

# Next Steps



## A Guide for Families New to Autism in Wisconsin

12th Edition



**Autism  
Society**  
Southeastern  
Wisconsin



**Autism  
Society**  
South Central  
Wisconsin



**Autism  
Society**  
Greater  
Wisconsin

# Acknowledgements

The 12th Edition of the Next Steps guide is published through collaboration with the Autism Society of Southeastern WI, the Autism Society of South Central WI and the Autism Society of Greater WI. We appreciate everyone who contributed valuable time and feedback during the development of this guide.

Parts of this guide were adapted from *After the Diagnosis of an Autism Spectrum Disorder: A Resource for Families Whose Child is Newly Diagnosed* with permission from the Indiana Resource Center for Autism. The Indiana Resource Center for Autism conducts training, consultations, engages in research, and disseminates information to build local capacity to support children and adults on the Autism spectrum. You can learn more at [iirc.indiana.edu/irca](http://iirc.indiana.edu/irca).

**“Really appreciate the  
positive and hopeful  
message of the Autism Society.  
It is great to find an organization that  
isn't all doom and gloom.”**  
- WI Parent of a child with Autism



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# About This Guide

After your child has been diagnosed with Autism, the future may seem uncertain and confusing. It can be overwhelming to enter a world with new, complex terminology, various professionals, and vast amounts of information and opinions from others. The intent of this booklet is to help you and your family begin your journey. We hope that this guide will explain the range of services to guide you in taking your next steps after an Autism diagnosis. People of all ages are diagnosed with Autism, but this guide is aimed at parents of children 8 and under.

For more information about what to do if you are concerned about your child's development, what you can do while you wait for a diagnosis, or for resources for adults recently diagnosed with Autism, please visit our website or give us a call. Contact information for your local Autism Society affiliate is located on page 7.

During the development of this guide, we asked the Autism community for advice and words of wisdom to share with families new to Autism. As a result, you'll see comments from other Wisconsin families throughout the guide.

Please call your local Autism Society Affiliate if you have questions about any of the services mentioned here or if you just need someone to talk to. We're here to share the journey, from diagnosis across the lifespan.

Published in October 2022.

# The Autism Society

As the nation's oldest leading grassroots Autism organization, the Autism Society and its 75 local affiliates serve over half a million members of the Autism community each year. It envisions a world where everyone in the Autism community is connected to the support they need, when they need it - including education, advocacy efforts, and supports and services throughout the lifespan. Because, the connection is you. <sup>TM</sup>

## **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 Values:**

**DIGNITY**, where the value and self-determination of every individual is upheld.

**EQUITY**, where everyone with Autism achieves the highest possible quality of life.

**INCLUSION**, where every person is integrated into society without barriers or exceptions in a collaborative environment.

**DIVERSITY**, where everyone is respected for their unique and individual differences.

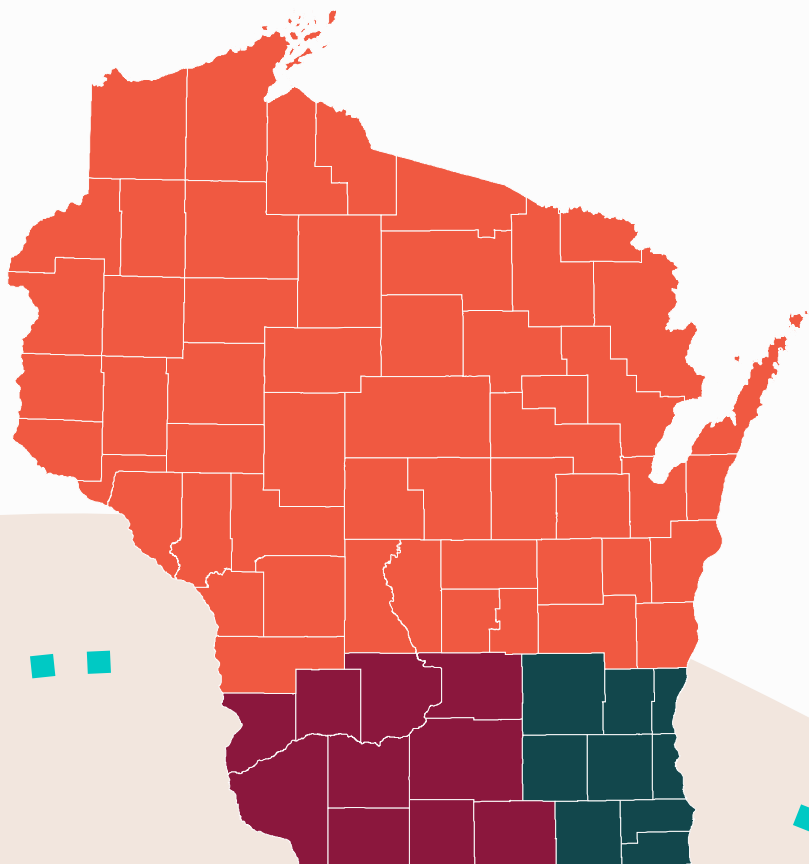
**INTEGRITY**, where we conduct ourselves with honor, truth, and respect in our thoughts, words and actions.

