Autism Society
Greater Akron

AUTISM GUIDE

for Children in Ohio

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WELCOME

The Autism Society of Greater Akron (ASGA) is proud to present the third edition of our comprehensive Autism Guide for Children in Ohio.

This guide was created to support anyone involved in the life of a child with Autism—including families, educators, service providers, and community members—throughout the state, especially in Medina, Portage, Stark, Summit, and Wayne counties. While the guide was originally developed for families with a new diagnosis, its purpose and reach have grown. Now, it serves as an ongoing resource that can be referenced time and again at any stage of the Autism journey.

Whether you're just beginning to seek support or have been navigating this path for years, you'll find helpful information, tools, and encouragement within these pages. While not every section may be relevant to your current needs, the guide is designed to be flexible and applicable throughout the years. What may not apply now could be exactly what you need later—and vice versa.

We know that understanding and supporting a child with Autism can sometimes feel overwhelming. This guide is not meant to provide all the answers, but it is a place to start—or restart—when you're looking for clarity, direction, and community. We encourage you to approach it in pieces: focus on one section at a time and know that support is just a phone call or email away. If you need help prioritizing next steps, our Helpline is always here for you at 330-940-1441 ext. 1 or info@autismakron.org.

ASGA is an affiliate of the Autism Society of America—the oldest and largest grassroots Autism organization in the U.S.—and ASGA has been rooted in the Greater Akron community since 1987. While we are not direct service providers, we're committed to empowering individuals and families through adapted community events, advocacy, education, information and referral, and support. Thanks to generous donations and grants, we're proud to offer many programs at low or no cost, and scholarships are always available to those in need.

Our approach is person-centered. We believe in respecting the unique needs of each child and family, and we support your right to make informed choices about the services you use—whether that's the type, scope, duration, or provider.

You can learn more about ASGA, sign up for our mailing list, and explore upcoming events, educational workshops, and community resources by visiting **www.autismakron.org**.

This journey is not one you need to walk alone. Whether you're a caregiver, teacher, therapist, or friend, this guide is here for you. Together, we can help every child with Autism reach their fullest potential.

The Autism Society of Greater Akron is your partner on this journey.
Give us a call…we're right here!

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Mission, Vision, and Manifesto

Our Mission.

We create connections, empowering everyone in the Autism community with the resources needed to live fully.

Our Vision.

Creating a world where everyone in the Autism community is connected to the support they need, when they need it.

Our Manifesto.

Because the experience of Autism is not one thing. Because it is many things. And because the connection between those experiences is you.

Because we see you. The way you think. The dreams you hold. The talents you bring. Because you can't be categorized into neat little diagnostic boxes. Because you break the mold.

Because sometimes you're quiet. Because sometimes you need help reaching for where you belong. Because sometimes what happens is not always right, fair, or just. Because there are keys to every door that looks locked.

Because no matter how you were born, the person you are is infinite—and you are the only you there is.

Because Autism is not going away, neither are we.

The connection is you.™

This Newly Diagnosed Guide was made possible thanks to ASGA's donors and supporters, including the following foundations who awarded ASGA grants to provide information to our local Autism community:

Akron Community Foundation
Lloyd & Louise Smith Foundation
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Introduction

Your child has just been diagnosed with a developmental disability called Autism Spectrum Disorder (ASD). You may be feeling intense sadness, fear, loneliness, grief, guilt, or disbelief. ***Please know that you are not alone.*** In the United States, the Centers for Disease Control estimates 1:31 eight-year-old children have a diagnosis of Autism[2]. An estimated 5.4 million adults in the United States have Autism[3]. You know your child best and, as time goes by, you will construct a path to help them navigate the world and to live their best life. You will better understand their behavior and learning style and be better equipped to help them progress.

> ***You are your child's most valuable advocate.***
> ***You will learn that many people can help, and that learning from the experiences and expertise of those who have walked this path before you will be helpful and supportive.***

The journey of Autism – and any disability – is a marathon, not a sprint. Take a minute to breathe and take things one day at a time. Dr. Steven Shore, a professor with Autism at Adelphi University, once said, "If you've met one person with Autism, you've met one person with Autism."

An **Autism diagnosis**[45] is most often made by a practitioner in a medical field (developmental pediatrician, pediatric neurologist, clinical psychologist, etc.) based on certain observed characteristics. The treatment, however, is most often educational and medical. The medical and educational systems are very different and, for the most part, not coordinated; therefore, you will quickly become your child's case manager, advocate, and team leader, navigating and seeking treatment and support from several appropriate avenues and agencies.

As your child's case manager, it is important to remain organized. Buy a binder with tabs, an accordion file or even a plastic box to keep all your child's records. You will need his diagnostic report, special education documents, therapy progress notes, etc., in the future, so keeping them in one place will make coordinating your team easier. This **article**[4] serves as a helpful guide on how to best organize your child's IEP.

A Word about Neurodiversity

Neurodiversity is a movement to support people outside of the mainstream in the way their brains work and focuses on developing their strengths and talents. The ***Child Mind Institute***[5] describes *neurodiversity* as the differences in the way people's brains work. Everyone's brain function is unique, and there is a wide range of ways that people perceive and respond to the world. Differences are to be embraced and encouraged.

This movement acknowledges that Autism, ADHD, and Learning Disabilities (LDs) cause impairments and can create obstacles that get in the way of people doing the things they want to do. However, as a framework, neurodiversity is about understanding human brain function and argues that diversity in human cognition is normal, and these differences can also bring gifts.

What is Autism?

Autism, or Autism Spectrum Disorder (ASD), is a developmental disability. Some common features of Autism include social communication challenges, repetitive behaviors, sensory sensitivities, and fixed interests. Autism is considered lifelong because it is a neurodevelopmental condition that affects how the brain functions.

The **Diagnostic and Statistical Manual of Mental Disorders (DSM-5)** [6] outlines specific criteria for diagnosing ASD. To receive an ASD diagnosis, an individual must exhibit persistent deficits in core areas: social communication and social interaction, as well as restricted, repetitive patterns of behavior, interests, and activities. However, there exists a wide range of symptoms, personal qualities, abilities, and disabilities within one diagnostic category. Individuals with Autism can be chatty or non-speaking, gifted or intellectually disabled, be hypersensitive to sound and light, or be comfortable playing percussion in a band. Children with Autism may have significant behavioral issues, or they may be unusually quiet and unresponsive. Some people with Autism have extraordinary abilities; others struggle to complete basic activities of daily living and are not safe alone.

What Causes Autism?

There is no known cause of Autism, and there is no blood test to diagnose ASD. Autism occurs in individuals from across all economic, ethnic, cultural, and educational groups. It is not caused by bad parenting or vaccinations. Several theories about Autism point toward a genetic predisposition, improved diagnoses, and environmental influences. Science knows that thousands of children are diagnosed each year and that the Autism spectrum is just that…a spectrum of challenges and needs that are specific to each individual. Some current data includes:

- Approximately 25-30% of Autistic children will be non-speaking or minimally verbal throughout their lives.
- Thirty-one percent of children with Autism are believed to have an **Intellectual Disability**[47],
- Twenty-five percent of children are in the borderline range, and,
- Forty-four percent had IQ scores in the average to above average range[48].

Note that IQ tests that do not require language skills, such as the Test of Nonverbal Intelligence (TONI) can offer more accurate information about a person and that while IQ is one indicator, there are many factors when considering treatment options.

Making Informed Decisions About Treatment

The Autism Society addresses the issue of treatment by affirming that each person who experiences Autism is a unique individual. To the maximum extent possible, informed decisions should be made by the individual with Autism and their family members in partnership with a multidisciplinary team.

The selection of current evidence-based intervention practices should be guided by objective assessment, goals, and outcomes. Services and support should be delivered with fidelity by qualified and appropriately trained professionals. All services should promote self-determination, enhance inclusive community engagement, and result in improved quality of life. Abuse of any kind is not acceptable.

No single service or intervention is likely to meet the needs of every individual with Autism. Each person should have broad and equal access to high-quality, individualized support and services. The selection of a program, service, or intervention method should be based on a comprehensive assessment of the person's abilities, needs, and interests. Services should be outcome-based to ensure they meet the individualized goals of the person with Autism.

The Board of the Autism Society of Greater Akron expects that individuals with Autism will have dignified, productive lives and reach their fullest potential through access to appropriate education, employment, community living opportunities, medical care, mental health services, and family support.

Autism and Related Health Issues

While children on the Autism spectrum are just like other children who get the common cold, flu, or other childhood illnesses, it is important to keep in mind the co-occurring medical and psychiatric conditions that can exist in individuals with ASD, including but not limited to:

- Anxiety
- Attention-Deficit/Hyperactivity Disorder (ADD/ADHD)
- Autoimmune Dysfunction
- Bipolar Disorder
- Depression
- Epilepsy
- Gastrointestinal problems
- Gender Identity
- Learning disabilities
- Mood Disorders
- Obsessive Compulsive Disorder (OCD)
- Poor coordination
- Schizophrenia
- Sensory issues
- Sleep Disorders

One of the reasons it is important to be aware of co-occurring medical and psychiatric conditions is because health issues – such as OCD, ADHD, depression, bipolar disorder, and others – have treatment avenues that may be helpful to a child's quality of life. In addition, it is important to note how communication challenges inherent in individuals with ASD may leave the person vulnerable to undiagnosed medical conditions. Common conditions such as constipation, headache, ear infection, or dental problems can be overlooked because the person cannot communicate that something is wrong. Pain can cause a behavior change that is mistakenly thought to be Autism but is an undiagnosed physical illness or problem.[7]

It is important to rule out medical problems when you see a behavior change. Your child's primary care provider (typically a pediatrician or family practice physician) should be your first resource when you are worried about health or other issues.

