

WEST VIRGINIA
EARLY CHILDHOOD
PROVIDER
QUARTERLY



After the Diagnosis

**Supporting WV Children with
ASD and Their Families**

Early Identification, Diagnosis, and Support



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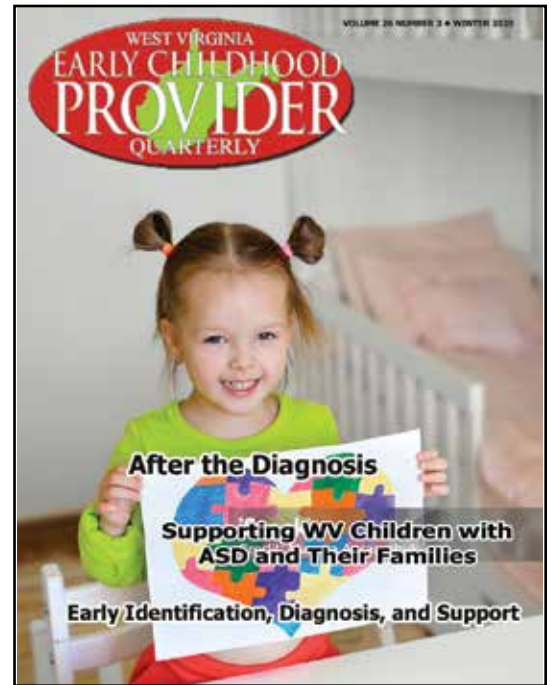
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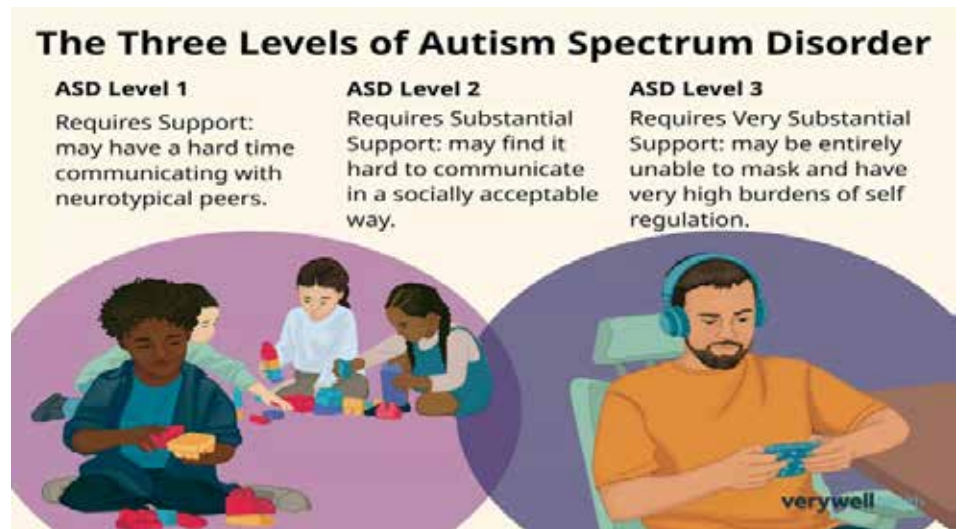
Autism Spectrum Disorder: Early Identification, Characteristics, and Supporting Families and Siblings

Submitted by Cynthia Dolland LeGrand, M.A., CCC-SLP, BCBA

Autism spectrum disorder (ASD) is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. Although autism can be diagnosed at any age, it is described as a “developmental disorder” because symptoms generally appear in the first 2 years of life.

Autism spectrum disorder has no single known cause. Given the complexity of the disorder, and the fact that symptoms and severity vary, there are probably many causes. Both genetics and environment may play a role.

There are no blood or physical medical tests to diagnose ASD, so a diagnosis must be made based on the presence or absence of certain skills and behaviors. An autism diagnosis must be made by a physician or a licensed psychologist. Most often, depending on the availability of professionals in the area, children are diagnosed by a licensed psychologist, a developmental pediatrician, or a pediatric neurologist.



A diagnosis of autism is made by using the criteria for ASD published in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This is a guide created by the American Psychiatric Association that health care providers use to diagnose mental disorders, which includes ASD.

People with ASD often have:

- Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviors
- Symptoms that affect their ability to function in school, work, and other areas of life

Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience from profound autism to high functioning autism (which used to be referred to as Asperger syndrome) and various levels of functioning in between.

According to the DSM-5, autism spectrum disorder (otherwise known as autism) has three levels. A person who is diagnosed with autism will also be labeled as being ASD Level 1, ASD Level 2, or ASD Level 3. The autism level they are diagnosed at is based on the severity of their symptoms and primarily based on how much support they

need in their everyday life. Levels of supports needed can change as children learn and grow.

People of all genders, races, ethnicities, and economic backgrounds can be diagnosed with ASD. Although ASD is a lifelong disorder, treatments and services can improve a person's symptoms and daily functioning. The American Academy of Pediatrics recommends that all children receive screening for autism. Caregivers should talk to their child's health care provider about ASD screening or evaluation.

- Currently the incidence of autism spectrum disorder (ASD) is 1 in 36, up from the previous rate of 1 in 44.
- 1 in 45 adults in the U.S. have autism.
- In the U.S., about 4 in 100 boys and 1 in 100 girls have autism. Around 3.9 percent of West Virginia's children have an ASD diagnosis. The average age of diagnosis in West Virginia is 4 years and 8 months of age.

Signs of autism in babies

By 6 months

- Few or no big smiles or other warm, joyful, and engaging expressions
- Limited or no eye contact

By 9 months

- Little or no back-and-forth sharing of sounds, smiles, or other facial expressions

Signs of autism in toddlers

By 12 months

- Little or no babbling
- Little or no back-and-forth gestures such as pointing, showing, reaching, or waving
- Little or no response to name

By 16 months

- Very few or no words

By 24 months

- Very few or no meaningful, two-word phrases (not including imitating or repeating)

Signs of autism at any age

- Loss of previously acquired speech, babbling, or social skills
- Avoidance of eye contact
- Persistent preference for solitude
- Difficulty understanding other people's feelings
- Delayed language development
- Persistent repetition of words or phrases (echolalia)
- Resistance to minor changes in routine or surroundings
- Restricted interests
- Repetitive behaviors (flapping, rocking, spinning, etc.)
- Unusual and intense reactions to sounds, smells, tastes, textures, lights, and/or colors

Age of autism diagnosis and early signs of autism can vary widely from child to child. Some children show early signs of autism within the first 12 months of life. In others, autism signs may not show up until 24 months of age or later. Importantly, some children with ASD gain new skills and meet developmental milestones until around 18 to 24 months of age, and then they stop gaining new skills or lose the skills they once had.

The American Academy of Pediatrics (AAP), the leading pediatric health organization in the United States, recommends that all children be screened for autism at ages 18 months and 24 months, in addition to undergoing developmental and behavioral screenings during their regular well-child visits at 9 months, 18 months, and 30 months. Research shows that by age 2, an ASD diagnosis by an experienced professional can be considered reliable.

If you have concerns about your child's development:

1. Learn the signs. The Centers for Disease Control and Prevention (CDC) Act Early program provides parents, childcare professionals, and pediatric clinicians with free resources, in English and Spanish, for monitoring a child's development. The program offers parent-friendly, research-based

milestone checklists for children as young as 2 months of age. The Milestone Tracker App can help parents track their child's development and share the information with their pediatricians.

2. Take the M-CHAT-R screening questionnaire. The M-CHAT-R™ (Modified Checklist for Autism in Toddlers, Revised) can help you determine if a professional should evaluate your child. This simple online autism screening questionnaire takes only a couple minutes to complete. If the answers suggest your child has a high probability for autism, please consult with your child's doctor.

3. Schedule an appointment with your child's pediatrician. If you have any concerns about your child's development, don't wait. Speak to your doctor now about screening your child for autism. You can use the Autism Speaks Resource Guide (<https://www.autismspeaks.org/resource-guide>) to find providers near you. While every child develops differently, early intervention can improve outcomes, often dramatically. For example, studies show that early intensive behavioral intervention (ABA) improves learning, communication, and social skills in young children with ASD.

Years of research recommend ear-



ly intervention, the earlier the better to help young children meet their potential. West Virginia Birth to Three offers services for all children with developmental disabilities including ASD. The Early Start Denver Model (ESDM) and other Naturalistic Developmental Behavioral Interventions (NDBI) are the evidence-based interventions that we recommend for young children with ASD.

Unfortunately, there are not very many ASD diagnosticians or service providers in West Virginia to continue services once a child has graduated from Birth to Three services. Almost every diagnostician and service provider/clinic have lengthy wait lists, some are 6 months to a year or longer. When a child has autism, we simply can't wait. That is why it is so import-

ant to get an evaluation while your child is still enrolled in WV Birth to Three, if possible. This gives you and your child a better chance of receiving continuous therapies rather than waiting months without services.

