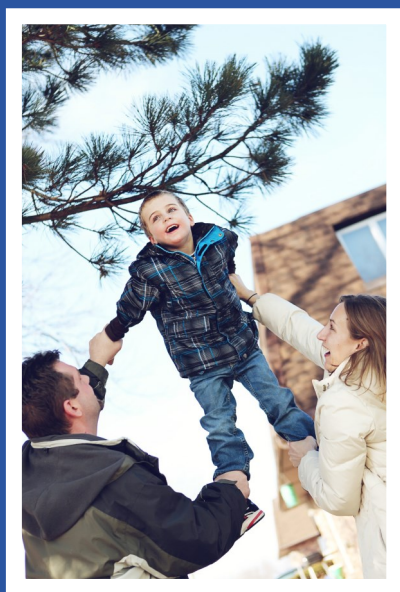


# NEXT STEPS

## A Guide for Families New to Autism Spectrum Disorder



 **AUTISM SOCIETY**

*Improving the Lives of All Affected by Autism*

*Wisconsin*

9th Edition 2014/2015

# ACKNOWLEDGEMENTS

The development of the 2014/2015 of this guide was a collaborative effort. We appreciate everyone who contributed valuable time and feedback during the development of this guide. Thank you to the following organizations for their contributions:

Autism Society of Southeastern Wisconsin

Navigating Autism

Northeast Regional Center for Children and Youth with Special Health Care Needs

Southeast Regional Center for Children and Youth with Special Health Care Needs

The printing of this guide was possible through a grant from Principal Financial Group.

We'd also like to extend a special thank you to Carrie Anciaux Photography for many of the images throughout the guide. Carrie's photos feature children and families affected by autism in Wisconsin.



# ABOUT THIS GUIDE

Long before receiving an Autism Spectrum Disorder diagnosis, you may have suspected that something was different about your child. Suspecting that something is different and receiving an autism diagnosis is not easy. You are likely feeling a mix of emotions: maybe relieved to have an answer, or anxious about the future, or even angry that this has happened to your family. These feelings, among others, are all normal for families who have a child with a new diagnosis of autism.

Trying to find the appropriate treatment and services for someone affected by autism can be challenging. The goal of this guide is to provide you with some ideas on where to start. We hope that this guide will give you information about what types of services are available, but only you will be able to decide what is best for your family. Please call us at the Autism Society if you have questions about any of the services mentioned here or if you just need someone to talk to. We are here for you!

This guide is designed for families who have recently received an Autism Spectrum Disorder diagnosis. For more information about what to do if you are concerned about your child's development or what you can do while you wait for a diagnosis, please visit our website or give us a call.

The terms autism, Autism Spectrum Disorder and ASD are used interchangeably throughout this guide.

"I wish I had contacted the Autism Society sooner. The people are great and the resources are really helpful."

Dad of 10 year old with autism



*Improving the Lives of All Affected by Autism*

*Wisconsin*

1477 Kenwood Dr.

Menasha, WI 54952

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

[www.asw4autism.org](http://www.asw4autism.org)

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“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.”  
Parent of a child with autism

# AUTISM SOCIETY OPTIONS POLICY

The Autism Society promotes the active and informed involvement of family members and the individual with autism in the planning of individualized, appropriate services and supports. The Board of the Autism Society believes 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 the family whenever possible. The service option designed for an individual with autism should result in improved quality of life. Abusive treatment of any kind is not an option.

We firmly believe that no single type of program or service will fill the needs of every individual with autism and that 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 lead dignified, productive lives in their communities and strive to reach their fullest potential.

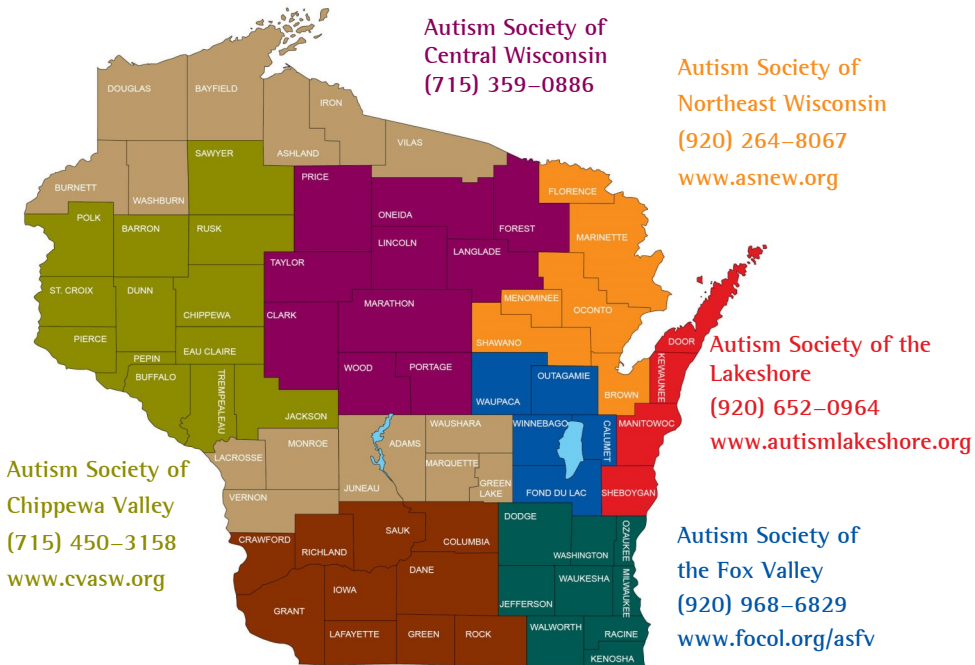
The Autism Society believes that all individuals with autism have the right to access appropriate services and supports based on their needs and desires.