# Autism Society in Wisconsin

Wisconsin has three Autism Society Affiliates: the Autism Society of Southeastern WI, the Autism Society of South Central WI, and the Autism Society of Greater WI.

Each Affiliate operates separately and supports the Autism community by connecting people to the resources they need through education, advocacy, support, information and referral, and community programming.

Below is a map of the Autism Society Affiliates in Wisconsin, color coded by service area.



## **Autism Society of Southeastern Wisconsin**

(414) 988-1260 • [assew.org](http://assew.org)

Autism Society of Southeastern WI serves the greater Milwaukee area and surrounding nine counties including Milwaukee, Waukesha, Racine, Kenosha, Dodge, Jefferson, Ozaukee, Walworth and Washington.

## **Autism Society of South Central Wisconsin**

(608) 630-9147 • [autismsouthcentral.org](http://autismsouthcentral.org)

Autism Society of South Central WI serves the greater Madison area and ten counties in south central and south western WI including Crawford, Columbia, Dane, Grant, Green, Iowa, Lafayette, Richland, Rock, and Sauk.

## **Autism Society of Greater Wisconsin**

(920) 558-4602 • [autismgreaterwi.org](http://autismgreaterwi.org)

Autism Society of Greater WI serves 53 counties in the central and northern part of the state. As part of their affiliate structure they have local chapters that provide support to different regions within their service area. Contact ASGW for more information about their local chapters.

### **ASGW Local Chapters**

- Central Wisconsin
- Fox Valley
- Lakeshore
- Northeast WI
- West Central Region

# Autism Society Options Policy

The Autism Society promotes the active and informed involvement of family members and individuals with Autism in the planning of individualized, appropriate services and supports. The Board of the Autism Society recognizes that each person with Autism is a unique individual. Each family and individual with Autism should have the right to learn about and then select the options that they feel are most appropriate for the individual with Autism. To the maximum extent possible, we believe that the decisions should be made by the individual with Autism in collaboration with family, guardians, and caregivers.

Services should enhance and strengthen natural family and community supports for the individual with Autism and his or her family whenever possible. A service option designed for an individual with Autism should result in improved quality of life. Abusive treatment of any kind is not an option.

No single type of program or service will fill the needs of every individual with Autism and each person should have access to support services. Selection of a program, service, or method of treatment should be on the basis of a full assessment of each person's abilities, needs, and interests. We believe that services should be outcome-based to ensure that they meet the individualized needs of a person with Autism.

With appropriate education, vocational training, community living options, and support systems, individuals with Autism can and do lead dignified, productive lives in their communities and strive to reach their fullest potential.

The Autism Society believes that all individuals with Autism have the right to access appropriate services and supports based on their needs and desires.

# Getting Started

## Getting Organized

Developing a system for organizing important information about your child can be extremely helpful throughout your journey with Autism. As you meet with professionals you will be asked for and given a lot of information about your child. Organizing appointment dates, outcomes, recommendations, milestones, concerns, etc. will help you keep track of information regarding your child's care. Some families find it helpful to keep a binder or filing system while others use forms of digital technology.

## What should I consider documenting?

- Call and email log – Include details about the date/time the call/email was made, the reason for the contact, and the results
- Appointments and meetings – Dates, times and locations of appointments. Who you met with and why. What were the recommendations and follow-up?
- Treatment approaches, dates, and how your child responds
- History of development (dates of milestones (first word, step), dates of initial concerns, date(s) of diagnoses)
- Emergency medical information
- Contact information for providers and therapists (health care, respite, treatment, etc.)
- Insurance information and billing
- Special education information – IEPs, meeting dates, etc.

# About Autism

## Learning About Autism

Learning about Autism is an important first step after a loved one has been identified as Autistic. The more you understand about Autism and Autistic neurology, the better equipped you'll be to support your child and make informed decisions about services that are best aligned with their unique strengths and needs.

Dr. Barry Prizant writes, "Autism isn't an illness. It's a different way of being human. Children with autism aren't sick; they are progressing through developmental stages as we all do. To help them, we don't need to change or fix them. We need to work to understand them, and then change what we do."

Autism is a developmental disability caused by differences in the brain. Autism is an umbrella term for a range of neurodevelopmental differences which impact the way that the brain processes and uses information. Autism impacts everyone differently; sometimes in very visible ways, and other times in very subtle or invisible ways.