If you get a diagnosis and would like for your child to get early, intense behavior therapy (Applied Behavior Analysis - ABA) you will need to get on the waitlist for providers in your area as soon as possible.

What is Applied Behavior Analysis? Most ABA clinics require a diagnosis of ASD to get on the waitlist. Even if you are unsure about these services or decide later that you do not want them, it's still recommended to get on the waitlist. Insurance now covers treatment of

ASD, but in order to bill for those services your child must have a diagnosis. No one has regretted getting on the waitlists but everyone has regretted when they didn't get on them sooner. If you want to get other therapies like speech, occupational, and physical therapy you can schedule appointments for evaluations 3-6 months before leaving WV Birth to Three services.

Your child may also be eligible for your county Pre-school. They offer Pre-K special needs classrooms as well as Universal Pre-K classrooms. Your WV Birth to Three service coordinator and team can help you navigate all of these upcoming transitions.

For more information, please visit <https://www.wvdhhr.org/birth23/>

Resources for families to learn more about ASD:

Autism Internet Modules: ASD Strategies in Action (<https://autisminternetmodules.org/>)

Autism Navigator – Online Courses for Professionals and Families (<https://autismnavigator.com/courses/>)

AFIRM – Autism Focused Intervention Resources & Modules (<https://afirm.fpg.unc.edu/>)

Help is in Your Hands – ESDM Project Learning Modules (<https://www.helpisinyourhands.org/>)

Resources online for siblings of children with ASD:

Sibling Support (<https://www.thhpediatrics.com/ASDs-Family-Hand-out-Sibling-Issues-1>)

Resources for finding information and resources for your child and family in WV:

WVU CED Autism Resources (<https://cedwvu.org/resources/autism-resources-in-west-virginia/>)

Mountaineer Autism Project (<https://mountaineerautismproject.com/>)

WV Autism Training Center at Marshall University (<https://www.marshall.edu/atc/>)

CARES Community Autism Resources & Education Systems (<https://wv-caresforautism.org/>)

WV Birth to Three ASD resources (<https://www.wvdhhr.org/birth23/aba.asp>)

ABCs of Autism: What We Have Learned From Bella (A Facebook page created by a WV Birth to Three Physical Therapist that is also the mom of a daughter with ASD)

West Virginia Birth to Three also has an ASD Community of Practice Virtual meeting the last Friday of each month at 12:00 noon for practitioners. Check the webinar training calendar to sign up.

General Resources:

Autism Speaks (<https://www.autismspeaks.org/>)

Autism Society (<https://autismsociety.org/>)

Autism Science Foundation (<https://autismsciencefoundation.org/>)

Organization for Autism Research (<https://researchautism.org/>)

Early Identification, Diagnosis, and Support for Children with Autism Spectrum Disorder

Submitted by Claire H. Baniak, PsyD, Co-Owner, Unlocked Potential, PLLC, Licensed Psychologist, WV

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects communication, social interactions, and behavior. One of the most important things to understand about ASD is that it's not a one-size-fits-all diagnosis. As the saying goes, "If you've met one person with autism, you've met one person with autism." The spectrum nature of the disorder means that each individual with ASD has their own unique strengths, challenges, and needs.

It's important to clarify that ASD is not the same as Intellectual Disability (formerly referred to as "Mental Retardation"). While some

individuals with ASD may have an intellectual disability, many others have average or above-average intelligence. Additionally, despite popular portrayals in movies and TV shows—such as the character of Dr. Sheldon Cooper from *The Big Bang Theory*—being autistic doesn't imply a "superpower" or extraordinary skill. Every person with autism has their own unique abilities and challenges.

Approximately 30 percent of people with autism have an intellectual disability. So, while autistic people are more likely to have an intellectual disability than the general population, many autistic people

have average or better intelligence, do well in school, and go on to live independent, meaningful lives.

When some people think about ASD, they think about aggressive and disruptive behaviors. However, autistic people have their own unique personalities. While some may be more irritable and have low frustration tolerance, others are pleasant, polite, and follow directions better than other children their age.

Importance of Early Intervention

Some children show signs of ASD as early as 12 months, while oth-



ers may not show signs until 24 months or later. Some children gain new skills and meet appropriate developmental milestones (i.e., walking, talking) at the expected ages but then abruptly lose skills or stop gaining skills at the same pace as other children their age. Most children can be diagnosed by an experienced professional by age 2; however, the average age of diagnosis in the US is 4 years old. Early identification of ASD and developmental and behavioral supports can significantly improve outcomes for children with ASD.

Why Early Identification Matters

Early identification of ASD leads to early intervention. All states in the US have early intervention programs that focus on the early identification and treatment of developmental delays and disorders. In West Virginia, the WV Birth to Three Program is an invaluable resource for children ages 0-3 that provides free intervention to families in their homes and communities. Children who are 3 years and older can receive free therapies and supports through the public school system.

Signs and Symptoms

The early signs of ASD can be subtle and vary widely from child to child, which can be confusing for first-time parents. It's important

to remember that these signs are not absolute; they exist on a spectrum, meaning they can appear in varying degrees and forms. Here are some common indicators to watch for.

Some autistic children lose speech, babbling, or social skills that they previously had. They may avoid eye contact or only make eye contact during certain times (like when they are requesting something from you). They may show a clear preference to be alone or play alone, especially when they are around other children their age. They may have difficulty finding what you are pointing to if you try to show them something. Autistic children are usually slower to use gestures, like waving "bye bye," pointing, and learning simple sign language. They often have trouble imitating others' body movements, facial expressions, or sounds.

When an autistic child develops language, they tend to be more repetitive in their use of words and phrases. They may be Gestalt Language Processors who learn phrases from shows or their parents and use them both in context (e.g., saying "Mm, mm, good" when they eat) and out of context (e.g., saying "Chase is on the case!" when the family goes outside). They may also echo words and phrases that they hear from others, but keep in mind

that all children echo sometimes! Autistic children may have trouble understanding how to have conversations and need to be explicitly taught how to ask follow-up questions or to appropriately respond to others. When others try to talk to them, they may ignore them or respond in a way that is inappropriate or unrelated. They can show irregular patterns of speech sound and quality, and may be overly loud, speak very quietly, have a flat tone (i.e., talking like a "robot"), or talk in a sing-songy voice.

In addition to challenges with social communication, autistic people show patterns of repetitive behavior, play skills, and thinking patterns. They may have difficulty with small changes in their routine or surroundings, or they may remember routines better than other children their age (e.g., remembering the route you drive to school and becoming distressed when you go a new direction). They tend to have strong, specific interests, like television shows, movies, or subjects (e.g., dinosaurs, space). When they are engaged in specific interests, many autistic people have excellent memories and attention spans.

Many autistic individuals engage in repetitive behaviors that can be soothing or enjoyable for them. These may include actions like

hand-flapping, spinning, jumping, rocking, or holding their hands in certain ways. Children with autism may also play with toys in unconventional ways, such as lining them up, focusing on specific parts (e.g., watching wheels spin), or exploring everyday objects like spatulas or string in a way that others may not. It is common for people with autism to show strong preferences for how things are. They may have a favorite cup, toy, seat at the table, or blanket and become very distressed when they do not have that item.

Oftentimes, people who have ASD show unusual and intense reactions to sounds, smells, tastes, textures, and/or lights. They may be overly sensitive to this input, or they may seek it out by turning the music up loudly, repeatedly crashing into objects, banging their heads on surfaces, or seeking tight hugs and squeezes. Likewise, they may cover their ears, close their eyes, look at objects from different angles, or avoid having their hands and heads touched or rubbed.

In order to meet diagnostic criteria for ASD, an individual must show signs in the early developmental period. That means that if someone starts to have difficulty with sensory input or trouble with social interactions when they are a teenager, the symptoms may be re-



lated to another diagnosis and not related to ASD. When a diagnosis is given, your child may be given a level of support (ranging from 1-3). These levels are intended to represent the amount of support your child requires right now, and they can change over time.

When to Seek a Diagnosis

If parents notice patterns of behavior that are consistent with several of the signs listed above, it is important to seek out a professional evaluation and consultation as soon as they are able. Walking is an important developmental milestone that leads the way for social communication. If your child is walking but is not pointing, waving, or using gestures or words consistently to get their point across, or if your child is not responding to their name most of the time after 9-12 months, it may be time to request an evaluation.

It's natural for parents to want to wait and see how their child develops, but early intervention can make a big difference. It's far better to act early and explore resources and support than to wait and see. Even if a child does not meet criteria for any specific diagnosis, they can receive services through the programs listed above. Parents can self-refer to most early intervention programs at any time and do not have to wait for a doctor to refer them.

Who Can Diagnose ASD?