Vaccinations and Covid-19

People with disabilities are in a high-risk category for getting sick with COVID because of co-occurring medical conditions. These conditions can include lung, heart, kidney disease, a weakened immune system, cancer, diabetes, some blood diseases, or conditions of the muscular or central nervous system; and, depending on the type and severity of the disability, individuals may have difficulty managing the disease or caring for themselves once they become ill. Autism is one of those high-risk disabilities for several reasons: many individuals have co-occurring medical conditions, have trouble communicating what is wrong (and/or can be non-speaking), and caring for themselves, and is hospitalized, would require a great deal of support.

COVID has become one of the top 10 causes of pediatric death, and tens of thousands of children and teens have been hospitalized because of the virus. While children and adolescents are typically at lower risk than adults of becoming severely ill or hospitalized from COVID, the effects of the virus are unpredictable. Medical and public health experts, including the U.S. Centers for Disease Control and Prevention (CDC) and the

American Academy of Pediatrics, recommend that children six months and older get a COVID vaccine to help protect them from contracting and spreading the virus.

Talk to your healthcare provider or someone who you trust with other aspects of guidance for your / your child's health. Tell your doctor what worries you have about being vaccinated. Your doctor has current, accurate information on vaccines and can answer your questions. Keep in mind that there is a thorough and careful process taken by federal regulatory agencies to ensure vaccines help protect from the coronavirus and other diseases such as flu, measles, and chicken pox.

Needle Anxiety: Did you know that about 25% of people have a fear of needles*?*
This rate may be even higher for people with disabilities. People with disabilities may be more sensitive to pain or have higher levels of anxiety than people without disabilities.

If needle anxiety is a barrier to getting the flu or COVID vaccine, there are effective strategies to help overcome needle anxiety:

- Schedule the appointment with a healthcare provider who is familiar to the person receiving the vaccine.
- Practice what will happen on the day of the appointment with a health professional or other trusted person. This helps with what to expect. Social stories or a visual schedule may help some people.
- Arrive early to the appointment. Feeling rushed can increase stress and anxiety.
- Bring comfort items such as music, a phone game, or a fidget toy.
- Talk to the health professional about any fears. This can be a doctor, nurse, or technician.
- Some people want to see the needle before a shot and other people do not. Talk to the health professional about what helps the person feel most comfortable.
- Ask the healthcare provider for adaptive pain management tools such as Shotblockers or a Buzzy©.

Some people might find it helpful to be distracted during the process through one of the following:

- Carrying on a conversation
- Listening to calm music
- Bringing a book to read or play a game on a phone or tablet
- Playing with a fidget

The information in this section was provided through a grant from the Vaccination Education Initiative (VEI) sponsored by The Autism Society of America. ASGA is a sub-grantee and participated in the VEI initiative, which addresses systemic barriers and promotes vaccine education, confidence, and access. Through the VEI, we strive to improve patient and population health by ensuring children, adults, and seniors with disabilities are included and supported.

The 2023 VEI is funded through a grant from the Aging and Disability Vaccination Collaborative (ADVC) and sponsored by USAging to increase access and uptake of vaccines with a focus on traditionally underserved communities such as the aging, BIPOC, Hispanic, LGBTQIA+, and rural populations with Autism and other disabilities.

For more information about needle anxiety, vaccination social stories, visual schedules, and other vaccination supports, visit ASGA's VEI website https://autismakron.org/vei.

Now let us get down to the details. We have organized the rest by steps and priorities.

STEP 1: Connect to Your County Board of Developmental Disabilities

Ages 0-3: All referrals for children under the age of 3 are made through **Ohio Early Intervention**[8] (formerly known as *Help Me Grow*). Your County Board of DD (CBDD) works in partnership with Ohio Early Intervention to provide developmental evaluations for children who have a suspected delay or who have a medical condition that has a high probability of resulting in a developmental delay.

Ages 3-5: There is a **County Board of Developmental Disabilities**[49] (CBDD) in each of Ohio's 88 counties. This is the government agency that provides funding and oversees and administers services to individuals with developmental disabilities, including Autism. Services include information and resources, **Individual Service Plan (ISP)**[50] development and revision, assistance in selecting providers and accessing services, service coordination, quality assurance monitoring, and crisis intervention. (Notably, the eligibility criteria and the services described here are separate from those involved in Medicaid home and community-based services.)

If your child is between the ages of 3-5 and has an IEP, they are already eligible for services from your CBDD. Simply call the **CBDD office in your county**[49] to discuss eligibility criteria and to schedule an Intake Interview. Take your child's official IEP document, Social Security card, and birth certificate to the Intake Interview appointment. Shortly after the interview, the CBDD will contact you to begin planning services.

Ages 6-15: Whether your child becomes eligible for CBDD services through Early Intervention or an earlier Intake Interview, at the ages of 6-15, another Intake Interview will be scheduled for your child so CBDD staff can determine continued eligibility. The CBDD will also complete the **Children's Ohio Eligibility Determination Instrument (C/OEDI)**[51] a tool that records information about a person's current functional abilities.

A Note About Intake Interviews: *Parents may be embarrassed and not want to admit their child has behaviors. For this reason and others, a parent may not fully convey how a child's Autism impacts the child and family. This is not the time or place to tell all the glowing things about your child; you are there to gain eligibility for services and funds. So focus on highlighting how your child's disability affects their ability to learn, safety, capacity to make friends, emotional regulation, and relationships with siblings and relatives. Stress how disability affects your family life, your ability to work outside of the home, your emotional balance, etc. Do not just think about the last few days; think about the last 6 months.* ***If your child is not doing things the way same-age peers are, then make that known during the Intake Interview.***

Once your child is deemed eligible for services/funds through your CBDD, they will be assigned a Service and Support Administrator (SSA) who will be your point of contact while your child is eligible for services. The SSA is your touchpoint for services and resource referrals, family engagement dollars, and paperwork for other statewide services in Ohio. Family engagement dollars allow families to access funding to promote community inclusion for individuals with a disability. Tell the CBDD staff what you need and ask if the Board can offer any help with the problem. Individual needs are different, and each County Board of DD has slightly different services and funding. If you feel your needs are not being addressed, individuals can request a different SSA.

Income does not impact eligibility. There is no income restriction for service coordination.

Age 16: For individuals who are 16 and older, eligibility requirements are again assessed by the CBDD. This is called *redetermination*. The Ohio Eligibility Determination Instrument (OEDI) is commonly used to measure an individual's need for continued services and resources. Both the COEDI and the OEDI are designed to be user-friendly documents that anyone rating the scores (an individual, guardian, or advocate, for instance) can readily understand. Evaluation Specialists are available to assist families through the redetermination process and to answer any questions.

Age 22+: This means that an individual 22+ years old can continue to receive services and resources through a CBDD if they have been found eligible before the age of 22. However, it is very difficult after the age of 22 years to be deemed *newly eligible* for services or resources. *ASGA recommends an Intake Interview shortly after a formal, medical diagnosis to avoid the 22-year cut-off.*

Referrals to a CBDD can be made by individuals, parents, physicians, teachers, or anyone who believes that a child (ages 3-22) may benefit from and qualify for services.

STEP 2: Identify and Prioritize Your Child's Treatment Options/Needs

Effective treatments exist. Effective interventions may reduce symptoms, improve cognitive ability and daily living skills, and maximize the ability of an individual to function and participate in the community. Remember that Autism is a spectrum disorder. Some people may need little to no treatment, while others may require intensive therapy.

The treatment approach that you choose should be a good fit for your child and your family. Treatments should be evidence-based, comprehensive, available, affordable, and support family involvement. The treatment philosophy should also make sense and fit into your family's value system.

What does your child need most? What is causing you the most concern? What caused you to seek out a diagnosis? Is it your child's behavior? Toilet training? Lack of speech? Problems at school? Does your older child need recreational opportunities, employment, or social skill building?

Once you have carefully and thoroughly identified the conditions and areas of support that require treatment, the question becomes what to treat, when to treat it, and how to treat it.

Ohio Early Intervention

If your child is not meeting a milestone or experiencing significant delays, the **Ohio Early Intervention**[8] (EI) program is a statewide system that provides coordinated services to parents of children ages 0-3 with disabilities or developmental delays.

EI is grounded in the philosophy that young children learn best from familiar people in familiar settings. That is why your local EI team, which includes a service coordinator and service providers, works with you in your home or other places where you and your family spend time to develop a coordinated plan.

EI provides support and resources to assist parents and caregivers that enhance children's learning and development through everyday routines. It is a collaborative home and community-based system where families and an EI team work together to provide ongoing support to your child. The intervention team gathers information to determine a child's eligibility and need for early intervention services, provides service coordination to ensure the protection of family and child rights, promotes advocacy and coordinate services, and partners with parents and other caregivers to support children as they learn and grow and focuses on enhancing child participation in existing and desired family, community and early childhood experiences.