Some of the core characteristics of Autism present as differences/ challenges with social interactions, and differences with verbal and non-verbal communication, both of which often impact relationships. While it varies from person to person, many people with Autism experience sensory challenges that can cause them to be overwhelmed and experience anxiety. Autistic individuals often demonstrate differences in information processing or thinking style which impacts learning and behavior. It is common for Autistic children or adults to engage in repetitive actions, like rocking, hand flapping, blinking, etc. Often, these actions serve to regulate the person during times of sensory or emotional overwhelm. Personal passions or highly focused interests are also common in the Autism community, and these interests are often intensely important to one's feelings of safety and comfort in a chaotic world.

To gain a better understanding of Autism, seek to learn from the lived experiences of the Autism community. Many Autistic advocates have written books and blogs, speak at conferences, and manage active social media accounts to help spread their message and lived experiences.

## **How Common Is Autism?**

As of December 2021, it was estimated that Autism affects about 1 in 44 children. This number comes from the Autism and Developmental Disabilities Monitoring Network (ADDM), established by the Centers for Disease Control and Prevention (CDC), which collects data on eight-year-olds living in 14 different communities throughout the United States. According to ADDM, Autism is about four times more likely to occur in boys than in girls and occurs in all racial, ethnic and socioeconomic groups.

**Read more about the prevalence of autism:**

[cdc.gov/ncbddd/autism/data.html](https://cdc.gov/ncbddd/autism/data.html)

## **What Is the Cause of Autism ?**

There is no known single cause for Autism, but it is generally accepted that it is caused by differences in brain structure or function. Researchers do not know the exact cause of Autism but are investigating a number of theories, including the links among heredity, genetics, and medical problems. There has been misinformation about the cause of Autism. It is not caused by vaccines or due to parenting style or nutrition.

In many families, there appears to be a pattern of Autism or related disabilities, further supporting the theory that the disorder has a genetic basis.

**Read more:**

[cdc.gov/ncbddd/autism/research.html#risk](https://cdc.gov/ncbddd/autism/research.html#risk)

# Special Considerations

## Women and Girls

Research shows that boys are four times more likely to be diagnosed than girls. However, girls and women are more likely to be underdiagnosed, misdiagnosed or diagnosed later in life. This can be because Autism may look different in girls as compared to boys. For example, girls may be less likely to display repetitive behaviors like sorting or lining up toys. Girls and women may also display “masking” behaviors, meaning that they may hide their differences to fit in, avoid bullying, and/or appear more like neurotypical peers. Masking can have a negative impact on mental health. Autistic girls and women are more likely to have anxiety and/or depression than are boys with Autism. Even though Autism may look different for girls and women as compared to boys and men, it is important to keep in mind that Autism can impact people of any gender.

## Racial & Ethnic Groups

While Autism occurs in children of all racial and ethnic groups, it's important to understand that research has indicated discrepancies in time of diagnosis between different racial and ethnic groups. Some reports show that more white children are identified with Autism than are Black, Hispanic, Asian, Pacific Islander, American Indian and Alaska Native. Some of the potential reasons for the discrepancies include stigma/bias, lack of access to healthcare services due to non-citizenship or low-income, and non-English primary language. Because of these differences in timing of diagnosis, children of different ethnic and racial groups may have more difficulty accessing therapy, services, and other accommodations that will help support their development. There are groups working to address these inequalities in Wisconsin so that all families can access the support they need, when they need it.

## Neurodiversity

As you learn about Autism, you might hear the term “neurodiversity”. Neurodiversity refers to the idea that our brains work and function differently from one another, and there is no right way of acting, thinking, and learning. Differences are not seen as deficits but are recognized as normal variation within humankind. People with Autism, ADHD, learning disabilities, and others are considered to be neurodiverse.

The word “neurodiversity” was first used in the 1990’s by Judy Singer, an Autistic sociologist. The neurodiversity movement has been an important part of de-stigmatizing thinking and learning differences and ensuring that people are valued and accepted for who they are.

## Identity First vs. Person First Language

In the field of disability, the concept of “person-first language” has encouraged us to separate one’s disability from one’s personhood. An example of person-first language is using the term “person with Autism”. This continues to be the most respectful way to communicate about disability for some. However, the majority of the Autism community prefers the identity-first language of “Autistic”, recognizing that their Autistic neurology is part of their personal identity. To honor and respect both preferences, this booklet will use both identity-first and person-first language throughout.

# Conferences & Workshops

Attending conferences and workshops is a great way to learn more about Autism while networking with other families.

Wisconsin Autism Society Affiliates, school districts, CESAs, and sometimes therapy providers offer workshops and trainings for families. Some workshops are offered along with parent support group meetings, while others are separate. To find local workshop opportunities, contact your local Autism Society Affiliate.