For many children, pediatricians are the first professionals to identify and discuss delays in developmental milestones. Most pediatric offices complete developmental screenings at specific well child visits. At their 18 month doctor's visit, you may be asked to complete an M-CHAT-R or a similar measure. These questionnaires ask

many questions that may be early indications of ASD. It will likely be completed again when your child is 24 months. If your pediatrician does not mention the results of the developmental screenings you complete, you should ask them to review it with you, especially if you have developmental concerns.

Professionals who are qualified to diagnose ASD should have knowledge of typical childhood development, understand the diagnostic criteria for ASD and how it can present across the lifespan, and be trained in the administration and interpretation of standardized measures that evaluate for ASD. Most commonly, the diagnosis is made by a developmental pediatrician or clinical psychologist who will administer standardized diagnostic tools, such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R).

What to Expect During the Evaluation

ASD evaluations involve gathering many pieces of information, often through parent interviews, observation of the child, and standardized tests. Sometimes, evaluations are done by teams of professionals, including medical doctors, speech language pathologists, and psy-

chologists, who may see the child on the same day or on different days. Other times, the evaluation may be done by one professional over the course of a lengthy appointment.

Many families feel a variety of emotions during the evaluation process, ranging from uncertainty, confusion, and sadness, to relief, happiness, and comfort. The words “Your child has autism” may not be easy to hear, but they often help parents understand their child’s unique strengths and challenges and provide a pathway forward.

Supports for Parents and Children

Parents may be wondering, What is early intervention? Early intervention involves therapies – most commonly speech, occupational, physical, and developmental or educational services. Applied Behavior Analysis (ABA) is a behavior therapy that uses strategies of reinforcement to build behaviors that are important to the family. When people think of behaviors, they commonly think of aggression or negative behavior. However, ABA can be used to build communication skills, teach positive social interactions, help with toilet training, and many other important aspects of daily living. Other types of behavior therapy and cog-

nitive behavioral therapy work on teaching children social and adaptive skills that can help them navigate school, friendships, and other challenging parts of the world. It is very important that all intervention plans are specifically tailored to the needs of the child.

Educational Supports

Let’s clarify something important: If your child is diagnosed with ASD, it doesn’t mean they will carry a permanent label throughout their life. Many parents worry about pursuing special education services through Individualized Education Plans (IEPs) due to concerns about labeling or placing their child in smaller classrooms. However, the goal of an IEP is to provide the support necessary to help your child succeed and thrive in the general education environment.

Parents and educators who form strong relationships and work together to understand the support a child needs and how to accomplish their goals are the most successful teams. The goal of an IEP is for the child to eventually no longer need an IEP because they are thriving in their educational environment.

When navigating the school system, it is important for parents to understand their child’s rights,

ask the questions that are on their minds, and to advocate on behalf of their autistic child.

Parental Support and Resources

Many parents of autistic children feel overwhelmed and under supported. The psychological impact of having a child with special needs is a unique stress that can only be understood by those who have walked in your shoes. While therapists, educators, and professionals can be a source of education and support for parents, nothing beats the personal experiences and knowledge of other parents who have the shared experience of raising an autistic child. Consider joining Facebook pages, including “Unpuzzled Parent Connect Support Page,” “Autism Moms Connection,” and “ABC’s of Autism: What We Have Learned from Bella”. The Autism Caregivers Sup-

port Conference happens annually and is advertised on these social media pages. Visit our Resource page at www.unlockedpotentialwv.com for more statewide resources, options for therapy providers, and information about diagnosis and recommendations.

A Strengths-Based Approach

Autistic individuals have unique talents and perspectives to offer the world. Many are highly creative, with an eye for detail and deep knowledge in specific areas—skills that are valuable in both schools and workplaces. Parents should never let others dictate what their child can or cannot achieve based solely on a diagnosis. Instead, by focusing on their strengths and interests, parents and therapists can help them grow and reach their full potential.

Promoting Advocacy and

Awareness

The world needs all kinds of minds. It is important for autistic people to be not just in the community but to also be part of the community. As a society, we should not assume that non-speaking means non-hearing - people with autism deserve respect and understanding. Raising awareness about ASD will help reduce stigma and promote inclusion.

Let’s Work Together for a Brighter Future

The supports available to autistic people are improving with time and knowledge, but there is still a long way to go to teach true acceptance and inclusion in the world. Whether we have autistic children or not, we should each strive to increase our knowledge about ASD. We should share helpful information with our children and our communities in order to make society a better, more welcoming place for our autistic neighbors and friends. With the right support, people with autism can thrive and achieve their fullest potentials.

Dr. Jenna Wallace and Dr. Claire Baniak are licensed child psychologists and co-owners of Unlocked Potential, PLLC, a practice that specializes in the diagnosis and treatment of neurodevelopmental disorders, including Autism, ADHD, learning disabilities, and intellectual disability.



Like Autism and Ice Cream: Supporting WV Children with ASD and Their Families

Submitted by Taylor McClanahan, LGSW, CARES Advocate

Autism Spectrum Disorder (ASD), often referred to simply as “autism,” is a neurodevelopmental disorder, but what does that mean? One way CARES helps explain the autism spectrum to families is the Ice Cream Shop/Truck Analogy, inspired by renowned autism advocate, Stephen Shore’s quote “when you meet one person with autism, you’ve met one person with autism” (2023). Imagine walking into an ice cream shop. You are expecting ice cream, and ice cream you will find, but there is a vast va-

riety of ways you can receive this ice cream and there is a big chance that your order will differ from another customer’s, despite it all being ice cream. This is a bit like the autism spectrum. Imagine instead of flavors in the buckets of the ice cream shop, we are seeing the area’s within an individual that autism may impact: communication, behavior, learning style, executive functioning, sensory processing, and social skills—you may likely have a combination of scoops. Now remember that just like your ice cream may come in a waffle cone,

a cake cone, or even a bowl—environment is a foundational factor. What resources, tools, and supports does a child with autism, and their family unit, have access to? Can we consider adjusting the environment to help this child reach their fullest potential and help the overall wellness of the family unit? Finally, we consider the toppings that give your ice cream its final touch on unique personality—genetics. Genetic mutations and variants, as well as epigenetics can and do have an influence on autism, in a variation that goes far beyond nuts and sprinkles (Sandin et al, 2017).

Early Identification

As a neurodevelopmental disorder, there are noted delays or peculiar behaviors that may indicate a child has autism. ASD can be reliably diagnosed in some children as early as two years old, and some signs may be noticed even earlier in childhood by parents and caregivers (Centers for Disease Control and Prevention, 2023). With early identification, intervention, and ongoing support, the quality of life



for a child and their family can be significantly improved. Early intervention can be life-changing for a child having ASD, as the developmental impact follows them throughout life. The earlier consistent, evidence-based intervention is provided to a child, the more positive cognitive, social, emotional, communication, and motor growth (McPherson, 2024). Also important is early identification, as for many families, the diagnosis can be a “ticket” in accessibility for early intervention services.

For many families in WV, it is a pediatrician, a WV Birth to Three provider, a child care teacher, or preschool/early elementary school teacher that may first notice early indicators that a child may have ASD. It is so important for service providers to remember that when we are working with parents and caregivers, that we avoid terms like “red flags” or “warning signs” when indicating characteristics of ASD, as they send the message to parents that autism is a bad or wrong thing to happen in their child’s life. It may be beneficial for the parent or caregiver’s mental and emotional well-being if we use terminology that is neutral, like “early signs” or “signs a child might benefit from being evaluated.” Just like ice cream and autism, the ways in which a parent

or caregiver’s response to the possibility of their child having ASD is a spectrum. Some parents may resist the notion that their child may be autistic. The harmful stigma and misconceptions surrounding ASD may leave some parents/caregivers making statements like “but she’s too smart” or “but my in-laws say my husband was the same as a little kid and he grew out of it” to rationalize that their child does not need to be evaluated for ASD. Other parents may have been watching their child miss developmental milestones with a sense of dread and are desperately seeking a clinician to hear their concerns and make an assessment that give them a clearer path in supporting their children. These reactions, across the spectrum, are valid and very human. It is important to remember the functional goal of the evaluation—to better identify how we can support the child and family to reach their fullest potential.

To receive an ASD diagnosis, a parent or caregiver may be referred by their child’s pediatrician to a qualified and experienced developmental pediatrician or clinical psychologist to administer an ASD diagnostic tool to determine if a child meets diagnostic criteria for ASD, including level of support needed. A parent may also request from their

pediatrician a referral to a developmental pediatrician or clinical psychologist. “Hurry up and wait” is a sardonic phrase adopted by many parents of children with autism in WV. And for many, the “hurry up and wait” process begins when seeking an ASD evaluation for their child. Once a referral has been made, families in WV can and often do face waiting three months, and sometimes up to a year, for their evaluation appointment.

