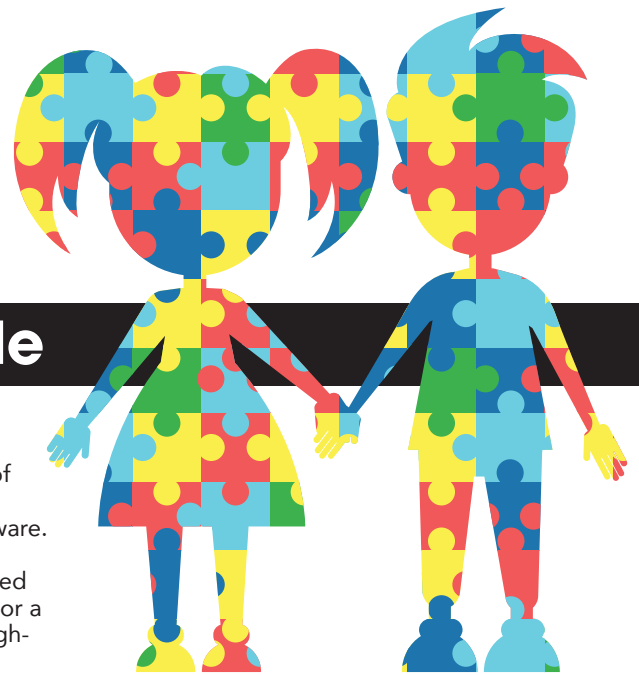


# Autism



## A Pittsburgh Resource Guide

By Kristi Wees

**A**pril is Autism Awareness month. With the most recent estimate of the prevalence of autism spectrum disorders (ASD) being 1 in 36 children (ages 3 - 17 in the US, 2016), most people are already aware. This condition has touched nearly every family and classroom in America. Undoubtedly, if you are reading this article you have been impacted by autism in some way. You may be a parent with a newly diagnosed child, or a teacher with a child with autism in your class or maybe have a friend or neighbor with this diagnosis.

This guide includes a few of the many organizations in the Pittsburgh area that are here to assist those with autism and their families. It's not meant to be a comprehensive "Yellow Pages", nor list every organization in Pittsburgh that works with this population. The goal is to provide a road map of some of the major categories that individuals with autism and their families may find helpful, not to overwhelm with "too many options". If you are an organization that works with this population, and are not listed in this article, I encourage you to reach out to those listed, and support their missions. You can also contact Pittsburgh Parent for advertising opportunities in upcoming editions focusing on special needs.

### Diagnosis

For any parent, getting the news of an autism diagnosis for their child can be traumatic. It is not something any parent prepares for. It is not mentioned in any of the pregnancy or parenting books that are read before your baby arrives. Yet for families across Pennsylvania, the reality of hearing their child has just been diagnosed with autism is happening daily. Parents whose child has an autism diagnosis, often share that they knew from an early age that something was "off" or "not quite right" with their child's development. They often speak of "red-flags" or warning signs that something was going on with their child. Many parents express "if only I would have known that was a warning sign, I could have helped my child sooner." So, in light of these parent's sentiments, here are some of those "red flags" (as reported by parents whose child was later diagnosed with AUTISM).

RED

FLAGS

- Colic
- Reflux
- Eczema
- W-sitting
- Toe-walking
- Poor Sleeper
- Head-banging
- Hand flapping
- Lining things up
- Stopped babbling
- Repetitive behavior
- Frequent ear infections
- Diarrhea/constipation
- Bothered by loud noises
- Not responding to name
- Recurrent colds/infections
- Never smiles/Never happy
- Speech regression/Loss of words
- Increased head circumference/Big head
- Intense tantrums and meltdowns (that cannot be re-directed)

If you are reading this and have concerns regarding ANY of these "red flags", start by having a conversation with your pediatrician or doctor, no matter what age your child is. Don't wait, a parent's intuition is NOT to be ignored. Routine screening for autism is done at the 18 & 24 month well child visits by most pediatricians, using a survey called MCHAT. If you still have concerns that are not being addressed by your pediatrician and your child is age 0 - 3yr old, you can call the Early Intervention services center for your county, for a free in-home evaluation.

A diagnosis of autism is usually made by a developmental pediatrician (MD), psychologist (PhD or PsyD), child psychiatrist (MD), neurologist (MD). Note: these professionals use NO medical test to diagnose autism (no blood, urine test, x-ray, MRI, CT Scan, etc.). Instead, the diagnosis is subjective, and is based solely on behavior and development without any diagnostic focus on possible underlying root causes of that behavior. The professional evaluating the child determines whether or not they meet a set of diagnostic criteria behaviors, which are outlined in a psychiatric manual known as the Diagnostic and Statistical Manual of Mental Disorders (5th ed.) (DSM-V)

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## Medical evaluation

Even though autism is diagnosed across the country without any biological data, a growing body of medical literature exists that is looking deeper at the biochemistry and medical co-occurring conditions in autism. The current medical literature estimates that between 9 - 70 percent of individuals with Autism have co-occurring gastrointestinal medical concerns (PMID: 24193577). Approximately one third of individuals of autism are found to have co-morbid seizure disorders, often un-diagnosed and thus un-treated (PMID: 25440829). Another portion of the autistic population suffers from possible immune system dysregulation and deficiencies (PMID: 19343198). One study found that 80 percent of children with autism have underlying mitochondrial dysfunction (PMID: 21119085). Mitochondria are the part of the cell that converts nutrients to energy for the entire body.