## Wisconsin Conferences and Training Opportunities

### Parents in Partnership

Leadership for parents of children ages 6 to 14

[wspei.org/families/pip.php](http://wspei.org/families/pip.php)

### Family Voices of Wisconsin

Did You Know, Now You Know training

[familyvoiceswi.org](http://familyvoiceswi.org)

### Circles of Life Conference

[circlesoflifeconference.com](http://circlesoflifeconference.com)

### Children Come First Conference

[wifamilyties.org/children-come-first-conference](http://wifamilyties.org/children-come-first-conference)

### Wisconsin Family Ties

Parent Peer Specialist Program

[wifamilyties.org](http://wifamilyties.org)

The Autism Society Affiliates in Wisconsin offer educational opportunities for parents, educators and other interested community members. If you are new to Autism a great place to start is by participating in an Autism 101 workshop or attending a new to Autism support group meeting.

## **Annual Autism Conference**

The Autism Society of Greater Wisconsin's Annual Conference is a three-day conference occurring in April of each year. The conference brings hundreds of Autistic individuals, parents, siblings, family members, educators, and other professionals together to learn, share resources, and support one another. The conference offers a wide variety of educational topics, networking opportunities, a resource hall, and family fun. Conference participants leave the conference feeling connected and empowered.  
[autismgreaterwi.org/conferences](http://autismgreaterwi.org/conferences)

## **Urban Autism Summit**

The Urban Autism Summit has been happening yearly since 2008. The conference focuses on addressing the needs of parents, caregivers and professionals in Milwaukee, and surrounding urban areas. There are two tracks for the day focusing on supporting Hispanic and African American families. The goal is to identify unique urban community needs, how to best reach parents and then connect them to resources and support. [aseww.org](http://aseww.org)

## **Adult Autism Conference**

INTEGRAL is an annual Autism conference like no other. It puts adults on the Autism spectrum front and center, not as a subject for others to discuss, but to come together and exchange perspectives with non-Autistic professionals and parents so that everyone can learn from each other. Autistic adults, teens, family members and professionals are welcome to attend. [integralautism.org](http://integralautism.org)

# Finding Support

## Parent Support

Some of the best advice experienced parents have shared is to connect with other parents and families who have been down a similar path. Other parents can help by giving emotional support and by helping you navigate the maze of services available. There are several ways you can connect with other parents in Wisconsin.

The Autism Society Affiliates in WI offer in-person and virtual support group meetings along with social events for parents of Autistic children. Attending a support group or social event with other parents can reduce feelings of isolation. You may also gain valuable information about local resources and tips on handling specific situations.

Autism Society Affiliates in Wisconsin also host Facebook groups that offer a place to connect with others, share ideas, and ask for recommendations regardless of your location. Call your local Autism Society Affiliate to find out more about these opportunities.

Parent to Parent of Wisconsin matches parents with other parents for one-on-one connections. [p2pwi.org](http://p2pwi.org) • 888-266-0028

## Respite Care

Respite care is temporary relief for caregivers and families who care for people with disabilities or other special needs. Getting an occasional break can be beneficial to both you and your child. The Respite Care Association of Wisconsin can give you more information about identifying and coordinating respite care. Many counties have funding available to help cover the costs of respite care.

### Respite Care Association of Wisconsin

608-222-2033 • [respitecarewi.org](http://respitecarewi.org)

## **Sibling & Grandparent Support**

An Autism diagnosis will affect members of your immediate and extended family, which is why siblings and grandparents may also need some additional support during this time. There are sibling groups across Wisconsin designed to help siblings connect with other brothers and sisters. Some groups are offered by Autism Society Affiliates. Check with your local affiliate to find a sibling group near you. There are also more and more emerging resources for grandparents.

### **Resources for Siblings**

**WisconSibs: Sisters and Brothers of People with Disabilities**

[wisconsibs.org](http://wisconsibs.org)

**Organization for Autism Research (OAR)**

[researchautism.org/how-we-help/families/sibling-support](http://researchautism.org/how-we-help/families/sibling-support)

**The Sibling Support Network**

[siblingsupport.org](http://siblingsupport.org)

### **Resources for Grandparents**

**Wisconsin Grandparents' Network**

[waisman.wisc.edu/grandparents](http://waisman.wisc.edu/grandparents)

**Autism Grandparents Club**

[autismgrandparentsclub.com](http://autismgrandparentsclub.com)



**"Find a local support group and attend a meeting**

**It's comforting**

**to meet other parents who can relate to the joys and concerns of having a child with Autism."**

**- Kelly, Appleton WI**

# Recreation

Finding fun activities and engaging with your local community is important for every child, including Autistic children. Autistic children can participate in most children's activities when given appropriate support. Don't be afraid to contact sponsoring organizations to find a way to include your child.

At times you may prefer groups designed especially for children with Autism and/or other disabilities. Some Autism Society Affiliates offer recreational opportunities designed specifically for children with Autism and their families, such as football camps, family outings, bike camps, and more. Call your local Affiliate to find out what is happening in your area. Below is a list of a few statewide recreational opportunities designed for children with disabilities.