Many families find it more beneficial to travel to out of state clinicians with shorter waiting lists, such as Nationwide Children’s Hospital in Ohio. Of course, this option is only available to families who have the financial and physical resources to be able to make this journey. Thanks to the “Child Find” mandate under the federal Individuals with Disabilities Education Act (IDEA), every school district has the responsibility of identifying and evaluating children in their district suspected of having disabilities. Parents or caregivers can formally request evaluation for special education services from their school district. For many families in West Virginia, Birth to Three supports families in the process of transition from their services into services provided through the family’s school system. While educational and med-

ical diagnoses differ, the earlier a child can be evaluated for special education services, the earlier a student (if eligible) may receive services and supports through an Individualized Education Program (IEP) that supports them within the education system. If a parent or caregiver formally requests a student be assessed for special education services (including qualifying under ASD), the school has 10 school days to provide a formal response in which it is typically standard to then have the parent or caregiver sign permission for their child to be evaluated by the school system.

Once permission is signed, the school district has 80 calendar days to evaluate the student and hold an eligibility meeting to determine if the student qualifies for special education services. If the student is eligible (including under the eligibility of ASD), the school district then has 30 calendar days to implement the IEP, but in many cases, the IEP is initiated as soon as the school can accommodate the plan. In some cases, this may be the very next day. So, it can and does occur that a child with autism is receiving school-based early intervention months before they have been medically evaluated for ASD.

ASD Identified, Now What?



Typically, there is no party thrown when a child is identified as autistic. There is no confetti raining from the ceiling and, in fact, many parents or caregivers may feel that the sky is falling on them. The harmful and very present negative stigma and misconceptions surrounding autism may make an ASD diagnosis seem devastating. Some parents may begin over-ruminating on prenatal behavior, genetic family history, and other factors of nurture or nature in the hopes of identifying the “fault” of the diagnosis. Although not common, some parents may deny the results of the evaluation, as their child “can’t have that la-

bel.” Many parents who eagerly sought an evaluation and find brief comfort in having a name to describe their child’s behaviors and delays, are soon left with an overwhelming fear of the unknown future. It is valid to encourage parents and caregivers to grieve. They are not grieving the loss of a child, as the child is still a whole human to love and cherish. Rather, they are grieving the expectations and dreams they had anticipated for their child and their own lives as parents.

The final step of grief is acceptance, paving the way for a future where you have made

peace with the circumstances of life that cannot be changed.

Emily Pearl Kingley’s short essay, *Welcome to Holland*, about a traveler en route to Italy surprisingly lands in Holland is an allegory for unexpectedly raising a child having disabilities, and encapsulates this grieving process for many parents of children having autism. It is so important to remind parents and caregivers of children newly diagnosed with ASD that this diagnosis is not the end of life, but rather the beginning of a life where the child and family are empowered to reach their fullest potential with the right supports.

The first question many parents or caregivers have upon receiving an ASD diagnosis is “what do I do now?” Again, early intervention is a priority. How-

ever, this is when “hurry up and wait” continues for many parents. Among evidence-based interventions for ASD, applied behavioral analysis (ABA) is considered the “gold standard.” This is never to say that any intervention cures autism, as there is no “cure.” However, decades of research suggests that consistent, evidence-based early intervention through ABA can significantly improve and impact positive developmental growth (Foxy & Mulick, 2016). In WV, if a child is referred by their pediatrician for ABA, and if a parent is not discouraged by misinformation concerning ASD treatment, and if the child’s insurance coverage or lack thereof is not a barrier, these parents will soon discover that ABA is likely inaccessible to them. We Develop ABA, a coalition dedicated to increasing accessibility for families

in WV to receive ABA, provided a comprehensive report in which it is stated that only four percent of children with autism in WV have access to quality ABA services, leaving the remaining 96 percent without this access (Mountaineer Autism Project, 2024). We Develop ABA also included that of the 55 counties in WV, only 11 counties have ABA clinics. Our state’s service gap is a service canyon for families of children having autism, leaving many feeling hopeless.

West Virginia Birth to Three is an invaluable resource for families in WV, as children from birth until the age of three can receive an Individualized Family Service Plan (IFSP) addressing the child’s developmental needs, which may include speech, occupa-



tional, and in some cases ABA services. A child's Birth to Three team can also support a family in helping them advocate for referral requests to pediatricians, in helping the family access services in their community, and helping transition a child's IFSP to an IEP in preschool. A student's school resource network, such as a social worker, can also assist families in directing them to community and advocacy resources. There are also agencies within WV, such as Community Autism Resources & Education Systems (CARES) that can help parents navigate services that may benefit their children having autism, as well as tools, such as the West Virginia University Centers for Excellence in Disabilities Autism Resource Map. This map can help families and service providers locate autism services by geography and the services themselves. Also, through the public education system, a student's IEP may be able to offer very beneficial supports. While IEPs are individualized, supports for students with autism may include access to services such as speech or occupational therapy, positive behavioral support plans, and visual supports such as daily transitional schedules or "first/then" charts. Access to early intervention may very well be access to living a life of a higher quality.

About the Family

Like ice cream and autism, each family is unique, but there are some common characteristics found in many families of children who have autism. The painful stigma surrounding autism can often leave families not only excluded from their communities but choosing to self-isolate—an untaught world can be unkind. While a parent may be able to face going to the grocery store with their child, even if their child may have sensory stims (rocking, flapping, etc.) or may become distressed and need to regulate, it is understandably difficult for this parent to cope with other shoppers staring, murmuring, or even openly commenting on how the child must be a brat or the parent must be an insufficiently parenting.

There can often be significant financial and interpersonal strain on a family in appropriately budgeting the family's resources to provide the child with their medical, educational, and social needs.

There is also to consider the lack of appropriate childcare outside of school and lack of access to medical services these families face in their "hurry up and wait" circumstances of waitlists. Other practical stressors, such as hypervigilance, lack of sleep, or a need to adhere

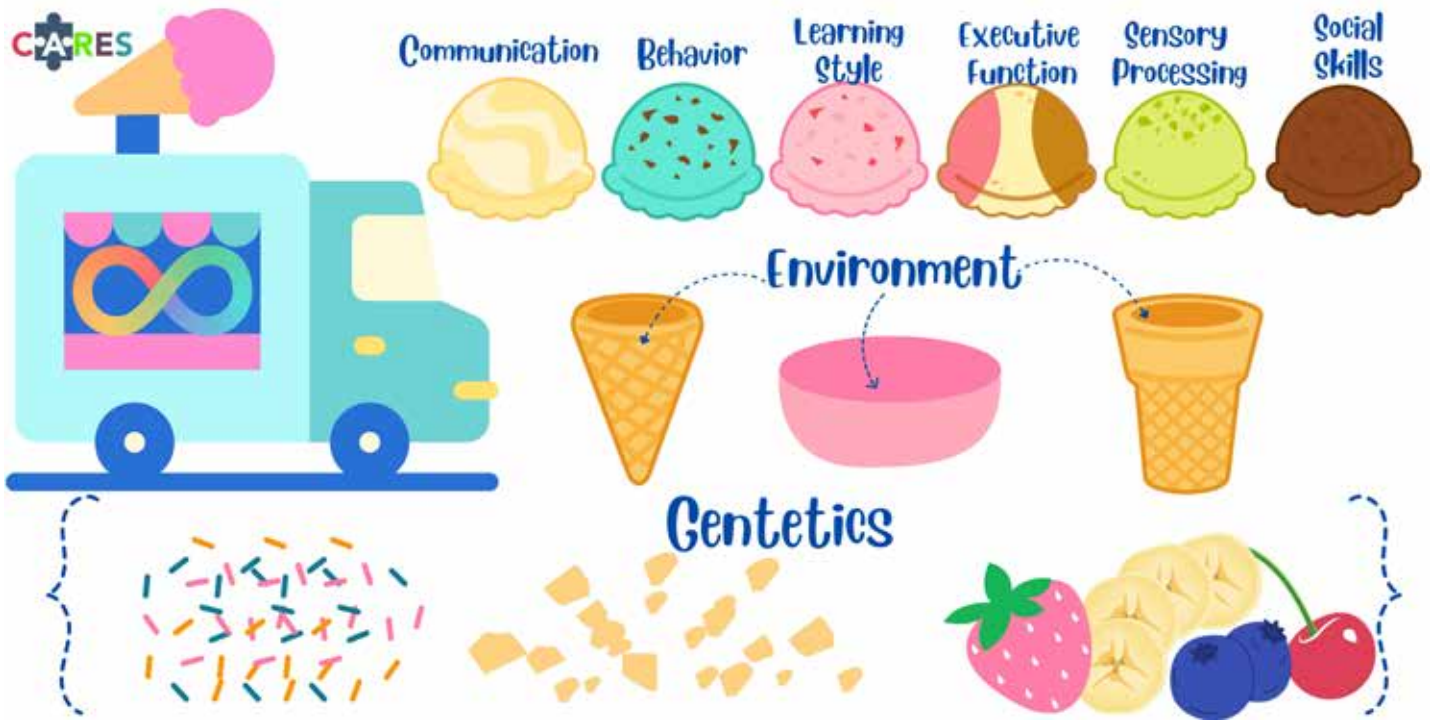
to a functional routine in order to provide their child the safety and stability that all parents want for their children, can leave parents in a state of burnout.