Does this suggest that autism may be a medical condition that manifests itself with behavioral symptoms? More research needs to be done in this area to know

for sure, but for now, parents need to request a medical work up with their child's doctor, to ensure their child does not have an underlying medical condition that may be causing or exasperating the symptoms that appear to be autism. Seeking the help of a patient advocate, medical navigator or health coach can assist a family with navigating this path forward for their child.

### Some of the diagnostic criteria for an autism diagnosis include:



- Persistent deficits in social communication and social interaction.
- Restricted, repetitive patterns of behavior, interests or activities.
- Symptoms, which cause clinically significant impairment in social, occupational or other important areas of current functioning.

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## Treatment / therapies (ABA, OT, Speech, etc.)

Once a child receives a diagnosis, one of the first worries on a parent's mind is usually, "What is the cure or treatment?" Most professionals who work in the field of autism will tell you there is no cure; however, if you speak with families you will learn that there are stories and anecdotes of children recovering from autism.

As far as treatments go, the American Academy of Pediatrics guidance to pediatricians in their resource called: "Management of Children with Autism Spectrum Disorders" outlines a number of behavioral therapies including Applied Behavioral Analysis (ABA), speech therapy, occupational therapy (including sensory integration) and psychopharmacology management.

This guidance is over ten-years-old and many more therapies have evolved since its last update. These include diet/nutritional therapies (including the gluten free-casein free diet), vision therapy (are the eyes working together and with the brain), auditory integration therapy (are the ears working together and with the brain), hippotherapy (horseback riding) and many more.

"Outsmarting Autism", a book written by Pittsburgh native and autism expert, Patricia S. Lemer, can help families prioritize the multitude therapies and treatments available.

No matter what treatments or therapies you decide to pursue for your loved one with autism, it is most important to focus on the desired outcomes and the relationship and rapport that the therapist has with you and your child. Most children enjoy therapies most of the time.

If, however therapy time turns into a "torturous" time for your child, speak with the therapist and re-evaluate if this therapy or the timing of this therapy is right for your child. Most families don't realize that they can request a change in therapist if the current one is not a "good fit." Most therapy practitioners will not be upset or offended by this request if they truly have the child and family's best interest in mind.

Another helpful treatment that has been recently introduced through

Pennsylvania legislation passed in 2016 and implemented in 2018 is medical cannabis (or medical marijuana). Autism is one of the qualifying conditions listed on this legislation. Parents and caregivers can learn more about the process through the state at the website listed in the resources section at the end of this article.

## Insurance and medical assistance

A major concern for most parents after diagnosis and therapies are identified is "How am I going to pay for all of this?" National statistics estimate the price of raising a child with autism is \$17,000 per year over and above the cost of raising a child without Autism (PMID: 24515505).

On the top of all parent's question list is, "Will my insurance cover these treatments?" The short answer is, "Maybe," depending on the type of insurance.

One avenue to investigate in Pennsylvania is a program called medical assistance (Medicaid for children with special health care needs). Many parents assume that they make too much income to qualify for Medicaid for their child, but in Pennsylvania there is a program that they may qualify for due to their child's challenges and diagnosis. This program is referred to as "PA-95" and the Pennsylvania Health Law Project has a helpful guide called: "Getting Medical Assistance for a Child (under 18) with a Severe Disability, Behavioral or Autism

Spectrum Disorder under the PH-95 Category ("loophole")."

If a child qualifies for PA-95 then this medical assistance acts as a secondary insurance to their primary insurance (for those children who have a primary), relieving some of the financial burden from medical and behavioral health costs. For help with this process and other resources for your child, you can call the Special Kids Network Hotline (1-800-986-4550) and request a home visit from an Elks Nurse.

Something else to keep in mind in Pennsylvania is that the medical and behavioral health services are administered separately. Since autism is considered a behavioral health condition in order to access services such as wrap-around (where behavioral health professionals come to your home to provide services), it is necessary for a family to get connected with Behavioral Health Rehabilitation Services (BHRS) provider.

Families can start this process by calling the Community Care Behavioral Health or Value Behavioral Health (call your medical assistance insurance carrier to determine which organization covers your area).

## Support for individual and family

Diagnosis, therapies and insurance, oh my! You can easily see how parents can become quickly overwhelmed! That is where the need for support comes in! Pittsburgh is fortunate to have a number of excellent organizations that provide family support and individual support to those with Autism.

