components necessary to make effective, behavioral change in individuals with neurological disabilities, such as autism spectrum disorders (ASD). The following are offered as 30 Indicators of a Quality ABA Program:

1. Begins early, before age 3
2. Leading to Independence - is Independence fostered?
3. Working closely with families - include extended family and caregivers
4. Provides a structured environment
5. Plans for generalization to natural environments
6. Hierarchy of instructional priorities - skills taught include mastery criteria
7. Curriculum includes: attending to elements in the environment, imitation skills, understanding and using language, playing appropriately with toys, and interacting socially.
8. Plans and prioritizes maintenance of mastered skills
9. Individualized programming
10. High rates of Active Student Responding (ASR)
11. Considers student motivation
12. Progress is monitored
13. Changes made are based on measures of progress
14. Conduct functional assessment/analysis of behavior - aberrant and academic
15. Immediate feedback is given to student
16. Predictability and routine are established
17. Use of accurate, immediate models and modeling, errorless strategies
18. Measures of baseline data are taken
19. Ongoing supervision is provided by a competent, trained individual
20. Low student to staff ratios (not too many students per staff)
21. Behavior plans, teaching sequences and programs are written
22. Monitoring of treatment integrity (the degree to which a program is implemented as intended)
23. Plans for transitions are considered and are in place
24. Uses empirically-validated teaching methods
25. Interdisciplinary; the team collaborates w/other disciplines, including medical staff as appropriate
26. Intensive teaching is available - increase in number of hours traditionally provided, if recommended

27. Treatment acceptability; program includes measures of social validity
28. Use of self-management procedures, when appropriate
29. Measures of fluency (accuracy/speed=fluency)
30. Teaches generative/pivotal skills

The indicators listed above are suggestions from information referenced by the following resources (click on the link to access each source):

- Baer, D., Taylor, M., Taylor, B. (2005). *Focus on behavior analysis in education*. Chapters 1 and 2. http://www.amazon.com/Focus-Behavior-Analysis-Education-Opportunities/dp/0131113399/ref=sr_1_1?ie=UTF8&qid=1318812547&sr=8-1
- Maine Administrators of Services for Children with Disabilities (2000). Report of the autism task force. Retrieved from <http://www.madsec.org/LinkClick.aspx?fileticket=YmikqkW4tFk%3D&tabid=81>.
- National Institutes for Health (1999). Mental health: A report of the surgeon general. Chapter 3. Retrieved from <http://profiles.nlm.nih.gov/ps/retrieve/ResourceMetadata/NNBBHS>.
- New York Department of Health (1999). Clinical practice guideline: Report of the recommendations. Retrieved from http://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism/ch4_pt2.htm.
- For more information... Los Angeles Families for Effective Autism Treatment – Components of a Quality ABA Program - http://www.lafeat.org/web/aba_components/
 - **To find a Board Certified Behavior Analyst (BCBA)** in your area visit www.bacb.com. The list of BCBA's is under "Find/Contact Certificants" on the left hand side of the home page. This section is updated regularly as new professionals become certified.

Resources Related To Positive Behavioral Support

Positive Behavior Support (PBS) - <http://myweb.usf.edu/~aheindel/PBSwebsite.html>

Positive Behavior Support (PBS) is a framework of behavioral assessment and intervention that is explicitly designed to promote improvements in an individual or family's quality of life. Grounded in the individual or family's goals and values, PBS uses functional assessments to identify the underlying purpose of a specific behavior, and then uses a package of interventions to prevent future occurrences of problem behaviors by making it less relevant and effective than a more age- and socially-appropriate skill taught as its replacement.

WV Association of Positive Behavior Support Network - <http://www.as.wvu.edu/wvpbs/>

The WV APBS Network's web site is home to information, resources, services, and links pertaining to Positive Behavior Support (PBS) in West Virginia and around the country. Here you will find trainings and providers for PBS services and learn about the methods used by PBS to understand and managing challenging behavior.

Definitions

ABA - Applied Behavioral Analysis - This is a well-established behavioral approach to autism treatment, most often appropriate for younger children.