In WV specifically, many families live in poverty, which is alone a significant barrier, and many of these families live in rural areas where their closest services are unattainable due to the travel required to access them. Also specific to WV, many grandparents or even great-grandparents are the primary caregivers for their autistic grandchildren. The culmination of these characteristics can put parents and caregivers in a state of mental and emotional distress, devastating the family unit (Woodman, 2014).

How can the Helpers Help?

Teachers, therapists, social workers, and other service providers are the helpers for many autistic children and their families. So, how can we help?

We can be mindful about how we talk about autism. Again, we do not seek red flags or warning signs for ASD. We see indicators of ASD, and we encourage parents to seek early identification and intervention for autism because we want to help this child grow happy and



healthy—we want to help. When it comes to if a person has autism or if a person is autistic, it is an issue of personal semantics of whether someone prefers person-first or identity-first language. When working with children in early childhood, it may be best practice to use the preferred terminology of the parent or caregiver. Finally, “autism/autistic” are not bad words to be whispered or murmured with hesitant dread. It is a condition within humans who, when supported, deserve and have a fulfilling childhood and life.

We can help through education. We can utilize our critical thinking and continue our education from qualified, evidence-based, and peer-reviewed sources in order to help families differentiate be-

tween information and misinformation regarding autism. We can help direct families to information that may benefit them. One excellent resource can be found in the Organization for Autism Research (OAR) website, which has a wealth of information on autism and supporting families impacted by autism, including support for siblings. We can collaborate as organizations within the communities of those we serve to help connect families with resources and support. We can also help families connect with other families of children with autism, building a network of support. This is autism advocacy.

We can and should always show patience and kindness toward our children with autism and their families. Our

parents and caregivers may need a “life-line” to instill hope, and sometimes we are that life-line. Due to social stigma, parents may already have the misconception that they are perceived as inadequate parents because they simply cannot access what the doctor prescribed. Due to several factors, a parent may seem distracted, nervous, somber, or even defensive concerning their children. Please show them patience, kindness, and respect.

We can help by being inclusive. In our classrooms and communities there are always opportunities to promote inclusion for children with autism and their families. Altering the environment such as provided spaces for sensory regulation or opportunities for mul-

timodal communication can help children with autism meaningfully participate within these environments. What is most important, however, is how we create a positive atmosphere that negates our social stigma toward autism. Can it be understood and accepted that a child with autism may cry or have a sensory meltdown and nothing is inherently wrong or bad about this child or their parents? Of course! Can it be understood and accepted that quirky behaviors related to autism, that do no harm, are therefore harmless? Of course! Any classroom, community space, and any individual is doing themselves a deep disservice if they fail to be inclusive to children with autism and their families, as they are part of the community. Letting a child access their village, is letting the child access their childhood, and we need to continue affirming to families that we want them in our village.

Ice Cream and Autism

Autism is a spectrum. The characteristics of autism, along with environment and genetics, leaves each autistic individual as their own super sundae. Parents can support children with autism, and we as helpers can serve these children and their families by helping them understand a child's flavor, and therefore how they can be best supported. A big impact

the adults in a child with autism's life have is through adjusting their environment in the way that best supports them, whether this is a token system used for brushing teeth at home or an education plan that facilitates positive behavioral and social growth, or receiving speech therapy to improve communication. Please remember that while many parents are actively and desperately trying to access ABA for their children, for most of them at this time, it is hard to access. If a scoop of ice cream cannot have a sturdy bowl, we must do everything we can to ensure it has a sturdy cone, while ordering more bowls. We can genuinely welcome and cherish our children with autism and their families and include them as community members. Humans, like ice cream and autism, are on a spectrum and it is important to meet and help them wherever they are in life. Autism is not a bad word or a bad thing to happen. Autistic people can and do live fulfilling lives when given the supports they need and deserve, and they in turn bring joyful value in the lives of others when given appropriate support. After all, like ice cream shops, autism can and should still be a happy place in life.

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After the Diagnosis: Evidence-Based Therapy of Applied Behavior Analysis

Submitted by Kathy Shapell, MA, and Susannah Poe, Ed. D., MAP Executive Committee

When your child receives a diagnosis of autism, you may be overwhelmed with questions about what this means for the future and wonder how your child can gain the skills to live independently as he or she grows older.

Hopefully your doctor has already provided you with helpful information on effective treatment and local resources, including Applied Behavior Analysis, or ABA. Decades of research show that Applied Behavior Analysis, provided by well-trained professionals, is the most successful approach to teaching skills and achieving goals for many autistic children and their families. With ABA, autistic people can build a wide range of foundational skills for everyday life: basic activities like getting dressed and using the bathroom, and practical skills like crossing the street and using public transportation. It also can help autistic children strengthen their communication and interpersonal skills—so they can be more connected as part of their family, school, and community.

ABA is not new and not just for children. It is firmly based on well-established principles of learning and behavior that have been successfully used by millions of people to achieve desired changes (like learning healthy eating habits, strengthening communication skills, stopping smoking, and improving worker safety in factories). With a proven track record, ABA interventions are widely recognized by health experts. Most everyone with insurance has coverage for ABA services for the treatment of autism, and Medicaid coverage for ABA therapy is available in all 50 states.

At its core, ABA is based on the values of compassion, respect, and self-determination. Each individualized intervention is designed with input from parents (and if possible, the child) to follow their own path and participate in society on their terms. From expressing daily decisions and preferences to eventually living on their own and succeeding at a job, ABA empowers an autistic person to make, communicate, and pursue their choices, including choosing to say “no” to what they do not want.



How Does It Work?

Each child's ABA treatment is carefully customized to their specific strengths, needs, and background. The ABA process begins with providers gathering information about a client: their preferences, needs, areas of strength and weakness. Providers, autistic people, and families then set goals to pursue together through a customized plan that breaks the learning of skills into manageable steps and small successes. Each plan includes science-based strategies and techniques that build confidence as the client learns, practices, and applies new skills in any situation. For children with autism, ABA often includes play-based activities, and parents or guardians receive training so that they can be full partners in providing the most effective support.

Consistency and patience are key to the success of ABA, sometimes requiring many hours a week of services over an extended period of time. Providers use data to determine when changes are needed and track when goals are met—then they collaborate with clients and families to select the next set of goals.

ABA services are also provided in collaboration with other professionals, including the client's pediatrician, speech pathologist, or other providers, to deliver personalized, complete care.

In West Virginia, parents and professionals involved with Mountaineer Autism Project and its We Develop ABA initiative are working to make ABA services more available. While WV providers often have long waiting lists for services, professionals and parents are working to provide better access to everyone regardless of location and income.

To learn more about these local efforts, as well as local providers, visit <https://mountaineerautismproject.com>.

Supporting Families Who Are Parenting a Child with Autism

Submitted by Sheila A. Zickefoose, MA, IMH-E®



When a child is diagnosed with an autism spectrum disorder, or a family is demonstrating concerns that their child may be affected by autism, it is critical that we are providing information and support. It can be challenging to know what to say and how to respond in meaningful ways. This article will provide you with foundational strategies to assist families to explore intentional ways of engaging their child to expand their opportunities for learning.

Relationships with families are always a critical part of your work yet your partnership with families having children with autism or other disabilities takes on a level of importance. Often these families experience

additional challenging situations and stressors. They have hopes and dreams for their child, just as any family does. However, those dreams may abruptly change, and that can feel like a huge loss. Empowering families with knowledge, empathizing with their feelings, and collaborating with them to develop new hopes for their child's future becomes foremost in our minds.

Meet the family with respect and be sensitive to their experience. Receiving a diagnosis is shocking even when it may have been suspected. It can feel awkward and uncomfortable and leave you feeling at a loss for words. Remember, families need to know you are a resource and support.

Things to consider:

- Lend a listening ear. They may need to have someone listen with no expectation of a response or unwanted advice. Let them vent, cry, and/or share their fears. Knowing someone can help them handle the tough stuff means everything.
- However, it does not mean you have to have all the answers! Let them know you may not have the answers they seek but you will figure it out together.
- Treating them and their child the same way you did prior to the diagnosis is important.
- They are still the family they were before diagnosis, maintaining the relationship is incredibly helpful. Many families want to ensure their child will have the same experiences as their friends.