It is recommended that parents complete a screening for their child at ages 2, 4, 6, 9, 12, 15, 18, 24 and 30 months, 3 years, 4 years and 5 years. The screening is free and takes the guesswork out of determining if your child is missing developmental milestones. Learn more about milestones through the **CDC Act Early initiative**[9].

Early Head Start (children ages 0-3) - Early Head Start[52] (EHS) programs serve infants and toddlers under the age of 3 and pregnant women. EHS programs provide intensive comprehensive child development and family support services to low-income infants and toddlers, their families, and to pregnant women and their families.

The Office of Special Education Programs (OSEP) and the Office of Head Start (OHS) jointly developed this resource to support programs that promote the inclusion of infants with significant disabilities and their families.

A significant disability in infancy refers to a specific developmental or medical condition experienced by an infant, from birth to 12 months. Significant disabilities in infancy can lead to developmental delays that increase over time and may interfere with the infant's acquisition of knowledge and skills needed for independence.

Infants with significant disabilities may require intensive individualized support to fully participate in daily experiences at home, in their communities, or an early care and education program. Early Head Start (EHS) programs offer this support, in careful and collaborative planning with families.

Importantly, the program promotes the physical, cognitive, social, and emotional development of infants and toddlers through safe and developmentally enriching caregiving. This prepares these children for continued growth and development and eventual success in school and life.

EHS programs also mobilize the local community to provide the resources and environment necessary to ensure a comprehensive, integrated array of services and support for children and families.

Head Start (children ages 3-5) is a federally funded school readiness program for children, ages 3-5. Head Start provides services to eligible children and families in early learning, health, and family well-being, while engaging parents and guardians as partners. Head Start includes preschool programs that serve these children.

> *Who is eligible? Children from low-income families, in foster care or experiencing homelessness, and children with developmental disabilities are eligible to be considered for participation. At least 10% of a program's enrollment must be children with disabilities.*

Head Start programs offer a variety of service models, depending on the local community's needs. Head Start programs may be in schools, childcare centers, and family childcare homes. Some programs also offer home-based services where a Home Visitor conducts weekly visits to children in their own home and works with the parent as the child's primary teacher.

Head Start includes Preschool Special Education for children ages 3-5 with disabilities.

To meet individual children's needs, districts offer a variety of preschool special education services. Children with disabilities may receive services in public schools, private preschools, or childcare centers.

For additional information on service providers in Ohio, visit the Early Care & Education Search Portal. [10]

Therapy Options

Traditional Therapy Options

- Applied Behavioral Analysis (ABA)
- Assistive Technology or Augmentative Communication (AAC)
- Floortime, aka Play Therapy

- Itinerant Therapies/Services (School Based)
- Occupational Therapy (OT)
- Physical Therapy (PT)
- Relationship Development Intervention (RDI)
- Social Skills Training (SST)
- Speech Therapy
- Verbal Behavior

Complementary and Alternative Therapies

To help relieve the symptoms of Autism that interfere with daily life, some healthcare professionals use treatments that are outside of what is typically recommended by family practitioners. Complementary and Alternative Therapy treatments refer to products or services that are used in addition to, or instead of, traditional medicine. They might include aquatics, art therapy, hippotherapy, auditory integration, special diets, dietary supplements, biologicals (for example, secretin), or mind-body medicine, i.e., yoga, mindfulness meditation, craniosacral manipulation, music, vision, acupuncture/acupressure and reiki (Blitz, 2023).[11]

Complementary and alternative treatments have an important place in supporting some traits of Autism, though neither they nor any mainstream treatment is likely to lead to a "cure" for those seeking it. When selecting treatments, however, it is important to ask these questions:

- What is the desired positive outcome?
- Are there risks associated with the treatment?
- What do researchers, my family physician, and other trusted sources say about the treatment?
- Can I afford the treatment if my insurance does not pay for it?
- What is the time commitment of the treatment?

Medication

There are no medications specifically developed to treat Autism. However, several medications used for other conditions that might occur with Autism may help with certain symptoms. Before taking any medication, speak with your physician about your child's symptoms.

Medications used to help manage the symptoms of Autism fall into several categories:

- **Antipsychotics.** Some newer antipsychotic medications may help with aggression, self-harm, and behavioral problems in both children and adults with Autism.
- **Antidepressants.** While many people with Autism take antidepressants, scientists are not sure if they actually help with Autism symptoms. Still, they may be useful for treating OCD, depression, and anxiety.
- **Stimulants.** Stimulants, generally used to treat ADHD, may also help with overlapping Autism symptoms, including inattention and hyperactivity.
- **Alpha-2 Adrenergic Agonists.** In the context of mental health, these medications, particularly guanfacine and clonidine, are sometimes prescribed off-label for conditions like ADHD. Although they are not the first-line treatment for these conditions, their ability to modulate certain aspects of brain function is well-noted by Autism professionals.
- **Anticonvulsants.** Some people with Autism also have epilepsy, requiring prescribed anti-seizure medications (Osborn, 2020).[12]

Evaluating Treatments

There is a difference between *evidence-based practices* (EBPs; those with quality research behind them), *emerging practices* (those with some good studies to support their efficacy), and *practices with no research base*. Early on, it is easy to be vulnerable to treatment options that promise a cure for Autism. It is important to understand which treatments are more likely to help your child based on data about them. Make sure you understand your child's diagnostic report and how it points to your child's needs. If you do not understand the terms and numbers on the report, ask for clarification from the professional who tested your child.

> *An initial diagnostic report does not offer enough information by itself to develop a treatment plan. Treatment options can change over time; your child's plan might be adjusted depending on your child's response.*

You will find information about effective, emerging, and non-effective treatments from the ***National Autism Center's National Standards Project, Phases I and II***[13]. This organization reviews all published studies about Autism treatments for children and constructs a list of 14 Established Interventions for children, adolescents, and young adults under the age of 22[14].

You can read more about each treatment and how the treatment was evaluated as well as the list of emerging and non-effective treatments on the ***Autism Society of America* website**[15]. You can download the Intervention and Therapies publication which describes effective treatments, the importance of professional judgment and data in making treatment decisions, and looks at family issues that affect treatment decisions.

The ***Association for Science in Autism Treatment***[16] allows you to look up a specific therapy to see if there are any studies to support its use. The site will tell you if the treatment is recommended, needs more research, or is not recommended.

The ***National Professional Development Center on Autism***[17] was a project funded by the Office of Special Education to promote the use of Evidence-Based Practices (EBPs) in schools because, by law, teaching practices must be based on evidence of effectiveness. They have identified 28 EBPs and even provided a comparison of those listed by the National Autism Center. The site defines each EBP and links to an internet module, which will teach you about the practice and why teachers might use it.

The ***Ohio Center for Autism and Low Incidence (OCALI)*** houses **Internet Modules**[18] that discuss EBPs. As a parent or caregiver, you can complete the modules at your own pace at any time of day. The modules are geared to adult learners and use text, pictures, videos, downloadable documents, and a pre-and post-test. The training is free, and while learners can use the course reports and certificates to earn professional development hours, the program is designed so every user gains knowledge and can implement the skills learned immediately.

You also may want to learn how to read the research. The ***Organization for Autism Research (OAR)***[19] uses applied science to answer questions about Autism that parents, families, individuals with Autism, teachers, and caregivers often encounter. OAR has a free publication, A Parent's Guide to Research | Organization for Autism Research (available in English and Spanish), on its website that explains how to identify valid research.

While you should understand how to evaluate treatments, several sources have already done this for you.

The federal government created guidelines for treatment for young children with Autism, ages birth-eight years. The guidelines specify that as soon as you suspect a child has Autism, you should begin providing a minimum of 25-40 hours/week of intensive, one-on-one services, year-round. However, some children may need high intensity at first and then lower over time as they improve. A more economical approach would be to start all children at low intensity, assess each child's response at a prespecified time, and step up the intensity if the response is slow.[20]

The report stopped short of recommending any one treatment methodology. What works for one child may not work for another. However, there is more research behind some methods than others. It makes sense to first look at treatments with longer track records instead of spending precious time and money on unproven ones.

Beware of personal testimonials claiming to cure or treat Autism.
These treatments have not been scientifically validated.

Identify Your Resources

Do your homework and decide on a particular treatment. However, be aware that not all interventions may be available and/or affordable in your area. Also, not everyone who practices a certain kind of treatment delivers it with the same expertise and fidelity. So, families should consider not only researching treatments but also carefully interviewing providers.

As your child progresses through treatment, you will want to monitor their improvement. Start by understanding your child's baseline performance, that is, the level at which they currently perform. Select a provider who will communicate the purpose of the goals they have selected, show you how your child is advancing, and answer any questions you might have. Also, ask the provider for a list of treatment goals; you should also be able to provide some input on these goals. For example, many parents need help early on with toilet training or speech and communication. There are resources to help you decide.

Contact the ***Autism Society of Greater Akron*** for a list of questions you may want to ask when interviewing treatment providers.

STEP 3: Evaluate Your Family's Financial Resources

Funding the needed educational and medical treatments related to Autism can be very costly. Family resource funding and Waivers may be viable options and are both administered by your local County Board of Developmental Disabilities. This section discusses some additional options for funding.