## **Special Olympics**

608-222-1324 • [specialolympicswisconsin.org](http://specialolympicswisconsin.org)

## **Sensory Friendly Films**

[amctheatres.com/programs/sensory-friendly-films](http://amctheatres.com/programs/sensory-friendly-films)

## **Miracle Leagues**

770-760-1933 • [miracleleague.com](http://miracleleague.com)

# “Take time for yourself.

It's really easy to get lost going to and from therapy and doctors' appointments. Know it's okay to find a sitter and leave everything behind. You are a super mom/dad but even super heroes need a break sometimes.

—Carol, DeForest WI



# Interventions and Therapies

## Making Decisions about Treatment

With appropriate services and support, training and information, children with Autism will grow, learn, and flourish.

Certain therapeutic or educational approaches might be helpful to children with Autism as they develop emotional regulation, communication skills, and independence. Intervention can help to lessen disruptive behaviors, and education can teach self-help skills for greater independence. But just as there is no one symptom or behavior that identifies people with Autism, there is no single treatment that will be effective for everyone who experiences Autism.

Descriptions of several treatment approaches are included in this guide. As each person responds to treatment differently, we cannot endorse any one treatment or program. Families should educate themselves about all options and choose what they feel is in the best interest of their child and family, based on their experience and what resources are available.

## Things to remember when considering treatment options.

- You, as a parent, are the best expert on your child.
- Each child is different and what works for one child may not work for your child.
- Your child will change over time as will the type of therapy that works for them.
- It's okay to switch therapy interventions or providers if doesn't feel right or you are not seeing the changes you would like.
- Interventions you choose should capitalize on areas of strength and interests.
- Finding a balance between therapy and fun is important. Remember to leave time for your child to be a kid and do the things they enjoy.

## Choosing a Treatment Provider

Available service providers differ from community to community within Wisconsin, and the quality of services and expertise can vary. Regardless, it's important to find a provider with professionals who you can trust. Ask other parents, visit programs or facilities, find out about the licensing of staff and their experience with children like yours, and ask for references. You are trusting this provider with your child, so don't be afraid to ask any question that will make you feel more comfortable. If you begin working with a professional who doesn't seem to connect with your child or who isn't able to provide documented outcomes, they might not be the right professional.

## Questions to Ask When Choosing a Treatment Provider

- Is this treatment based on scientific evidence?
- What treatment approach(es) does your company follow?
- What are the goals of the treatment?
- How much does this cost?
- Is the treatment covered by insurance or Medicaid?
- How will I be involved in the treatment?
- How is progress measured?
- Where does the majority of the treatment take place?
- What are the training requirements of the staff who will be working with my child?

## Early Intensive Behavioral Intervention (EIBI)

Studies have shown that early interventions can support development in the areas of behavior, social competence, communication, and cognition in Autistic children. EIBI typically begins when the child is first diagnosed and continues 2 to 3 years. It usually consists of 20-40 hours of individual instruction each week and involves the whole family working closely with a team of professionals to provide therapy based on a child's specific needs.

Applied Behavior Analysis and Early Start Denver Model are the most common approaches to early intervention. However, families have also reported success with other approaches, so it is important to do some research to find what works best for your child.

## Intervention and Therapy Resources

### Comprehensive list of types of interventions and therapies

[autismsociety.org/resources/intervention-and-therapies/](https://autismsociety.org/resources/intervention-and-therapies/)

### A Parent's Guide to Research

[researchautism.org/resources/a-parents-guide-to-research/](https://researchautism.org/resources/a-parents-guide-to-research/)

### Potentially Dangerous Products and Therapies

[fda.gov/consumers/consumer-updates/be-aware-potentially-dangerous-products-and-therapies-claim-treat-autism](https://fda.gov/consumers/consumer-updates/be-aware-potentially-dangerous-products-and-therapies-claim-treat-autism)

### A Parent's Guide to Evidence-Based Practice & Autism

[nationalautismcenter.org/resources/for-families/](https://nationalautismcenter.org/resources/for-families/)

"Although a diagnosis can be scary, parents should know that there are many professionals and other parents who can

**provide support  
to you and your child.**

I have learned that my child's behaviors  
indicate specific needs."

- Kristin, Wausau WI

## **Applied Behavior Analysis (ABA)**

Applied behavior analysis (ABA) is an intensive therapy that is designed to help children on the spectrum develop social and emotional skills and improve communication. ABA teaches skills and expected behavior by rewarding good behaviors and discouraging negative behaviors. It can be done in several different settings, including the home, school, and places in the community.

The key principals of ABA are that human behavior is influenced by events or stimuli in the environment and that behavior that's followed by positive consequences is more likely to happen again. ABA therapists work one-on-one with children to understand behaviors and then increase behaviors that improve a child's quality of life (such as communication) and decrease behaviors that interfere with a child's quality of life (such as aggression).

## **Early Start Denver Model (ESDM)**

ESDM is an early intervention behavioral therapy for children with Autism based on the methods of applied behavior analysis (ABA). It is a play-based therapy that helps Autistic children develop social communication skills, play skills, relationships and language through everyday activities.