- Be prepared with information and resources available. It may not be the time to jump into sharing a lot of that at once; however, having it at the tips of your fingers can help you feel prepared. It may be most helpful at first to simply share that you have access to that information and want to help them explore that when they are ready.

It is important to note that these conversations are not a one and done thing. Just as we are growing and expanding our knowledge in supporting the child and family, the family is also processing through this. Questions and their confidence will ebb and flow and that means their need for support does as well. Checking in with them frequently should be foremost in practice. Not only are we checking in on how things are going for the child, but we also want to check in with how they are really doing in providing the care and supporting their child's needs. Parents may like some help but do not know who to ask or be aware that there is someone able to help. Inquire about their needs for information, but also their need for emotional support. Do they need to cry, complain, scream? Are they finding time for themselves to relax, simply think, or release their stress? Remember the adage, you must take care of yourself to be able to care for others and impress that upon families.

You may be thinking you are not able to be all this for a family. One part of providing the information and support they need is helping them to create a team for their family and building a community that includes friends, family, other families, and people with autism to support one another. Help parents to become their child's best advocate. The information you provide will be critical in building their awareness of services available to support the family to meet the unique needs of their child.

We also want to begin helping parents to help their child, as soon as possible and that's not diagnosis dependent! As families are sharing their concerns, or you are identifying signs for a potential autism diagnosis, it is essential you begin to support families to engage more effectively with their baby or child. This will, of course, begin to build those basic skills that all children need to be more successful with the basic tenants of learning. Focus on evidence-based practices for educational and behavioral interventions. The ideas we are going to explore are also critical once a child has a diagnosis.

Let's explore a few strategies to begin to support families in engaging their little ones more effectively.

- Encourage parents to interact and talk with their child even if they may not be responding as we would like or expect. We often hear that children with autism are in their own little world. They can be extremely overwhelmed with everything that is happening around them – noises, sights, sounds, demands. Parents and teachers need to work their way into the child's world where they feel safe. Intentionally creating opportunities where they are engaged with their child and following their child's lead in activities is a great place to begin. These continued attempts will allow parents to work their way into the child's routines making way for learning.
- Help the family to identify the child's interests. We know that the best way to engage a young child is to focus on the toys, foods, and/or routines that the baby/child enjoys. This can be done by observing the child as they move about their home and the places familiar to them:
 - what catches their attention,
 - what do they interact with,

- are there certain foods and drinks that are go to favorites,
- are there types of foods that the child is more likely to eat.

Once you have helped the family to identify some of these, those items can be used in attempts to engage with the child. As parents begin to do that, encourage them to hold the items next to their face as they are working to gain the baby/child's attention. Presenting items in this way begins to link the preferred items to the parent, reinforcing interaction and engagement with the item and the individual.

- Finally, focus on imitation of actions and vocalizations. Initially this should be the parent imitating the actions and vocalizations of the baby/child. Once the child's attention is garnered, teach the family how to expand on those imitations, encouraging the child to imitate the adult.

Does this leave you feeling you have a lot to learn? Research is constantly changing, and we have a responsibility to stay-on-top of the latest information for ourselves and families. I have pulled together some important links for you to do just that! I mentioned earlier that it is important to provide information and support using evidence-based practices. Each of these links is rooted in the best available research and are identified as the most appropriate strategies to improve the outcomes of children with autism.

- **Autism Focused Intervention Resources and Modules** – <https://afirm.fpg.unc.edu> - Free online training modules targeting 27 evidence-based practices, nine of which are specifically researched for infants and toddlers. Each of the practices highlights developmental domains and ages that research has shown to be effective.



- **Autism Internet Modules** – <https://autisminternetmodules.org> - Fifty free online training modules targeting understanding and support for individuals with autism spectrum disorders, including 2 modules specific to the infant/toddler population.

- **Autism Speaks** – 100 Day Kit for Families of Young Children Newly Diagnosed with Autism - <https://www.autismspeaks.org/tool-kit/100-day-kit-young-children> - “Knowledge is power, particularly in the days after an autism diagnosis. The Autism Speaks 100 Day Kit helps families of children aged four and under make the best possible use of the 100 days following the diagnosis. A 100 Day Kit for school age children is also available.” (Autism Speaks, 2024). Not only will this kit support families, it will also help you to learn more about autism and the services children may need.

- **Early Start Denver Model (ESDM)** - <https://www.esdm.co/> - “ESDM is based on the empirical knowledge base of infant/toddler learning and developmental principles and the impairing effects of early autism on development. ESDM addresses all developmental areas in which children are behind, (however) it mainly focuses on boosting children’s social-emotional, cognitive, and language abilities because development in these domains is particularly affected by autism.” (Rogers, et al., 2024)

- **Family Engagement – National Center for Pyramid Model Innovations** – <https://challengingbehavior.org/implementation/family-engagement/> - At every level of supporting children with challenging behavior, families are the key to success. These resources will support you in exploring a variety of ways to gain meaningful engagement and provide practical support. Many of our systems in WV provide training on the implementation of the Pyramid Model. Contact the professional develop-

ment staff in your area of early childhood education - WV Birth to Three, Child Care Resource and Referral Agencies, WV Positive Behavioral Interventions and Support.

- **Help Is In your Hands** – <https://helpisinyourhands.org/course> - Four free online training modules for both parents and practitioners, each containing 4-5 brief lessons. Focused on naturalistic approaches to strategies from the Early Start Denver Model and Applied Behavior Analysis, designed to help practitioners coach parents and other caregivers in building independent learning for children.

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Early Identification and Diagnosis: How Can We Support Families Through the Transition?

Submitted by Breanna Adkins, EdD, OTR/L, BCP, IMH-E ®

“Do you think my child has autism?” This is a question early childhood professionals, such as occupational therapists, speech therapists, physical therapists, and developmental specialists, get asked by families they work with all the time. This question never gets easier to answer, no matter how much experience one has working with young children and their families. Honesty is always the best and most ethical practice, but providing honest opinions is easier said than done.

As many as 1 in 36 children in the United States have Autism Spectrum Disorder (ASD), with 3.9 percent of children in West Virginia being reported with the diagnosis from their caregivers (National Autism Data Center 2024; National Survey of Children’s Health, 2021). The average age at which children receive an ASD diagnosis is between 3 and 5 years old; however, signs of ASD can be identified within the first year of a child’s life (Pierce et al., 2019; van ‘t Hof et al., 2020). Research has shown that ASD can reliably be diagnosed as early as 18 months of age; yet in practice, children are being di-



agnosed much later (Pierce et al., 2016). In the last decade, there have been widespread health initiatives from organizations such as the American Academy of Pediatrics and the U.S. Department of Health to emphasize the importance of early identification and

intervention for children with ASD in practice. Early identification of ASD is a critical first step to receiving early intervention services, such as occupational, speech, and physical therapies, among others, as the research is clear that early intervention with children with

ASD leads to better outcomes later in life (Clark et al., 2017; Pierce et al., 2016; Pierce et al., 2019).

As a new graduate occupational therapist working in early intervention, I wanted to be the best therapist I could for my families, and the first time a family asked me, “Do you think my child has autism?” I completely panicked. I told that family, “No, I don’t think so! I think we just have some things we need to work on.” But down in my gut, I thought maybe the child had signs of ASD.

There are a variety of signs and symptoms that collectively could indicate a child may have ASD. For children between 1-2 years old, some warning signs to look for are:

- Talk or babble using repetitive consonant sounds such as “bah-bah-bah” with little intonation in their speech
- Sensory-seeking behaviors such as flapping their hands or fascination with things that spin
- Carrying non-toy or non-age appropriate items around for an extended time
- Finding their own way to play with toys, such as only spinning the wheels on a toy car and never pushing it across the floor
- Poor sleep and difficulty soothing self or being soothed
- Not responding when their name is being called, not

making eye contact with caregivers

- Not using gestures or pointing to objects they want
- Not being interested in playing with others or even noticing others are in the same room as them (Pierce et al., 2019; UC San Diego School of Medicine, 2024).

Experts in the field note that many typically developing children will, at some point, have one or more of these symptoms. Also, many children who will later go on to be diagnosed with ASD will first be screened for hearing impairment due to not turning to their names when called, not following simple commands, and not talking at the appropriate developmental stage. However, when another health issue cannot explain multiple symptoms, a formal diagnostic evaluation for ASD is recommended.

When that child had almost aged out of the WV Birth to Three, they were diagnosed with Level 2 Autism. That child is thriving now, but I felt terrible for possibly leading them astray from resources that could’ve potentially helped with earlier identification and family support. Now that I am a much more experienced therapist with more years and training, I have a different approach to that question.