ADD/ADHD - Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder - Many children on the autism spectrum are also diagnosed with ADD or ADHD.

AS - Asperger syndrome - Rediscovered as a diagnosis in the 1980's, Asperger is at the high end of the autism spectrum. Individuals with Asperger syndrome may be very bright and capable, but may also have serious difficulties with social interaction, or have unusually low tolerance for loud noise, bright lights, crowds, etc.

ASD - Autistic Spectrum Disorder - This refers to any of the diagnoses within the autism spectrum, from Asperger Syndrome at the high end to classic autism at the low end.

DIR - Developmental, Individual-Difference, Relationship-Based (DIR) Model - is the basis for the Floortime method of treatment which involves, among other things, a form of therapeutic play.

Echolalia or echolalic - Some children with autism do use language, but tend to repeat what they've heard rather than create novel phrases on their own. When a child is echolalic, he is "echoing" what he's heard.

FBA - Functional Behavioral Assessment - is a process of identifying the underlying causes or functions of a challenging behavior through direct observation, interviews with parents and teachers and review of a child's records. This information is used to develop a behavior support plan for the individual. Functional Behavioral Assessment is a key part of the positive behavior support approach.

HFA - High Functioning Autism - Generally refers to individuals who are verbal and academically capable, but who are not diagnosed with Asperger syndrome. Like "classic autism," this really isn't a medical term but it does help to define an individual's profile.

IDEA - Individuals with Disabilities Education Act (formerly EHA) - This law states that children with disabilities have the right to a free appropriate public education, including procedural protections and the right to an education that is standards based. The latest amendments to this special education law were passed in 2004.

IEP - Individualized Educational Program - A written document derived from Part B of IDEA (Individuals With Disabilities Educational Act), that is designed to meet a child's individual educational program needs. The main purposes for an IEP are to set reasonable learning goals and to state the services that the school district will provide for a child with special educational needs.

IFSP - Individualized Family Service Plan - A written document, derived from Part C of IDEA (Individuals With Disabilities Educational Act), that is formulated in collaboration with the family to meet the needs of the child with a developmental disability or delay, to assist the family in its care for a child's educational, therapeutic, and health needs, and to deal with the family's needs to the extent which the family wishes assistance.

NT - Neurotypical - This term refers to siblings and classmates who are not diagnosed with any disorder.

OCD - Obsessive Compulsive Disorder - This is the disorder that Monk, the TV detective, is coping with. Many children with autism also have elements of OCD.

ODD - Oppositional Defiant Disorder - Some children with autism may also be diagnosed with ODD.

On the Spectrum - Anyone with any diagnosis that falls anywhere within the autism spectrum.

PBS - Positive Behavior Support - is a comprehensive team approach that uses the principals of applied behavior analysis to focus on preventing problems before they occur by making changes in the environment, teaching new skills and improving quality of life.

PDD-NOS - Pervasive Developmental Disorder--Not Otherwise Specified - This term is used for children who meet most, but not all, of the criteria for autism. Children with this disorder have basically the same pattern of strengths and weaknesses as children with autism, and benefit from the same interventions. It's important to note that PDD-NOS does NOT mean high or low functioning -- so individuals with this diagnosis may be very different from one another. The PDD-NOS diagnosis was removed from the latest version of the Diagnostic and Statistical Manual of Mental Disorders (May, 2013) and is now subsumed under the diagnostic category "Autism Spectrum Disorders."

PECS - Picture Exchange Communication System - This system uses pictures instead of words, and has been very successful in helping non-verbal autistic children to communicate.

RDI - Relationship Development Intervention - A relatively new and growing therapeutic approach which places parents and therapists in a "coaching" relationship to their child.

Section 504 of the Rehabilitation Act - A civil rights statute designed to eliminate discrimination on the basis of disability in any program or activity receiving federal financial assistance. Some individuals who do not qualify for services under IDEA may receive services and/or accommodations under Section 504.

SPD - Sensory Processing Disorder - (sometimes called "sensory integration" or SI) is a term that refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioral responses

WV Team Autism 2014 Membership

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