Private Insurance

All 50 states and the District of Columbia have laws that require insurance coverage for Autism services. Despite federal and state mandates that insurance plans to cover behavioral treatments for children with Autism, this coverage has been inconsistent in Ohio. Check the *Summary Plan Description* of your health insurance plan online to see what is covered. In Ohio, behavioral services for Autism up to age 14 are supposed to be covered, but there are exceptions. For example, employers who self-insure are regulated under federal law (ERISA) and may be exempt from state-mandated benefits. The ***Ohio Autism Insurance Coalition***[21] has information that can help you understand your benefits, find coverage, and navigate the insurance process. Ohio requires meaningful coverage for Autism under state-regulated plans. Ohio's Autism Insurance Bill, HB 463, was signed into law in 2017.

To which plan types does the State of Ohio Autism Insurance Law apply?

- Individual Plans - YES
- Fully Insured Large Group Plans - YES
- Fully Insured Small Group Plans - YES

What services are covered by law?

- Diagnostic testing
- Speech therapy
- Occupational therapy
- Clinical Therapeutic Intervention, including Applied Behavior Analysis (ABA therapy)
- Mental/behavioral health outpatient services

Does Ohio have caps on coverage?

- Coverage is limited to individuals with Autism aged 0-14 years. Benefits are subject to maximum annual or weekly limits.
- Speech therapy is subject to a maximum annual limit of 20 visits.
- Occupational therapy is subject to a maximum annual limit of 20 visits.
- ABA therapy is subject to a maximum weekly limit of 20 hours.
- Mental/behavioral health outpatient services are subject to a maximum annual limit of 30 visits.

There are still some insurance plans that do not cover Autism services/treatments in HB 463, despite its legal mandate. If your family's insurance plan does not include Autism services, call the HR department at your place of employment or the central offices of your insurance company and advocate for your child.

The Ohio Autism Insurance Coalition explains the actions that families can take when trying to receive benefits for ABA Therapy from their insurance plans.[21]

Social Security

Social Security provides a monthly income to adults whose disability impedes their ability to work as well as to children with Autism who qualify medically if they have substantial functional limits. There are several programs under the Social Security umbrella and the medical criteria are different for children and adults; more information can be found on the **Social Security Administration website[53].**

Qualification for **Supplemental Security Income (SSI)[22]** is based on medical standards and income. SSI provides monthly cash payments to help meet the basic needs of children who have a physical or mental disability or who are blind. If you care for a child or teenager with a disability and have limited income, savings, and other resources, your child may be eligible for SSI. Individuals who are denied SSI based on medical criteria may appeal the decision.

For both children and adults, SSI imposes strict income and asset limitations which cannot be appealed. Under a process called *deeming*, the individual's medical records and income are reviewed. A portion of the family's income is considered for a child under 18, but once the child turns 18, only their income and assets are used. You may find more information about this process as well as current income levels on the **Social Security Administration website.[23]** Visit ASGA's website for a recorded webinar, Autismakron.org/webinars.

Social Security Disability Insurance (SSDI) [24] is a program where a child or adult with a disability may qualify under a retired, disabled, or deceased parent's work record. SSDI usually translates into higher benefits, however, there are some income restrictions. An adult with a disability who has enough work credits on his own and then stops working for reasons related to their disability or who works under a certain income threshold may qualify on their work record.

- To apply for all these programs, go to www.ssa.gov or you may visit your local Social Security Administration (SSA) office in person. You can find your local office on the SSA website or call SSA at 800-772-1213 to set up an appointment.
- It is a good time to get a state-issued ID card for the person who is applying at the Ohio BMV.

One reason social security claims are denied is failure to provide enough information.

Bring as much documentation as possible to your appointment. This would include your child's diagnostic report, therapy progress notes, your child's latest IEP, school evaluations, list of the names, addresses, and phone numbers of all your child's doctors and therapists as well as proof of income. You will also want to review the ***Child Disability* or *Adult Disability Starter Kit***[25] on the SSA website to get a checklist of items you will need. Before applying, you can attend an educational seminar that will help you prepare the application. Contact ASGA if you need assistance locating a seminar.

Medicaid

Medicaid[26] is a joint federal and state program that helps cover medical costs for some people with limited income and resources. The federal government has general rules that all state Medicaid programs must follow, but each state runs its program. Qualifying for Medicaid is dependent on the parent/guardian's income. If your child receives Supplemental Security Income (SSI, also income-based) or the Waiver (eligibility is based upon the person's support needs and is determined by your local CBDD), they will also receive Medicaid benefits. In 2019, Ohio took steps to expand Medicaid coverage to include behavioral health services for children with Autism, providing them with access to crucial therapies and treatments. Even if your child does not receive SSI, you may still qualify for one of the other Medicaid programs in Ohio.

In addition, adults with Autism may be eligible for *Medicaid Buy-In*. The **Medicaid Buy-In**[27] program allows individuals with disabilities who are employed, earning income, and may not otherwise qualify for Medicaid due to their earnings, to "buy in" to Medicaid coverage by paying a premium. This program enables individuals with disabilities, including adults with Autism, to retain their Medicaid coverage while they are working or earning an income that would typically disqualify them from standard Medicaid coverage. The Buy-In program helps bridge the gap between employment and healthcare coverage for individuals with disabilities who might need Medicaid benefits to supplement their private insurance or cover services their private insurance might not fully address.

What are Medicaid Waivers?

In the 1950s and 1960s, if a child received an Autism diagnosis, parents were instructed to institutionalize their child. Medicaid paid money directly to the institution to tend to every child there. In the late 1960s, parents questioned and often refused this treatment, saying they wanted their children at home because it was better for the child, better for the family, better for the community, and it was cheaper. The federal government allowed states to *waive* the requirement that an individual live in an institution to receive access to these Medicaid funds. Waivers provide money for individuals with developmental disabilities to live in the community with services and support and to learn skills that will allow them to live more independently.

Funding for waiver programs comes from state and federal Medicaid dollars, and the local CBDDs must provide a local match to use those funds. Services across counties may differ based on the amount of county-matched dollars available. In Ohio, the Ohio Department of Developmental Disabilities and the Ohio Department of Job and Family Services govern the waivers and respective CBDDs administer the Medicaid funds to individuals with disabilities.

The distribution of waivers is determined by need, family income is not considered for waiver eligibility.

Obtaining a waiver for in-home support does not necessarily mean that there will be 24-hour supervision. (There are exceptions for emergencies, such as the illness or death of a caregiver.) There are four basic waiver programs for which an individual with Autism/disability may qualify: the Individual Options (IO) Waiver, the Self-Empowered Life (SELF) Waiver, the Level 1 Waiver, and the Participant-Directed Waiver.[54]

Waivers are not a mandated, governmental program. Obtaining a waiver depends on the individual needing a certain level of care and/or support and available funding. ***Diagnosis of a disability does not automatically*** **equal services.** Recent changes to Ohio's Waiting List for home and community-based services waivers make it easier to identify a person's needs and coordinate services. Modifications to the **Waiting List**[28] include a **statewide assessment tool**[55] used to better understand a person's need for services and any current or immediate needs they may have.

In Ohio, there are four types of waivers:

1. ***Level One Waiver:*** Provides up to $5,000 a year for a menu of items including homemaker personal care, respite services, non-medical transportation, employment supports, day programs, etc.
2. ***Individual Options (IO) Waiver:*** No cap; funding is determined and based on functional need and provides a greater level of support. Typically provided for extraordinary needs or after the child moves out of the family home.
3. ***SELF Waiver:*** Self-directed with a greater range of providers and different services including Functional Behavioral Assessment and Clinical/Therapeutic Intervention. This waiver can be a funding source for an individual who needs behavioral intervention not covered by insurance or a school program. Refer to the Medicaid Waiver website.
4. ***Participant-Directed Waiver:*** Participant-direction means the person using a waiver can make some decisions about the staff they hire or some of the services purchased with their waiver budget.

Adults choosing participant direction may direct their services, or they can choose their representative, including a friend, family member, or legal guardian.

Grants and Payment Options

Sometimes the established funding resources at your disposal do not cover the amount of therapy or the program you want for your child. In that case, you may want to explore private organizations that award grants to families of children with Autism or other disabilities. The Lucas County Board of DD has compiled a **resource list of funding sources**[29] that are not necessarily exclusive to families living in the Lucas County area or for young children.

Another grant and funding resource database can be found through ***Financial Resources and Discounts for Students with Disabilities***[30]. This expansive list mentions funding sources that pertain to college scholarships, public transportation, assistive technology, bill assistance, and much more.

Here are some other ideas to consider:

- Ask if your provider has a sliding fee scale.

- Use providers connected to universities. Student professionals usually provide the same services at a lower rate because they are learning their craft. Student professionals are supervised and monitored by experienced providers.
- Inquire as to whether an ABA provider would send a registered behavioral therapist (RBT) from their staff to implement your child's program at home.
- Ask extended family for contributions in lieu of a toy.

Tax Deductions and Credits[56]

Parents of children with disabilities should familiarize themselves with tax deductions and credits and take care to document all expenses related to their child's medical care, development, and therapy.

STEP 4: Become Familiar with Special Education

A child's school can be your key partner for the next 22 years*, so it is important to be educated about your rights and your child's rights under the law, as well as how to advocate for them. *When it comes to special education, parental involvement is paramount to the success of a child.

Special education refers to a range of services that can be provided in different ways and different settings. There is no "one size fits all" approach to special education. It is tailored to meet the needs of students with disabilities. Special education focuses on helping kids with disabilities learn, but it does not mean placing kids in a special classroom all day long. Federal law says that children who receive special education services should learn in the same classrooms as other students as much as possible. This is known as the least restrictive environment (LRE).