Designed for children ages 12–48 months, ESDM focuses on boosting children's social-emotional, cognitive and language domains through play-based activities with parents and therapist. It can be used in many settings, including at home, at a clinic, or in school in both group settings and one-on-one.

## **Occupational Therapy (OT)**

OT is used to develop functional living skills such as self-care skills and play/social skills. It is also used to help Autistic children who have difficulty processing sensory information (touch, movement, sight, etc.)

## **Physical Therapy (PT)**

PT is used to develop gross motor skills such as walking, jumping and climbing stairs. Physical therapy may be appropriate for Autistic children who need help improving muscle tone, balance and/or coordination.

## **Speech Therapy (ST)**

The main goal of speech therapy is to help people improve their communication. Working with a Speech-Language Pathologist (SLP) can help a child develop their spoken language and improve their non-verbal communication skills. Speech therapy can also help with social skills including conversation and concept skills and learning to read body language.

## **Augmentative and Alternative Communication (AAT)**

AAC is a way for individuals to communicate without verbalizing words. Many Autistic children have difficulty with verbal communication and can benefit from AAC interventions. AAC can greatly improve a child's ability to communicate their thoughts and needs. AAC can include different methods of communication including sign language, visual boards, picture communication systems and devices producing voice output like computers or iPads.  
[asha.org/public/speech/disorders/AAC](http://asha.org/public/speech/disorders/AAC)

## **Assistive Technology (AT)**

AT is any product or device that is "used to increase, maintain, or improve functional capabilities of individuals with disabilities." AT can be used in many ways to assist Autistic individuals in their day-to-day life including communication, play, learning and using social skills, managing sensory challenges, staying safe and executive functioning skills.

## Complementary Therapies and Activities

While early educational intervention can be important to improving the quality of life for Autistic individuals, some parents and professionals believe other treatment approaches play an important role in improving skills related to communication and behavioral/emotional regulation for those with Autism. These complementary therapies might include music, art, recreational, sport or animal therapies, among many others, and might be undertaken on an individual basis or through an educational/recreational program.

All of these therapies can help by increasing communication skills, developing social interaction and providing a sense of accomplishment. They can provide a non-threatening and low-stress way for an Autistic child to develop positive relationships. They can also lead to productive and purposeful hobbies, which are critical to quality of life for everyone.

## Alternative Medicine

Alternative Medicine treatments refer to methods outside of mainstream medicine that may be used in conjunction with proven treatments. Because there is little or no scientific data available on the effectiveness or safety of Alternative Medicine treatments, it is especially important for you to keep informed when you are considering them for your child. We recommend talking to your health care provider before beginning any complementary health approaches.

Be skeptical of anyone who pressures you to buy more than you can afford, tries to use guilt to close a sale, or promises a cure.

## National Institutes of Health: National Center for Complementary and Alternative Medicine:

[nccih.nih.gov/health/be-an-informed-consumer](https://nccih.nih.gov/health/be-an-informed-consumer)

# Medical Diagnosis versus Educational Determination

Your child may need both a medical diagnosis of Autism and an educational determination of Autism to receive the full range of support available to them. A medical diagnosis of Autism does not mean that a child is automatically eligible for special education. Likewise, a child with an educational determination of Autism does not automatically qualify for therapies and support outside of school that would typically be covered by insurance.

## **A Medical Diagnosis of Autism**

A medical diagnosis is made by a psychologist, developmental pediatrician, or other specialized physician based on an assessment of symptoms and diagnostic tests. A medical diagnosis of Autism Spectrum Disorder is most frequently made according to the Diagnostic and Statistical Manual (DSM-5, released 2013) of the American Psychiatric Association. This manual guides physicians in diagnosing Autism Spectrum Disorder according to a specific set of criteria.

A medical diagnosis is needed to receive services based on insurance or government-funded programs.

## **An Educational Determination of Autism**

An educational determination is made by a multidisciplinary evaluation team of various school professionals and is based on the regulations governing the Individuals with Disabilities Education Act (IDEA). To qualify for special education the team must also determine that the child's disability adversely affects his or her educational performance and results in a need for special education services.

An educational determination is needed to received services at school, although your child may also qualify for services based on a delay in a developmental area, or due to emotional or behavioral concerns.

"Remember that your child has Autism, it doesn't have them.  
Our son has taught us so much on this journey, and looking back  
**I wouldn't trade any of it  
for the world."**

- Beth, Rhinelander WI



# Education

## Children Under Three

The Wisconsin Birth to 3 Program is an early intervention special education program that supports the growth and development of children under the age of 3 who have delays or disabilities.

A team of professionals works with your family to develop services shaped by your family's individual needs, culture and beliefs. The services your family receives support your child's development and growth, and expands your family's knowledge, skills, and abilities. The Birth to 3 Program mission is to help children grow and learn to their fullest potential.