When a family has concerns about possible ASD, being educated and familiar with the most up-to-date research and resources in that community is paramount. If the family is asking this question, they have reason to believe their child may have ASD, and therefore, asking follow-up questions such as “What makes you think that?” or “Have you read or seen something that concerns you?” can be an excellent first step to supporting them and validating their concerns. Other ways to support families are to help them speak with their child’s pediatrician (when permitted) about their concerns, identify resources in the community for further testing, and continue to facilitate a strong therapeutic relationship throughout the journey.

Often, families don’t even know where to begin when it comes to testing or screening for ASD. It is up to the early childhood team to help the family navigate this very intimidating and scary time. Most practices that evaluate children for ASD require a referral from the primary care provider, usually the child’s pediatrician, before scheduling an evaluation. The waiting list in West Virginia for testing can be up to 1 year or longer due to high demand with little resources.

Professionals who can formally

diagnose ASD include developmental pediatricians, child psychologists and psychiatrists, and pediatric neurologists. Other early childhood professionals can administer ASD-specific screening and standardized assessment tools such as the Modified Checklist for Autism in Toddlers (M-CHAT) and the Autism Diagnostic Observation Schedule (ADOS). Still, these tools cannot medically diagnose ASD but rather help gather additional information about skills and behavioral patterns.

Becoming familiar with the providers and practices in your community who evaluate children for ASD can be very helpful in providing insight to families about what to expect when their child goes for an ASD evaluation. If applicable, providing intervention notes from your sessions can also benefit the ASD diagnostic team. Attending the child's evaluation, when permitted and if able, is another way to support the family. Not only can you serve as another pillar of support in this potentially difficult time, but you can also be another person gathering information to help the family process later. The amount of information and recommendations provided to the families during an ASD evaluation is vast and often overwhelming. Having another professional there to help "interpret" the results has

been noted as extremely helpful by families.

So how do I handle the question of "Do you think my child has autism?" now as an experienced OT? With open-ended questions to gather more information about the caregivers' concerns, validation of feelings, and provision of resources when they are ready. By being there to talk through their fears, worries, and questions. I remind them that I am there for their child AND them. Practitioners should always avoid giving a definitive answer to that question unless they are one of the professionals who can formally diagnose ASD. However, ignoring the question or being vague is also something that practitioners should try to avoid. This doesn't validate the caregivers' concerns and can jeopardize the therapeutic relationship and trust you have built with the family.

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Supporting Families

Submitted by Alexis Perry, Family Support Specialist, WV Autism Training Center

Families and community members involved in a child's life are going to make an impact on the way that child learns, develops, and behaves. This is especially true with a child who is diagnosed with autism and who needs additional supports. The West Virginia Autism Training Center's (WVATC) mission is to support individuals with autism spectrum disorders as they pursue a life of quality, and this means supporting the people in that child's life as well.

As the Family Support Specialist with the WVATC, I am typically the first point of contact for prospective clients and families. Whether they are calling to find out how to register for services, get an autism diagnosis, find a therapist in their area who works with children on the spectrum, or recently received a diagnosis and do not know where to start. This can be a stressful and frustrating time for families as they try to navigate the world of autism, possibly for the first time. I talk to families every day, from all over the state of West Virginia; and I listen. When I hear their struggles, it inspires me to work even harder on their behalf.

The word "waitlist" is a scary thing when you have a child who has significant needs. This is why we provide clients with immediate online resources until they can get connected with an Autism Specialist in their region. The WVATC seeks to provide services to as many West Virginia residents as possible, regardless of age. It is common to receive calls from schools, friends, neighbors, social workers, and counselors who are trying to find help for the people with autism in their communities. A sense of community is crucial to supporting the development of a child and this type of outreach is what it takes to create one that is strong and supportive for a child on the autism spectrum.

The immediate resources provided when a client completes a registration with the WVATC, fall under Tier I services. One of those resources is the Lending Library, where clients can request autism-specific books and awareness materials mailed to their home. They can also request an ID card that display one's name, address, contact numbers, date of birth, communication ability, and medical needs to be carried on one's person. Additional space to alert others to fears and dislikes along with calming strategies known to best help are included as options. "All About Me" documents are another Tier 1 tangible that are designed to provide detailed information about the individual with ASD in handout form. Details such as the individual's name, nickname, birthdate, parents' name and contact

information are included, along with “activities I do and do not like to do.” Goals are listed, along with support strategies. This document provides valuable information to others (doctors, teachers, neighbors, etc.) about the individual, about autism spectrum disorder, and about how to best interact with the person.

Once a client has completed the necessary registration, I will then complete the needs intake assessment with the client and family, sometimes more than one family member may be present, or others in their community such as a teacher or social worker. During the intake assessment we talk about strengths and challenges with the client and family including: educational needs, social skills, communication, sensory sensitivities, mental/emotional health, behaviors, and transitions. The needs intake assessment is designed to gather as much detail to assess the tier and service delivery for the client. This assessment helps the Autism Specialists to personalize service with each client and help them based on their specific needs. The intake assessment will determine whether the client will be considered Tier II or Tier III.

Tier II Services: Targeted

Tier II services provide information and supports to individuals, their families, educators, community professionals, and others supporting them. Tier II clients should expect that services will be narrowly focused and have a service timeline that is well-defined. Tier II will be designated for those clients who need brief, short-term, and narrowly focused services. Tier II supports typically* take place in the form of coaching (both virtually and via phone) and will include anywhere from 2-6 sessions and last no longer than 4 months.

Examples:

- Adult in need of employment readiness skill development
- Adolescent in need of transition planning
- Family in need of waiver understanding and/or application assistance
- Client facing one or two specific challenges (toileting, elopement, health/sexuality understanding, employment preparation, etc.)

Tier III Services: Intensive

Tier III services rely on a team-based approach and provide highly individualized support and training. Teams typically include family members, the individual with ASD, educational and/or behavioral health staff, and others involved in the individual’s life. An Autism Specialist facilitates training, coaching, and the development of a Positive Behavior Support (PBS) plan through collaboration with team members. Individualized skill development programs are developed by the team and implemented across all settings (home, community, and school) with an emphasis on improving quality of life. Tier III services will be designated for those clients who need intensive services likely requiring more comprehensive

and extensive supports lasting beyond the timeframe outlined in Tier II services above. Tier III clients typically* will include a timeframe of no longer than 1 year.

Examples:

- Adult in need of significant employment, independent living, or other related supports
- Adolescent experiencing self-regulation skill deficits resulting in significant challenges and interfering with educational or community participation
- Family seeking support to identify, develop, and implement a PBSP in the home environment
- Client facing several intensive challenges (aggressive behaviors, severe communication deficits, unmet sensory needs, regulation skill deficits, etc.)

The WVATC provides services to anyone who is a resident of West Virginia with a clinical diagnosis of autism, no matter their age and at no cost. Although some wait time can be expected for services to begin, clients and families will have contact with WVATC staff while they wait. Part of my job is to reach out to the families waiting for services and provide resources and information, and ask about any changes that may have occurred so that the Autism Specialists have the most up-to-date information. A common resource shared is videos that provide basic information on commonly requested challenging topics, such as creating visuals, managing meltdowns, sensory needs, and preparing for transitions.

Even if tiered services with the WVATC are not exactly what a family is looking for, we provide access to the WVATC's resource manual with information on ABA therapy, speech therapy, occupational therapy, advocacy, counseling, waiver contacts, medical services, diagnostic assessments, dietitians, and more across the state.

One of my favorite things about this program is the way the WVATC approaches services. It is a team-based, collaborative service that involves the individual client, their family members, community members, educational members, and WVATC staff members. Building up the community around the client is going to ensure that they have the supports in place to thrive, just as the mission statement embodies, to pursue a life of quality. Supporting families involves more than just registering a client for service. It involves listening, acknowledging the needs a family has, having empathy, and doing everything you can to help them and the community that surrounds them. The WVATC always accepts new clients and encourages anyone who needs help, or knows someone who does, to contact the WVATC.

Parent Blocks

NEWSLETTER



"Providing resources to parents throughout West Virginia"

Volume 21, Issue 1, Winter 2025

Noah

Submitted by Jhamaia Murphy

When I had my son Noah, I was very excited. I was a first-time mom who wanted nothing more in life than for my child to develop properly both physically and mentally and reach every milestone that babies are supposed to in a timely manner. Noah was doing these things

for the first year of his life, until one day he just stopped. He no longer responded to his name, stopped communicating (laughing, attempting to speak), had minimal to no eye contact with others, stopped being playful and would stare as if he were looking into space. All his accomplishments and

milestones that he had reached suddenly disappeared. He would not hold his own bottles or even attempt to use utensils. He stopped playing with his favorite toys. He had no interest in anyone



or anything. A cheerful little boy turned into one who would cry for no reason, or so I thought. There was a reason that I would eventually discover. I was confused, lost, scared and worried. The only thing I could think of doing was speak to his pediatrician and figure out where to go from there. I began to wonder what all of this meant and what could be going on with my baby boy. I began to question exactly what I needed to do with and for my son.