The Individuals with Disabilities Education Act (IDEA) is the federal law that defines and regulates special education. It requires public schools to provide special education services to children ages 3 to 21 who meet certain criteria. These interventions are designed to help individuals with disabilities achieve a higher level of personal self-sufficiency and success in school and their community, which may not be available if the students were only given access to a general classroom experience. IDEA states that public schools must provide students with disabilities a free and appropriate public education (FAPE). The law also gives parents the right to be part of the process and legal recourse if the law is not followed.

A Guide to Parent Rights in Special Education[31] can be downloaded from the Ohio Department of Education website in a variety of languages; it explains parents' rights in the special education process. School districts are required to offer this publication to parents once a year, but this may happen *after* the school meeting. Parents can familiarize themselves with their rights *before* they meet with their school district. The ***Ohio Operating Standards for the Education of Children with Disabilities***[32] is a document that states how school districts and other educational agencies implement special education and related services in Ohio. Find more on the **Ohio Department of Education website**[33].

Check out the Wrights Law website[34] and educate yourself about your child's rights and your rights as a parent in the special education world. The book, From Emotions to Advocacy: The Special Education Survival Guide, is also a critical read.

Requesting School Services for Children Ages 3-5

Under federal law, public schools must look for, identify, and evaluate kids who need special education in the community. This is called *Child Find*, and it applies to kids from birth through age 21, including those who are homeschooled or in private schools, have immigrant status or are homeless.

If you or your child's physician suspects that your child may have a disability, making them eligible for special education services, call the office of your home public school district and request an evaluation for your child. Before a child can receive special education and related services for the first time, a full and individual initial evaluation of the child must be conducted to see if the child has a disability and is eligible for special education. Put your **request for a special education evaluation in writing**[57] and include your reasons for the request (i.e., “My child has a diagnosis of ASD,” or “My child is being evaluated for ASD,“ or “My child has been in the Early Intervention program, and it is suspected that he has a disability,“ or “He is 3 and has a speech delay“, etc.).

Note: Diagnosing autism involves two main components: medical diagnosis and educational diagnosis. These processes are typically carried out by different professionals and serve distinct purposes, yet they can complement each other in providing a comprehensive understanding of an individual's needs.

1. Medical Diagnosis: [35]

Medical professionals involved: Pediatricians, child psychiatrists, neurologists, and developmental pediatricians are often involved in the medical diagnosis of Autism.

Focus: Medical diagnosis primarily focuses on assessing and identifying the clinical symptoms and developmental aspects associated with Autism spectrum disorder (ASD).

Methods: This diagnosis involves a thorough examination of the individual's medical and developmental history, behavioral observations, and standardized assessments, such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R).

Purpose: The purpose of medical diagnosis is to determine whether an individual meets the criteria for ASD based on recognized medical and psychiatric criteria, such as those outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

2. Educational Diagnosis:

Educational professionals involved: School psychologists, special education teachers, and other educational specialists are typically involved in the educational diagnosis of Autism.

Focus: Educational diagnosis concentrates on assessing how Autism affects an individual's learning and functioning within an educational setting. It aims to identify the specific educational needs and support required.

Methods: Educational diagnosis involves classroom observations, academic assessments, and evaluations of social and adaptive functioning within the educational context.

Purpose: Educational diagnosis is to determine the impact of Autism on learning and participation in an educational environment. It helps design individualized educational programs (IEPs) and accommodations to support the student's academic and social success. While medical and educational diagnoses are distinct, they often overlap. Information gathered during medical diagnosis can inform educational strategies, and vice versa. Collaboration between medical and educational professionals is crucial to developing a comprehensive understanding of the individual's strengths and challenges, leading to more effective support and intervention strategies. Integrated, multidisciplinary approaches can provide a more holistic view of the individual with Autism and contribute to better outcomes in both medical and educational settings.

An educational evaluation may include standardized tests and informal methods like observations, interviews, review of school records, and work samples. All public K-12 schools have evaluation systems.

Evaluations are conducted at least every three years after your child has been placed in special education. Reevaluations can also occur more frequently if conditions warrant or if you or your child’s teacher request a reevaluation. Informed parental consent is necessary for reevaluations.

Ask for a response to your evaluation request within 5 business days (though, by law, the district has 30 days to respond) and ask for a signed permission to evaluate your child as soon as possible. Give dates and times you are available to sign the paperwork. Special Education law includes timetables and once you sign permission to test, the clock starts ticking. The district has 60 days to complete the evaluation.

For preschool students ages 3 to 5, the school district will likely schedule a home-based, community-based or school-based visit to collect information from you. Later, the school district will schedule a play-based assessment where your child will interact with and be evaluated by a preschool teacher, a speech therapist, an occupational therapist, and/or other professionals (school nurse, school psychologist, physical therapist, etc. if needed.) The team will then write a report about your child's strengths and challenges and share this with you. Your child must qualify for services, meaning he must exhibit developmental delays that impede learning in one or more of the following areas: physical development, cognitive development, communication development, and social or emotional development.

> *The presence of a disability doesn't automatically guarantee a child will get services. To be eligible, the disability must affect how the child learns in a school environment.*

What is an IEP?

When a child receives special education services under the Individuals with Disabilities Education Act (IDEA), he or she must have an Individualized Education Program (IEP). An IEP is a written, legal document listing, among other things, the special education services that the child will receive to meet his needs. A child must be 3 years of age or older to qualify for an IEP. An IEP is developed by a team normally comprised of a general education teacher, a special education teacher, a district representative, a school psychologist, an occupational, physical, and speech therapist, and you.

An IEP is offered free to families of children in public schools and outlines the goals and any support services that may be needed for a child to succeed in school.

Every effort is made to help children learn alongside their peers who do not have disabilities. But sometimes the level of support needed cannot be met in a general classroom, so students are educated in a specialized learning classroom that is more appropriate for their needs. These classes have fewer students per teacher and allow for more one-on-one instruction. The teacher usually has training in helping kids with special educational needs. Students spend most of their day in a small group classroom and join the regular classes whenever possible — for example, lunch, gym, or the arts.

Your child's IEP should be reviewed annually to update goals and make sure your child is getting the support that is needed. *However, IEPs can be changed at any time on an as-needed basis.* If you think your child needs more, fewer, or different services, you can request a team meeting to discuss your concerns.

The IEP is a legal document, and the special education plans inside your child's IEP cannot be started without your signature. If you are happy with the steps the school will take to educate your child, sign the IEP. However, if you have doubts about the strategies and plans mapped in your child's IEP, you have every right not to sign the IEP until you and the school agree.

At every IEP meeting, you should receive a copy of *A Guide to Parent Rights in Special Education*. Take time to read this document as it outlines your rights and your child's rights according to IDEA and the Ohio Operating Standards. It also gives parents information and resources to help them understand their child's special education supports and services.

Placement Options

The school will offer you **placement options**[45], usually in a preschool classroom. The model in Ohio is to have children with different kinds of disabilities included with some typical peers for four-half days each week during the school year (about 10 – 12 hours per week). Every public school district is required to have an inclusive preschool classroom in one of their elementary buildings. An inclusive preschool allows typically developing children to attend school with children who have disabilities. High-quality inclusive classrooms with higher ratios of typical peers were found to have a significant impact on children with disabilities, allowing the growth of language skills and social-emotional skills. Disability professionals, such as Intervention Specialists, Student Aides, and special educators, are present in the preschool classroom to help guide your child and to ensure that the goals of the IEP are being addressed. Transportation is usually included.

However, if the district does not have openings in a preschool classroom or if the team does not feel your child can successfully participate in a classroom setting, the district is required to offer itinerant services, i.e., a special education teacher who comes to the home or daycare setting to work with your child.

Special Education Meetings

IEP team meetings can be very emotional. Remember that while most educators have entered the field because they want to help children, your district may or may not have expertise in Autism. In addition, the school must offer your child an “appropriate” program, not necessarily the best one; schools have competing priorities, resources, and funding challenges. You have one priority – your child.

You know your child best, and you are part of their IEP team. Be assertive about your priorities and your child’s needs but in a way that respects the other team members. Build relationships with school staff. Learn to listen, ask questions and negotiate. Make an effort to understand where the school is coming from. You may have to meet the school district halfway. For example, instead of demanding a particular service (such as, a one-on-one aide), present the core problem to the team (e.g., “My child has trouble staying on task”), and ask how the team proposes to handle the situation. This respects the staff’s professionalism and allows them to produce solutions they are more likely to use. They may come up with the solution you want but if they don’t, then you can present your request, “How about …?”

School districts often have a Parent Mentor on staff who guides families through the special education process by helping families understand their rights and responsibilities, attending IEP meetings and other meetings at the request of families or staff, and connecting the family to resources. **Parent mentor services are free.** You can find a list of Parent Mentors on the **Ohio Coalition for the Education of Children with Disabilities (OCECD) website**[36]. OCECD is a statewide nonprofit organization with a mission to ensure that every Ohio child with special needs receives a free, appropriate, public education in the least restrictive environment to enable that child to reach his/her highest potential.