To find the Birth to 3 contact in your county visit:

[dhs.wisconsin.gov/birthto3/contacts/primarycontact.htm](https://dhs.wisconsin.gov/birthto3/contacts/primarycontact.htm)

## Children Three and Older

Public schools in Wisconsin must provide services to children with disabilities who qualify, from ages 3 to 21. You, your doctor, a teacher, or anyone else can ask the school to decide if your child needs special education by submitting a referral. Once referred, a school must evaluate a child to determine whether or not the child meets special education eligibility criteria.

Once a child is determined to be eligible for special education services, a team including parents, teachers, therapists, and school administrators will meet to develop an Individualized Education Program (IEP) or a 504 plan. Any services, accommodations, or supports that your child needs for his or her education should be written into their plan.

## Special Education Resources

Laws entitling children with disabilities to a free and appropriate public education give parents a voice when determining the educational placement and services a student receives. It is important to understand the laws governing special education to be a full partner with educators. Your Autism Society Affiliate can help you connect with resources to get you started.

## Education Resource Organizations

### **Wisconsin Family Assistance Center for Education, Training and Support (WI FACETS)**

An organization that supports families and others with training, information and referral services, and individual assistance related to the education of children with disabilities. For more information, please see: [wifacets.org](http://wifacets.org) • 877-374-0511

### **Wisconsin Statewide Parent-Educator Initiative (WSPEI)**

An organization that works to create partnerships between special education parents and educators by providing family engagement coordinators and phone support services. [wspei.org](http://wspei.org) • 877-844-4925

## Online Education Resources

### **Department of Public Instruction (DPI)**

DPI's special education department's website on special education has extensive resources to check out: [dpi.wi.gov/sped](http://dpi.wi.gov/sped)

**Wisconsin Department of Public Instruction: Services for Children with Autism** • [dpi.wi.gov/sped/program/autism](http://dpi.wi.gov/sped/program/autism)

**Wisconsin Department of Public Instruction: Special Education Eligibility** • [dpi.wi.gov/sped/laws-procedures-bulletins/laws/eligibility](http://dpi.wi.gov/sped/laws-procedures-bulletins/laws/eligibility)

### **An Introduction to Special Education**

[dpi.wi.gov/sites/default/files/imce/families-students/intro-se.pdf](http://dpi.wi.gov/sites/default/files/imce/families-students/intro-se.pdf)

### **Special Education in Plain Language**

[dpi.wi.gov/sites/default/files/imce/sped/pdf/spec-ed-plain-langenglish.pdf](http://dpi.wi.gov/sites/default/files/imce/sped/pdf/spec-ed-plain-langenglish.pdf)

# Paying For What You Need

In the state of Wisconsin there are multiple programs that provide assistance to help cover the cost of Autism programs and services. The first step is to check with your current health insurance company to ask what they cover. If you do not have health insurance or your health insurance does not cover all your child's health care costs, you can apply for Medicaid and Katie Beckett. You also should consider applying for the Children's Long Term Support (CLTS) Waiver to help cover the cost of items/services that insurance will not cover.

## Private Health Insurance

Wisconsin law mandates that most health insurers cover certain treatments for individuals with Autism. If you have private health insurance, it will be important to understand your benefits. Health insurance plans differ in what treatments are covered, how much the plan will pay, and how much you have to pay for each treatment (co-pays). The Wisconsin Office of the Commissioner of Insurance (OCI) monitors and enforces state insurance laws and can answer your questions about how Wisconsin laws impact your health plans.

For more information about mandated coverage for Autism services, please see the Frequently Asked Questions document on the OCI website: [oci.wi.gov/rules/faq\\_autism.pdf](http://oci.wi.gov/rules/faq_autism.pdf) or call 800-236-8517.

## **Wisconsin Medicaid/BadgerCare Plus**

Medicaid is a public insurance program funded by the federal government and the state of WI, Department of Health Services. Medicaid eligibility can be based on the family's income and/or the child's level of disability. Medicaid may cover services or products that private insurance does not cover. A behavior benefit is available for certain children who are MA eligible.

For more information go to the DHS website:  
[dhs.wisconsin.gov/badgercareplus/index.htm](https://dhs.wisconsin.gov/badgercareplus/index.htm)

## **Katie Beckett Program**

Children who are not eligible for other Medicaid programs because the income or assets of their parents are too high may be eligible for Medicaid through the Katie Beckett Program. A child may be eligible for this source of Medicaid even if they are currently covered under a private health insurance policy.