- Continued on the next page

WV Parent Blocks Newsletter is a project of West Virginia Early Childhood Training Connections and Resources, a collaborative project of West Virginia Department of Human Services/Bureau for Family Assistance/Division of Early Care and Education; West Virginia Department of Human Services/Bureau for Family Assistance/WV Head Start State Collaboration Office; West Virginia Department of Health/Bureau for Public Health/Office of Maternal, Child and Family Health/West Virginia Birth to Three; and West Virginia Department of Health/Bureau for Public Health/Office of Maternal, Child and Family Health/West Virginia Home Visitation Program and is supported and administered by River Valley Child Development Services.

Permission to photocopy

Step one, noticing the changes in my son and advocating for some answers began a lifelong journey for us. Several tests, brain scans, questions, and discussions were needed. Although the pediatrician felt Noah was a perfectly physically healthy child, he needed more intervention which led to step two in our process, a psychologist getting involved for the behavioral changes and concerns. I was referred to Birth to Three. Birth to Three provides services to children in their homes who have delays, both diagnosed and undiagnosed. The program offers speech, occupational, developmental, and physical therapy. This program helps tremendously, not only in the development of the child, but also assisting the caregivers with support and direction. After being seen by a few psychologists, Noah was diagnosed with autism spectrum disorder.

Autism affects a person neurologically and psychologically with the way they interact and socialize with others. Hearing that your child has been diagnosed with autism can be devastating. But as I can attest to, with time, learning, therapy, support, your child/family member can flourish and live a normal life just as anyone else. Noah was and continues to be assessed to see what he can do on his own and what interventions can be provided to make him more successful in all aspects of his life, and the start to all of this was the Birth to Three program.

After graduating from the Birth to Three program due to turning three, Noah and I needed more support for his continued progression. Step three began at the Developmental Therapy Center in Huntington, where Noah began receiving services on an outpatient basis. This



center has the most loving and caring staff who want to help your children progress at their own pace. Not only can they get services at the center, but services are also provided in the school systems. Noah is now seven and in first grade. Which leads me to step four.

Step four involves advocating for your child in the school system. Noah had to get an IEP before even starting school. An IEP is an individualized education program that provides specific guidelines to meet your child's needs. As a parent of a child with a disability, I want to let you know that having this in place is particularly important and that there is nothing wrong if your child has an IEP in place. Do what is best to get help. Be your child's advocate, take the steps necessary, and most importantly, one day at a time. You will encounter some instances where you will be challenged, and you must know and look for assistance to meet and advocate for your child. Behavioral support, parent networks, mentoring, and engagement are all needed when your child is in school. There are also programs that assist you in advocating for

your child if needed such as CARES- (Community Autism Resources and Education Systems) and the Legal Aid of WV-FAST (Family Advocacy Support and Training) programs which can be found online.

Step five can include advocating for and obtaining assistance with government and community agencies to assist with training, teaching, guiding, and supporting families. This could mean applying for Medicaid (to assist with costs associated with medical care such as appointments and incontinent supplies), Social Security/Supplemental Security Income (to also aid with finances), IDD Waiver to assist with services to teach, train, support and guide leading to the highest level of independence possible, and paying attention to or attending legislative events to bring awareness and secure funding to aid those with autism. Look at your circle of people around you as well. Educate your friends and family on what autism looks like. Explain the need for acceptance and understanding.

To our autism community, you are amazing, and you make this world a better place. Being able to get the resources your child needs is a wonderful thing. Never give up. Plan as you can. Fight for inclusion, help and support. Speak out. Empower yourself with knowledge-read books, ask questions, argue your stance, and keep up with trends. Know that as your loved one grows and changes, you will need to as well. I write this article to you with lots of information, hoping that it spreads awareness to just the beginning of living with autism. I know I have many more years to learn and grow and will never stop advocating for the best for my son and others.

Tips for Talking with Parents about Developmental Concerns



TIPS

EXAMPLES

Always:

Talk about development regularly

Talk with parents regularly about their child's development – not only at times of concern -- and provide them with resources so they can track milestones at home.

I am so happy to be Taylor's new teacher! I care a lot about making sure all my children are on track in terms of how they play, learn, speak, act, and move for their age, so I will be looking for and tracking Taylor's developmental milestones and sharing his progress with you regularly. It would be great if you would look for milestones at home, too, and let me know what you're seeing as well. I have some free milestone checklists that can help.

Share resources

Encourage families to use [milestone checklists](#) or the [Milestone Moments booklet](#) to monitor their child's development at home. Find these free resources here: www.cdc.gov/Milestones

A great way to monitor Taylor's developmental milestones is with these checklists. They can help you understand typical milestones he should be reaching for his age and those to look for as he gets older. You can place them on the refrigerator for quick and easy reference throughout the day.

Use good listening skills

- Listen closely, make eye contact, nod when appropriate, and be silent when the parent is speaking
- Repeat the parent's main points when you respond so he or she will know you heard and understood
- Consider how the parent feels about what he or she is saying
- Watch and listen closely for clues to those feelings and acknowledge them when you respond
- Probe for more information when necessary

It sounds like you are pretty worried and I hear you saying that you do not hear Taylor speak clearly at home. Is that correct?

Let's talk about what you have noticed at home. Can you describe specific situations?

Is there anything else about Taylor's development you'd like to talk about?

When you have concerns to share:

Highlight the child's strengths

- Let the parent know what the child does well and the milestones he or she is meeting
- Keep the conversation positive

We love having Taylor in class. He follows the classroom rules and really loves to sing, dance, and act during our circle time.

Make sure you are well prepared

- Invest time in building meaningful relationships with the parents and discuss developmental progress regularly
- Complete a [milestone checklist](#) for the child's age to help the parent know that you are basing your comments on facts and not just feelings

Since our last meeting, I have noticed a few things about Taylor that I would like to discuss with you. I've been completing a milestone checklist for him, like I do for all the children, and I see he is meeting his cognitive milestones very well. However, he is not meeting a few of his language/communication milestones. For one, I have noticed that Taylor doesn't speak clearly enough for most people to understand. As you can see on the checklist, a five-year-old typically speaks clearly.

Encourage the parent to share any concerns with the child's doctor

- Remember it's not your role to make or even suggest a diagnosis
- Remind parents of the importance of acting early on concerns

There might not be anything to be concerned about, but I do think it's important to talk to Taylor's doctor about this in the next few weeks to be sure. Take this checklist with you when you go, share it, and ask the doctor for a developmental screening. This will help the doctor and you to know whether Taylor might need a little extra help. Getting help early can make a big difference! Let me know if you need anything from me for that doctor's appointment.

Follow-up with the family in a few weeks

Thank you for taking time to meet with me again. I know the last time we talked about Taylor's development, we were concerned about his language skills. Have you been able to talk with Taylor's doctor about this?



www.cdc.gov/ActEarly
1-800-CDC-INFO (1-800-232-4636)



Download CDC's
Milestone Tracker App



Learn the Signs. Act Early.

Tips for Talking with Parents about Developmental Concerns

How to Respond

If parents disagree with you about their child's behavior or abilities

Try: Sometimes children behave differently at home than they do at school. I'm only able to share with you what I've seen in the classroom. How does Taylor act when he's around other children in the neighborhood?

If a parent gets angry or upset

Try: I understand that you are upset. Like you, I want what's best for Taylor. That's why it's so important for me to share with you what I am seeing. If he does need some extra help, I want him to have the opportunity to get it as soon as possible. Do you want to discuss your questions and concerns now, or would you rather think about this a little more and meet again (in a couple of days, next week, etc.)?

(If the parent hasn't already been given a milestone checklist, give one and suggest that he or she fill it out and bring it back.)

If a parent reports that the doctor said to wait and see

Try: While it's true that every child develops at his or her own pace, there are certain milestones we typically see from most children by Taylor's age. If you are concerned, you can reach out to early intervention directly to see if Taylor qualifies for help through free or low-cost services. You don't need a doctor's referral. Acting early may make a real difference for Taylor, so it's better to find out for sure. If his development is delayed enough to qualify for help, you can get those services started right away and then follow-up with the doctor.

Be Mindful of Cultural Differences

Not all cultures place the same emphasis on particular developmental milestones. When communicating with families, be aware of your own cultural biases in making decisions about how to communicate with families.

Additional Resources

- For a FREE 1-hour online training about developmental monitoring and communicating with parents, including videos of sample conversations (Module 4) visit www.cdc.gov/WatchMeTraining
- For [tips on why and how to use *Learn the Signs. Act Early.* materials](#) in your classroom and to access free materials visit www.cdc.gov/ActEarly
- Share the [How to Help Your Child](#) and [How to Talk with the Doctor](#) tip sheets with parents: www.cdc.gov/Concerned