Or look for an advocate in your area of the state to assist you with your issue if you cannot resolve it yourself, or if you want support through the process. Contact the Ohio Coalition for the Education of Children with Disabilities. Anyone who has working knowledge about your child and his disability may attend the IEP meeting with you for support. Take notes of all your calls and meetings as you may need them later. (See Call Recordkeeping Form in the Appendix.)

The school district is only required to have your signature on the first IEP. After the first IEP, the school district may carry out consecutive IEP’s without your signature (consent). If the school district implements the IEP without your signature, you may exercise your procedural safeguard rights to address the area of disagreement.

Parental Rights in Special Education

#1 Right To Participate: Every parent has the right to participate in all decision-making meetings held to develop an IEP for their child. These meetings are backed by FAPE (Free and Appropriate Education) and include the child's eligibility, evaluation, educational placement and any other matter pertaining to his education. In the case there isn't a parent available for these meetings, a surrogate parent can be appointed by the school district or the court system to adequately represent the child.

#2 Right To Written Notice: You have the right to receive written notice before any changes are made in your child's special education plan. This pertains to changes in disability identification, additional evaluations and educational placement initiated by the school district.

#3 Right To Consent: Parents have the right to provide informed, written consent (in the form of a signature) for the special education IEP. This should be before the assessment process or the provision of special education and related services. This consent is necessary before any changes are done to the program already in place. Parents should only supply their signature once they have a clear understanding of the IEP team proceedings. Also, you have a right to request an interpreter if your native language is different from English or if you are deaf. You can also have all IEP documents and written notices translated. *Keep in mind; parents have the right to refuse the evaluation or educational placement of their child.*

#4 Right To Access Educational Records: If your child is enrolled in special education and has an IEP, you have the right to their educational records. This means you can…inspect, evaluate, and request copies of your child's educational records.

#5 Right To Request a Hearing: You have the right to request a hearing for any complaints concerning the provision of FAPE. During the hearing, you can request that an advocate, attorney, or if appropriate, your child be present. Furthermore, parents have the choice to make the hearing public.

#6 Right To Keep Child in Current Placement: You have the right to disagree with any proposals to change your child's placement. When a disagreement surfaces, your child should remain in their current program until resolved.

#7 Right To Mediation: When a disagreement arises, parents are free to seek voluntary and impartial mediation to help find a mutually agreed-upon solution regarding their child's special education IEP.

#8 Right To Information on Disciplinary Action: Children enrolled in special education have specific rules when it comes to suspension or expulsion. If these instances extend for more than ten days, an IEP meeting should be called to assess how your child's disability could be contributing to his misconduct.

Requesting School Services for Ages 5-22

The process of qualifying for special education services is similar for older students except that the tests are no longer play-based but more standardized (IQ test, adaptive skills, language assessments, etc.). However, the same timelines apply. The IEP team must review and rewrite the IEP each year.

In addition, school personnel evaluate your child every 3 years to update their level of performance and to confirm they still qualify for services.

Students on an IEP can stay in school until the age of 22. Special Education is designed to prepare students with disabilities for further education, employment, and independent living. So, the years between ages 18 and 22 are traditionally used to help students learn additional life and vocational skills.

Ohio Autism Scholarship Program and Jon Peterson Special Needs Scholarship Program

Many children make progress in a public preschool setting. However, because many doctors – and research supports – that children should receive 10 – 25 hours a week of intensive, one-on-one educational intervention, the state of Ohio offers an alternative. The ***Autism Scholarship Program (ASP)*** allows parents with a student who qualifies under the special education identification of Autism, the ability to opt out of public education services and receive funding to place their child in a program run by a privately registered provider, i.e., a specialized, private school for children with Autism. The program empowers parents in choosing the best educational setting for their children with Autism, allowing them to access specialized services and programs that meet their unique needs and contribute to their educational success. ASP provides financial assistance to eligible families, helping them afford educational options that may better address the specific challenges associated with Autism.

In addition, the state of Ohio sponsors the **Jon Peterson Special Needs (JPSN) Scholarship Program,** a program that provides scholarships to families with students with disabilities the choice to send their child to a special education program other than the one operated by their school district of residence to receive the education and the services outlined in their IEP. *A family may apply for only one scholarship per year.*

More information about the ASP and the JPSN scholarships may be found on the Ohio Department of Education[39] website. But do not hesitate to contact the ***Autism Society of Greater Akron*** for an explanation of the programs or to find approved providers who accept the ASP and the JPSN in your area.

STEP 5: Plan for Your Child's Future in Your Absence

ASGA hopes that our children with Autism will grow up to be working, financially independent adults; however, current statistics confirm that many adults with Autism will not be able to live alone and support themselves. As a parent, you will have more peace of mind if you can provide some resources for caregivers to use after you are gone. It will make it easier for a future caregiver, even a neurotypical sibling, to step up if they know that finances will not be a burden.

Many parents of neurotypical children start a college fund when their children are small. But college savings accounts can only be used for education. Your child with Autism may or may not go to college. In the past, people with disabilities had to keep asset values and income levels low for fear of jeopardizing their government benefits. Fortunately, there is a way to save for your child's future expenses that will not impact his government benefits (with some limitations):

> STABLE Account (sometimes called ABLE Account) [40] allows people with disabilities to save and even invest without penalty.

If employed, additional contributions to the STABLE Account are allowed. The money can be placed in a savings account or one of four investment plans, allowing the account(s) to grow like a retirement account. A monthly prefilled debit card is available for spending. For more information about STABLE accounts, visit ASGA's website for a recorded webinar, AutismAkron.org/webinars.

Unlike a Special Needs Trust (see below), the money can be used for any "disability-related expenses," which include housing, medical needs, education, etc. The account is simple to set up online, and the parent/guardian or, if appropriate, the individual, can be the administrator.

Special Needs Trusts (SNT) allow assets to be left for your child without impact on their government benefits. Funds in this type of account can only be used for "amenities," that is, things not covered by government benefits. For example, if you would like your child to continue to take a vacation to his favorite destination each year, the trust can fund this. It should be set up by an attorney well-versed in this type of law. To learn more about Special Needs Trusts, visit ASGA's website for a recorded webinar, AutismAkron.org/webinars.

Call the **Autism Society of Greater Akron** for a referral to a specialist in your area. There are some costs attached to opening an SNT, and a parent must choose someone to act as a trustee to disperse the funds. Unlike the STABLE Account, there is no limit to yearly contributions. You do not need to be wealthy to set up an SNT, and it can remain unfunded until you die when your assets (house, life insurance policy, retirement accounts, etc.) are willed to the Trust.

Guardianship/Power of Attorney: Individuals with Autism display great differences in decision-making capability. But regardless of their capacity, when they reach the age of 18, they are legally recognized as adults. That means they make their own decisions regarding medical care, finances, education, and other important matters. Is your loved one capable of doing this or do you need to explore forms of guardianship or power of attorney?

There are many forms of guardianship. In general, the court may grant the guardian the power to make medical decisions, determine living arrangements, social settings, manage property and handle financial affairs such as banking, investments and expenses, including household and long-term care costs and taxes. As parents, if you are unable to name someone in your family or a close friend the guardian of your adult child with Autism, a judge will appoint an attorney as the guardian. Refer to your county's Probate Court for paperwork to start the process.

A power of attorney (POA) is a legal document that allows someone else to act on your adult child's behalf. Like guardianship, there are many forms of POA, and in Ohio, you can create your own. If the POA complies with Ohio's requirements, any POA you create is just as legal as one drafted by a lawyer. To learn more, visit ASGA's website for the recorded webinar - AutismAkron.org/webinars.

Charting the LifeCourse – Tools to help you envision a Good Life

In conjunction with The Ohio State University Nisonger Center and the University of Missouri- Kansas City's Institute for Human Development, ASGA introduces the **One-Page Person-Centered Description**[41].

The One-Page Person Centered Description is deceptively simple, and in this simplicity lies its strength. Essentially, it is a brief overview of what is important to your child and how he/she needs to be supported. The One-Page Person-Centered Description helps to build better relationships with anyone providing support, it provides a way to express and advocate for what really matters to your child, it provides a record that moves with your child as he/she transitions from service to service or to multiple services, and it can act as a reminder to regularly update the information to reflect your child's changing circumstances and aspirations. The most important thing is that the people working with your child (camp counselors, doctors, family members, babysitters, teachers, and hospital personnel) will understand his specific needs and the best ways to comfort, care for, and support him.

Charting the LifeCourse offers a set of tools and resources designed to assist individuals and their families in planning and navigating life experiences, especially for those with disabilities. Charting the LifeCourse takes a holistic view of an individual's life, considering various aspects such as education, employment, relationships and community involvement. This comprehensive perspective helps in creating well-rounded life plans.

STEP 6: A Few Other Thoughts

It takes an immense amount of energy and creativity to take care of someone who is on the Autism spectrum. Research often explores the challenges faced by parents and caregivers providing care to individuals with Autism. However, it is important to note that every person with Autism is unique. Not comparing challenges can be crucial for caregiver well-being.

Take Care of Yourself

Facts surrounding an Autism diagnosis speak to the need for parents to take care of themselves. A diagnosis of Autism can be overwhelming and upsetting, and it is important to recognize those feelings. Remember HALT – hungry, angry, lonely, and tired. If you are experiencing these feelings, make sure to take some time for yourself.