For more information go to the DHS website:  
[dhs.wisconsin.gov/kbp/index.htm](https://dhs.wisconsin.gov/kbp/index.htm)

# **“Be your child's biggest advocate.**

**No one must be a bigger cheerleader for your child than you. If you don't think something is working - tell someone. If you think your child is not getting enough services or too much - say something.”**

**-Carol, DeForest WI**

## Children's Long Term Support (CLTS) Waiver

The Children's Long-Term Support (CLTS) Program helps children with disabilities and their families through supports and services that help children grow and live their best lives. Funding may be used to support a range of different services that are identified based on an assessment of your child's specific needs and identified goals or outcomes. Services may include daily living skills training, service coordination, adaptive aids, communication aids, consumer education and training, counseling and therapeutic services, home modifications, and respite care, among others.

For more information about eligibility, allowable services, and how to apply, go to the DHS website: [www.dhs.wisconsin.gov/clts/index.htm](http://www.dhs.wisconsin.gov/clts/index.htm)

## Supplemental Security Income

Supplemental Security Income (SSI) is monthly cash benefit based on disability and family income. In Wisconsin, people who receive SSI automatically get Medicaid coverage.

For more information and to find out if you are eligible, go to the DHS website: [dhs.wisconsin.gov/ssi/index.htm](http://dhs.wisconsin.gov/ssi/index.htm)

## Resources

Autism Society Affiliates are available to talk you through the options above or to help you find other resources to pay for what you need. See map on page 6 to find your local Affiliate.

ABC for Health, Inc. provides health benefits counseling and limited legal services to help families navigate health coverage options and overturn inappropriate denials of eligibility and covered services. 800-585-4222.

"Your child will do amazing things. They just do it on their own time. Be there for them and never give up on them. Always be there for them as they reach their milestones.

**Teach them to be  
proud of who they are."**

- Julie, Viola WI



## Local Resource Guide

Your local Autism Society is a great first place to start when you are looking for Autism information. Each Affiliate in WI has an Information and Resources specialist along with a database with listings of local resources.

### **Autism Society of South Central WI**

608-630-9147 • [autismsouthcentral.org/resource-directory](http://autismsouthcentral.org/resource-directory)

### **Autism Society of Greater WI**

888-428-8476 • [autismgreaterwi.org/find-resources](http://autismgreaterwi.org/find-resources)

### **Autism Society of Southeastern WI**

414-988-1260 • [assew.org/resource-guide-2-2](http://assew.org/resource-guide-2-2)

## National Resources

### **Autism Society of America**

Creating connections, empowering the Autism community with the resources needed to live fully. [autismsociety.org](http://autismsociety.org)

### **Autism Internet Modules**

Provides free online learning opportunities.  
[autisminternetmodules.org](http://autisminternetmodules.org)

### **Autistic Self Advocacy Network (ASAN)**

Seeks to advance the principles of the disability rights movement with regard to autism. [autisticadvocacy.org](http://autisticadvocacy.org)

### **Organization for Autism Research (OAR)**

Focus on applied research. [researchautism.org](http://researchautism.org)

# Statewide Resources

## Disability Rights Wisconsin

Focus on access to services and legal rights.

800-928-8778 • [info@drwi.org](mailto:info@drwi.org) • [disabilityrightswi.org](http://disabilityrightswi.org)

## Family Voices of Wisconsin

Focus on access to resources and community supports.

800-422-7145 (parents only) • [familyvoiceswi.org](http://familyvoiceswi.org)

## National Alliance on Mental Illness (NAMI)

Offering education, support and advocacy.

800-236-2988 • [nami@namiwisconsin.org](mailto:nami@namiwisconsin.org) • [namiwisconsin.org](http://namiwisconsin.org)

## Wisconsin Board for People with Developmental Disabilities

Legislative advocacy, community supports.

608-266-7826 • [bpddhelp@wi-bpdd.org](mailto:bpddhelp@wi-bpdd.org) • [wi-bpdd.org](http://wi-bpdd.org)

## Wisconsin Family Ties

Parent-run organization that works with families that include children with social, emotional, or behavioral challenges.

800-422-7145 • [wifamilyties.org](http://wifamilyties.org)

## Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN)

Help families get answers, find services, and connect to community resources.

[dhs.wisconsin.gov/cyshcn/regionalcenters.htm](http://dhs.wisconsin.gov/cyshcn/regionalcenters.htm)

**"Include your child/loved one**

**in all decision making,**

**to the extent possible, as soon as it is age appropriate. 'Nothing about us without us!'"**

**- Robert, Kaukauna WI**

### **Autism Society of Southeastern Wisconsin**

3720 N. 124th Street, Suite O

Wauwatosa, WI 53222

414-988-1260

[assew.org](http://assew.org)

### **Autism Society of South Central Wisconsin**

437 S. Yellowstone Drive, Suite 217A

Madison, WI 53719

608-630-9147

[autismsouthcentral.org](http://autismsouthcentral.org)

### **Autism Society of Greater Wisconsin**

1477 Kenwood Drive

Menasha, WI 54952

888-428-8476 or (920) 558-4602

[autismgreaterwi.org](http://autismgreaterwi.org)



# **The connection is you.**