Autism Connection of Pennsylvania is a wealth of information. They hold seminars, a yearly conference, and facilitate over 60 support groups state wide, including The Biochemistry of Autism group, which I lead, groups for siblings of individuals with Autism, and even one for grandparents! Other family support organizations include: Autism Caring Center, Parents in Toto and Parent to Parent of Pennsylvania.


Support can take a lot of forms for families, so it is worth mentioning that local places of worship are another option with many area churches (such as Victory Family Church and the South Hills Bible Chapel) and synagogues, having not only special needs ministries for children on the autism spectrum

### Early Intervention Services by counties surrounding Pittsburgh

- Allegheny County - Alliance for Infants and Toddlers: 412-885-6000
- Butler County - Center for Community Resources: 724-431-3748
- Armstrong County - Family Counseling Center: 724-545-1234
- Beaver County - Beaver County Direct Services Unit: 724-891-2827
- Lawrence County - Human Services Center: 724-658-3578


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but also group opportunities for parents and caregivers.

If getting out of the house to attend a support group is next to impossible due to your schedule or your child's needs, there are online options as well, with countless Facebook groups for autism support.

## Education

You don't have to wait until your child with special needs is school age to get help in Pennsylvania. By law, the Early Intervention groups listed previously serve children diagnosed with autism and other special needs before age three.

In Allegheny County, children enter the DART (Discovery, Assessment Referral and Tracking) or LEAP programs from three through age five.

Once they enter kindergarten, depending on the severity of a child's needs, a number of options are available through the home school district until the 22nd birthday.

Two legal documents are important to understand when navigating the educational system for children with special needs are: The Individualized Education Plan (IEP) and the 504 Plan.

The IEP is part of the Federal legislation - Individuals with Disabilities Education Act (IDEA 2004) which identifies an individual child's unique learning needs, the services the school must provide and how progress is to be measured.

The 504 Plan is part of the federal legislation Section 504 of the Rehabilitation Act of 1973 and is a civil rights law that prohibits

discrimination against individuals with disabilities, allowing children to receive accommodations and modifications, such as special seating, or extra time to complete assignments or tests.

While these laws may all sound like alphabet soup and the acronyms may make your head spin, don't worry, you are not alone. The good news is plenty of organizations are out there to help you navigate it all, and even advocate for you. In Pittsburgh, we have the Parent Education & Advocacy Leadership Center (PEAL), whose sole mission is to educate and empower families to ensure that children and young adults with special health care needs lead rich lives as full members of their schools and communities. They offer training classes, videos and resources for families at no charge.

## Activities and Recreation

Whew! At the end of the day you may find little time left for leisure and recreation after spending countless hours at therapies, on the phone with the insurance company, attending IEP meetings or a support group meeting. Make time for fun a top priority! Spending time as a family in your community can go a long way in providing an improved quality of life for all!

Some of the amazing opportunities for involvement in Pittsburgh include The Pittsburgh Cultural Trust's commitment to providing "sensory friendly" performances of musicals, plays and ballet in the Theater District such as "The Nutcracker" and

"Wicked".

If sports are more your thing, Pittsburgh, being the town that bleeds black and gold, has no shortage of adaptive sports including Miracle League (baseball), Mighty Penguins (sled hockey) and even snow skiing through Three Rivers Adaptive Sports.

You can also find seasonal special needs and sensory friendly activities such as "Sensory Friendly Santa" (the Autism Connection of PA hosts this each December) and Special-Needs Easter Egg Hunts (Victory Family Church in Cranberry and others). Look for programs at local libraries (Storytime: Sensory Discoveries at Carnegie Library Pittsburgh) and community centers (Friendship Circle of Pittsburgh) across our region that provide accommodations to those who need them.

Across our region you now know that we have many resources for individuals and families impacted by autism. The most important thing to remember is that YOU ARE NOT ALONE... and YOU know your child BEST. Period. ■

*Kristi Wees is the Chief Advocacy Officer at [www.EmpoweredAdvocacy.com](http://www.EmpoweredAdvocacy.com). She advocates along-side families each and every day for the best quality of life for their children and their entire family, specializing in Autism, ADHD, PANDAS, developmental delays and Mitochondrial disorders.*

The author would like to thank Jennifer Salamon at Autism Connection of Pennsylvania for her help and resources in preparing this article.

## Sources and resources

- **Autism Prevalence:** <https://www.cdc.gov/nchs/data/databriefs/db291.pdf>
- **MCHAT screening:** <https://m-chat.org>
- **AAP's "Management of Children with Autism Spectrum Disorders"** : <http://pediatrics.aappublications.org/content/pediatrics/120/5/1162.full.pdf>
- **Pennsylvania Medical Marijuana Program:** <https://www.pa.gov/guides/pennsylvania-medical-marijuana-program/>
- **PA-95:** <http://www.phlp.org/wp-content/uploads/2014/07/PH-95-guide-7-17-2014.pdf>
- **IEP and 504 info:** <http://www.wrightslaw.com>
- **PMID: Pubmed ID#:** <http://www.ncbi.nlm.nih.gov/pubmed>