- **Join a Support Group**: After your child receives an Autism diagnosis, your current friendships might change. Parents of neurotypical children often will not understand your experience. Know that you will make additional friends in the Autism community who can support you and understand your journey. Call ASGA's Helpline, (330) 940-1441, to inquire about locations and times of parent-led support groups. Joining a support group with other parents of children with Autism can help you feel less alone and simply talking to people who understand and empathize with your struggles can feel good.
- **Practice self-care:** Practicing self-care might seem indulgent but do not underestimate how powerful it can be. If you have a busy schedule, you can start small. Take a 10-minute walk in the morning or soak in the bathtub for 15 minutes at the end of a long day. Build mindful time into your life.
- **Ask for help**: Don't be embarrassed to reach out to your support system to ask for help. Family, friends, neighbors or responsible teens can help with babysitting when you need some time for yourself or when you are investigating resources that can better equip you to care for your child. ***This may mean letting others care for your child so you can take a break.***

Prioritize Your Relationship:

> *Autism can present unique challenges in relationships. Studies indicate that couples raising a child with Autism face similar divorce rates as the general population, yet they often encounter heightened marital conflicts.*

Given the differing ways men and women respond to an Autism diagnosis, carve out time for each other amidst the demands. Don't hesitate to seek support from friends, family, and caregivers if needed. Share the daily responsibilities equitably to avoid burdening one partner excessively; mutual support is crucial. Effective communication is paramount; even amid disagreements, listen to your partner's perspective on what's best for your child.

While there's no one-size-fits-all approach to navigating a relationship when Autism is involved, maintaining honest and open dialogue is essential. Both parents share the goal of ensuring the best outcomes for their child with Autism. A strong relationship benefits everyone involved. Take proactive steps together, formulate plans, and learn to compromise, fostering mutual understanding and appreciation for your child's strengths while addressing their needs effectively across different settings.

Extended Family Involvement

Grandparents and extended family play an important role in the life of a child with Autism. The **Interactive Autism Network** released a study in 2009 that found that grandparents were often the first to raise concerns that their grandchild was not meeting the expected milestones[42].

In addition, other key findings from grandparents include:

- Almost a third (31 percent) of respondents reported that they were the first to voice concerns about a grandchild's developmental delays.
- Seventy-two percent said they are involved in making treatment decisions for their grandchildren.

- More than 36 percent said they provided at least some level of direct care for a child with Autism at least once a week, while 18 percent said they were their grandchild's primary babysitter.
- Nearly 14 percent reported that they and their adult children had moved closer to each other so that the grandparents could help the family manage all that is involved with the child's ASD.
- About 25 percent of respondents reported spending up to $99 a month to help meet their grandchild's needs. Some said they contribute as much as $1,000 a month, often for such things as therapeutic toys or recreational activities.

At the same time, grandparents are concerned about their own adult child’s emotional well-being and health as they watch them experience the stress of being primary caregivers to children who have substantial needs.

There are also grandparents raising grandchildren with Autism, creating different challenges unique to this situation. Grandparents have often lost their parents and, therefore, cannot benefit from the caregiving or emotional support provided by great-grandparents. Grandparents raising children with Autism can feel a unique drain on their limited resources and energy.

It is important for grandparents to also recognize their limitations and to seek help and support from counseling professionals, a circle of friends, and other family members.

Family Considerations

Growing up with a sibling with a disability often develops siblings who are caring, more mature than their peers and responsible. They realize that their parents are stressed and that a lot of family time and resources are directed to their siblings. On the other hand, some siblings grow up to resent their brother or sister with a disability and the parents who are doing their best to raise them. It is important that siblings can speak candidly about their experience as a brother or sister of a child with Autism. Take time to ask your typical sibling what they need. To talk? To get away for a while? It is important to carve out time that is just for your typical child(ren). Ask the ***Autism Society of Greater Akron*** about **respite programs**[43] in your area that supply quality care for your child with Autism.

A great resource with ideas for showing your typical child that you care is the **Sibling Support Project**[44]. The Sibling Support Project is the first national program dedicated to recognizing, promoting and addressing the life-long and ever-changing concerns of millions of siblings of people with developmental, health and mental health concerns. Read *What Siblings Would Like Parents and Service Providers to Know* on their website. This group initiated the concept of *Sibshops*, a recreational group just for siblings of kids with disabilities to help connect them with other sibs, give them a place to express their joys and concerns, teach them about Autism, help them solve problems and let them have fun. Contact the ***Autism Society of Greater Akron*** for help in locating a *Sibshop* near you.

> *Adult siblings of individuals with disabilities admit that it was helpful when their parents created some special time for them without their siblings.*

It was also helpful when parents had some expectations of the child with disabilities, for example, requiring him to do appropriate chores, instead of excusing him because of his Autism. Adult siblings also state that they appreciated being recognized for their achievements.

Neurodivergent Travel

Traveling can be stressful for everyone. For travelers with Autism, schedule changes, new sights and sounds, airport delays, and unfamiliar foods can pose additional challenges.

The travel industry has designed incredible programs to support neurodivergent individuals of any age in navigating airports, hotels, resorts, and attractions. Look into special programs that may be of assistance to you, such as *TSA Cares*, *Wings for All,* a *DPNA* code on your ticket, or a *Hidden Disabilities Sunflower* worn on your jacket or bag.

TSA Cares[58] assists travelers with disabilities and medical conditions and others who may need additional assistance with screening. *TSA Cares* is staffed to provide travelers with information on what to expect during the screening process. Their telephone number is (855) 787-2227.

A *DPNA* code, which stands for Disabled Passengers with Intellectual or Developmental Disability Needing Assistance, can be mentioned at the time of booking, and airlines will be more geared up to render them special assistance. This could include boarding first if long queues cause stress, boarding last if a degree of claustrophobia is present, receiving a hot meal on priority, window seats for those on the Autism spectrum if required, and/or children with Autism being able to be seated with their caregivers. The *DPNA* code originates from the International Air Transport Association.

A *Hidden Disabilities Sunflower* is a simple tool for an individual to voluntarily share that he/she has a disability or condition that may not be immediately apparent – and that he/she may need a helping hand or more time in shops, at work, on transport or in public spaces. A traveler can discreetly highlight the type of support he/she needs on a personalized **Sunflower Card.**[59]

One Final Thought

The Autism Society of Greater Akron hopes that this guide will be one of many resources to help you on your Autism journey. Autism is a marathon, not a sprint. Take each day for what it is and know that tomorrow will be different. Over time, it does get easier as children with Autism progress…and they do, leading happy and fulfilled lives for them.

The most important thing is to love and nurture your child for who they are. Appreciate the victories as their achievements. If you compare your child to his neurotypical peers, you will not appreciate your child for who they are and the many unique strengths they bring to us as parents, siblings, friends, and society.

> *The Autism Society of Greater Akron provides support, education, and advocacy to individuals with Autism and their families as they face the Autism journey.*
> ***You are not alone.*** *We will travel this road together.*

Appendix I-Document Links

2 Centers for Disease Control (CDC) - *Leading national public health institute of the United States providing information on health issues in kids with ASD.* www.cdc.gov/autism

3 Key Findings: *CDC Releases First Estimates of Number of Adults Living with Autism Spectrum Disorder in US* https://rb.gy/043an3

4 How to organize your child's IEP binder - *An IEP binder can help you keep track of your child's Individualized Education Program.* https://www.understood.org/en/articles/how-to-organize-your-childs-iep-binder

5 Child Mind Institute - The Child Mind Institute is dedicated to transforming the lives of children and families struggling with mental health and learning disorders by giving them the help they need to thrive. *https://childmind.org/*

6 The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition - This manual will help clinicians and researchers define and classify mental disorders, which can improve diagnoses, treatment and research. *https://www.psychiatry.org/psychiatrists/practice/dsm*

7 Furfaro, H. (2018, July 25). *Conditions that accompany Autism, explained. SPECTRUM.* https://www.spectrumnews.org/news/conditions-accompany-Autism-explained

8 Ohio Early Intervention- A statewide system that provides coordinated services to parents of infants and toddlers with disabilities or developmental delays in Ohio. https://ohioearlyintervention.org/

9 CDC's Learn the Signs. Act Early. https://www.cdc.gov/ncbddd/actearly/index.html

10 Ohio Bold Beginning! *Search for Early Care and Education Programs* - https://childcaresearch.ohio.gov/

11 Blitz, R, (2023, March 29). *Complementary and alternative therapies for Autism*. https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/complementary-and-alternative-therapies-for-autism-what-parents-need-to-know.aspx

12 Osborne, K, (2023). *What drugs are used for treating Autism?* AppliedBehavioralAnalysisEdu.org. https://www.appliedbehavioranalysisedu.org/what-drugs-are-used-for-treating-Autism/

13 & 14 & 15 Autism Society of America - Provides critical information about which interventions have been shown to be effective for individuals with ASD. https://autismsociety.org/

16 Association for Science in Autism Treatment – A detailed list of psychological, educational, therapeutic and biomedical Interventions. Learn what works, what needs more research and what does not work or is untested. www.asatonline.org/for-parents/learn-more-about-specific-treatments

17 National Professional Development Center on Autism - Promotes the use of evidence-based practices (EBPs) for children and youth with ASD, birth to 22 years of age. The site defines each EBP and links to an Internet module that details the practice. https://autismpdc.fpg.unc.edu/ebps/

18 OCALI Autism Internet Modules (AIM) - Provide information and professional development for anyone who supports, instructs, works with, or lives with someone with Autism. www.Autisminternetmodules.org; **OCALI Lending Library** - Gives access to over 5,000 resources for any resident of Ohio who is 18 years or older, including books, DVD's, assessment tools and assistive technology. https://ocali.org/lending-library

19 Organization for Autism Research (OAR) - Uses science to address the social, educational, and treatment concerns of self-advocates, parents, Autism professionals, and caregivers. Offers A Parent's Guide to Research (available in English and Spanish). www.researchAutism.org/resources/a-parents-guide-to-research

20 Kasari, C. (27, August 2019). How much behavioral therapy does an autistic child need? SPECTRUM.

https://www.spectrumnews.org/opinion/viewpoint/how-much-behavioral-therapy-does-an-autistic-child-need/

21 Ohio Autism Insurance Coalition - Helps people understand their benefits, find coverage, and navigate the insurance process. www.asdohio.com. For actions that families can take when trying to receive benefits for ABA Therapy from their insurance plans, https://www.asdohio.com/resources/aba-in-plans/

22 Supplemental Security Income (SSI) – Program imposes Income and Asset Limitations. Learn more at www.ssa.gov/ssi/text-child-ussi.htm

23 Social Security Administration – Federal income supplement program based on medical qualification and income. The medical criteria for children and adults can be found on the Social Security website in the Blue Book section. www.ssa.gov/disability/professionals/bluebook

24 Social Security Disability Insurance (SSDI) - A disabled child or adult may qualify under a retired, disabled, or deceased parent's work record. www.ssa.gov/planners/disability/qualify.html#anchor8

25 Social Security Administration (SSA) – You can apply for programs in person at your local office. Find a list of offices and a checklist of items you will need on the SSA website.
Office Locations: https://secure.ssa.gov/ICON/main.jsp
Disability Starter Kits: www.ssa.gov/disability/disability_starter_kits.htm

26 Medicaid.gov - The government website for the Medicaid program. https://www.medicaid.gov/

27 Medicaid Buy-In for Workers with Disabilities (MBIWD) - Ohio Medicaid program that provides health care coverage to working Ohioans with disabilities. MBIWD was created to enable Ohioans with disabilities to work and keep their health care coverage. www.medicaid.ohio.gov/FOR-OHIOANS/Programs/MBIWD

28 Changes to **Ohio's Waiver Waiting List** for home and community-based services waivers make it easier to identify a person's needs and coordinate needed services.
https://dodd.ohio.gov/waivers-and-services/Ohio%20Waiver%20Waiting%20List/ohios-waiver-waiting-list

29 Private Funding Resources – Some organizations give grants to families of children with Autism. A list can be found on the Lucas Board of Developmental Disabilities website. https://lucasdd.org/finding-funds

30 Financial Resources and Discounts for Students with Disabilities - Provides assistive technology devices and education about them to individuals with Autism and their families and has a grant and funding resource database. https://www.itaalk.org/grants

31 A Guide to Parent Rights in Special Education – A guide to the Individuals with Disabilities Education Act (IDEA) which protects the rights of students with disabilities and the rights of their parents.
https://education.ohio.gov/Topics/Special-Education/A-Guide-to-Parent-Rights-in-Special-Education

32 The Ohio Operating Standards for the Education of Children with Disabilities - Details how school districts and other educational agencies implement special education and related services in Ohio.
https://education.ohio.gov/Topics/Special-Education/Federal-and-State-Requirements/Operational-Standards-and-Guidance.

33 Ohio Department of Education - Contains resources for parents concerning their child's education in the State of Ohio. https://education.ohio.gov/

34 Wrights Law - Provides parents, educators, advocates, and attorneys with information about special education law and advocacy for children with disabilities. www.wrightslaw.com

35 ASGA's Guide for Parents and Caregivers - Getting a Medical Diagnosis for Autism in Children –
https://autismakron.org/wp-content/uploads/Guide-for-Getting-a-Medical-Diagnosis-for-Autism-in-Children.pdf

36 Parent Mentors - Help parents understand the special education system and connect them with resources. Find a list on the Ohio Coalition for the Education of Children with Disabilities website. www.ocecd.org/ContactaParentMentor.aspx

37 Call Recording Form - Free to download https://www.teacherspayteachers.com/Product/FREE-Parent-Teacher-Communication-Log-Forms-for-Documenting-Phone-Calls-344961

38 Parental Rights in Special Education - This guide can help you understand your rights and your child's rights according to IDEA and the Ohio Operating Standards. It also gives you information and resources to help you understand your child's special education supports and services. https://education.ohio.gov/getattachment/Topics/Special-Education/A-Guide-to-Parent-Rights-in-Special-Education/ODE_ParentRights_040617.pdf.aspx

39 Autism Scholarship Program (ASP) and the Jon Peterson Scholarship (JPSP) – Gives the parents of children with Autism who qualify for a scholarship the choice to send the child to a special education program other than the one operated by the school district of residence. https://education.ohio.gov/Topics/Other-Resources/Scholarships/Autism-Scholarship-Program

40 The STABLE Account - Allows people with disabilities to save and invest without penalty. www.stableaccount.com

41 Charting the LifeCourse Nexus - Exchange Knowledge /Build Capacity- This framework and tools will help you organize your ideas, visions, and goals, as well as problem-solving, navigate, and advocate for support. https://www.lifecoursetools.com/

42 Interactive Autism Network is a research registry that matches researchers and their studies to families who qualify to participate in and benefit from the research. www.iancommunity.org

43 Respite Programs - https://archrespite.org/ including places like **Rotary Camp** – A respite location offering weekend respite and more. www.akronymca.org/rotarycamp

44 Sibling Support Project - Group that initiated the concept of Sibshops, a recreational group just for sibs of kids with disabilities. www.siblingsupport.org

45 ASGA's School Selection Guide – This list of questions is intended to be a guide as you search for a school. https://autismakron.org/wp-content/uploads/School-Selection-Guide_Final.pdf

46 ASGA's Countdown to a Successful School Year for Students with Autism
https://autismakron.org/wp-content/uploads/Countdown-to-a-Successful-School-Year-for-Students-with-Autism.pdf

47 Children's Hospital of Philadelphia Intellectual Disability and ASD
https://www.research.chop.edu/car-autism-roadmap/intellectual-disability-and-asd

48 Autism Spectrum Disorder and IQ – A Complex Interplay - PMC (nih.gov)
https://pmc.ncbi.nlm.nih.gov/articles/PMC9058071/

49 County Board of Developmental Disabilities (CBDD) – Find your CBDD.
https://dodd.ohio.gov/county-boards/all-county-boards-resources/4-find-your-county-board

50 Individualized Service Plan (ISP) - begins when an individual leaves/graduates from high school. It is an important document in adult planning as it details the supports, activities, and resources required for individuals with disabilities to achieve their personal goals. https://dodd.ohio.gov/about-us/our-programs/Ohio+IS

51 Children's Ohio Eligibility Determination Instrument (C/OEDI) - a tool that records information about a person's current functional abilities**.** https://dodd.ohio.gov/forms-and-rules/forms/coedi-answer-sheet

52 Early Head Start (EHS) - programs serve infants and toddlers under the age of 3 and pregnant women. https://eclkc.ohs.acf.hhs.gov/programs/article/about-early-head-start-program

53 Social Security Administration Disability Evaluation Criteria – includes information for both children and adults. https://www.ssa.gov/disability/professionals/bluebook/

54 Waivers in Ohio – The Ohio Board of Developmental Disabilities website provides information on each waiver including a waiver comparison chart. https://dodd.ohio.gov/waivers-and-services/waivers

55 Waiting List Assessment Tool - https://dodd.ohio.gov/county-boards/assessments/assessment-immediate-current-need

56 Tax Deductions and Credits
https://www.specialneedsalliance.org/the-voice/tax-tips-for-parents-of-a-child-with-special-needs/
https://www.kiplinger.com/taxes/tax-breaks-for-parents-of-children-with-disabilities

57 Sample Letter to request an initial evaluation for special education services
https://www.disabilityrightsohio.org/letter-writing-requesting-initial-eval

58 TSA Cares - provides information on security procedures to help passengers with disabilities better prepare for the security screening process. https://www.tsa.gov/travel/tsa-cares

59 Sunflower Program - assists those traveling with hidden disabilities needing a little extra patience, care, and explanation during their travel experience. https://www.akroncantonairport.com/sunflower-program/

Considerations

Autism Society of Greater Akron affirms that each person who experiences Autism is a unique individual. To the maximum extent possible, informed decisions should be made by the individual with Autism and their family members in partnership with a multidisciplinary team. ASGA does not endorse any specific diagnostician, recognizing that there isn't a universal approach suitable for all individuals with Autism. It's recommended to explore various diagnosticians and understand different viewpoints to find the provider best suited to your needs and those of your Autistic individual. When considering interventions or therapies, be cautious of providers making unrealistic promises or claims of "cures," and seek evidence-based practices supported by scientific data. Don't hesitate to seek guidance from impartial sources, gather feedback from others who have used similar services, or reach out to ASGA at 330-940-1441 x1 or info@autismakron.org.

The information contained within this guide is accurate as of its last revision date. Users are advised to verify any critical details or consult with relevant experts or authorities to ensure the currency and applicability of the information to their specific circumstances. We disclaim any liability for actions taken based on the information contained herein.

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