# WHERE TO ASK QUESTIONS

## Autism Society State & Local Affiliates

Autism Society affiliates are your best source for information about autism in Wisconsin. Autism Society Affiliates provide support, education, information & referral, awareness and advocacy. In addition to the state affiliate, there are 7 local Autism Society affiliates offering services in Wisconsin. If you're located in a county colored in tan, there is currently no local affiliate serving your area.



State Office:  
Autism Society Wisconsin  
(920) 558-4602  
[asw@asw4autism.org](mailto:asw@asw4autism.org)

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

Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs, including autism, and the providers who serve them. The Centers are staffed by specialists who can help get answers, find services and connect you to community resources.

### Northern Regional Center (CYSHCN)

Marathon County Health Department  
1000 Lake View Drive #100

Wausau, WI 54403

1-866-640-4106

[www.co.marathon.wi.us/cyshcn.asp](http://www.co.marathon.wi.us/cyshcn.asp)

### Northeast Regional Center for CYSHCN

Children's Hospital of WI—Fox Valley  
325 N. Commercial Street, Suite 400

Neenah, WI 54956

1-877-568-5205

[www.northeastregionalcenter.org](http://www.northeastregionalcenter.org)

### Western Regional Center for CYSHCN

Chippewa County Department of Public Health

711 N. Bridge Street, Room 121

Chippewa Falls, WI 54729

1-800-400-3678

[www.co.chippewa.wi.us/ccdph/CSHCN](http://www.co.chippewa.wi.us/ccdph/CSHCN)

### Southeast Regional Center for CYSHCN

Children's Hospital of Wisconsin  
9000 W. Wisconsin Ave

Wauwatosa, WI 53226

1-800-234-5437

[www.southeastregionalcenter.org](http://www.southeastregionalcenter.org)

### Southern Regional Center for CYSHCN

Waisman Resource Center, Room 102  
1500 Highland Ave.

Madison, WI 53705

1-800-532-3321

[www.waisman.wisc.edu/cshcn](http://www.waisman.wisc.edu/cshcn)

### Great Lakes Intertribal Council for CYSHCN

2932 Highway 47

Lac du Flambeau, WI 54538

1-800-472-7207

[www.glitc.org](http://www.glitc.org)

## Wisconsin First Step

Wisconsin First Step provides an information and referral hotline for families of children, age birth to 21, with special needs, including autism. The hotline is open 24 hours a day, 7 days a week. Calls are free and confidential. They also provide a comprehensive database and an autism specific resource directory.

1-800-642-7837

[www.mch-hotlines.org](http://www.mch-hotlines.org)

# LEARNING ABOUT AUTISM

Learning about autism will help you make informed decisions for your family. Because research is conducted constantly, learning about autism should also be an ongoing activity so you can stay on top of emerging information. As with other parts of your life, to be a good consumer, it is important to stay informed.

Autism Spectrum Disorder (ASD) is a developmental disability caused by differences in the brain. Autism can impact a person's functioning at different levels, from very mildly to severely. There is usually nothing about how a person with autism looks that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most people. The thinking and learning abilities of people with autism can vary – from gifted to significantly challenged.

People with autism may have problems with social, emotional, and communication skills. Their sensory system might also be affected. They might repeat certain behaviors and might not want change in their daily activities. Many people with autism also have different ways of learning, paying attention, or reacting to things. Autism begins during early childhood and last throughout a person's life.



“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



A child or adult with Autism Spectrum Disorder might:

- not play "pretend" games (pretend to "feed" a doll)
- not point at objects to show interest (point at an airplane flying over)
- not look at objects when another person points at them
- not respond to name
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled
- appear to be unaware when other people talk to them but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound

Information taken from:

[http://www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/autismfactsheet.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/autismfactsheet.pdf)

Autism Spectrum Disorder is diagnosed using guidelines from the Diagnostic and Statistical Manual (DSM), published by the American Psychiatric Association. The American Psychiatric Association recently released the newest, 5<sup>th</sup> edition (DSM-5) in May of 2013 which included important changes to the criteria used to diagnose Autism Spectrum Disorder. You can find more information about the diagnostic criteria at their website: [www.dsm5.org](http://www.dsm5.org).



## How Common is Autism?

As of March 2014, it was estimated that Autism Spectrum Disorder affects about 1 in 68 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 Spectrum Disorder is almost 5 times more likely to occur in boys (1 in 42) than in girls (1 in 189) and occurs in all racial, ethnic and socioeconomic groups.

Read more about the prevalence of autism: [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html)



## What Is the Cause of Autism Spectrum Disorder?

Autism has no single known cause. Instead, research indicates that more than one factor may contribute to the cause of autism. Many researchers believe that several genes, possibly in combination with environmental factors, may contribute to autism.

While more research is needed to identify all the causes, it is clear that poor parenting does not cause autism.

### Online Resources

- Autism Society of America  
[www.autism-society.org](http://www.autism-society.org)
- Autism Speaks: 100 Days Kit  
[www.autismspeaks.org/family-services/tool-kits/100-day-kit](http://www.autismspeaks.org/family-services/tool-kits/100-day-kit)
- National Center of Birth Defects and Developmental Disabilities  
[www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html)
- National Professional Development Center on Autism Spectrum Disorders: Foundations of ASD Free Online Course  
<http://autismfdc.fpg.unc.edu/content/foundations-autism-spectrum-disorders-online-course-content>

# GETTING INFORMED

Educational opportunities, like conferences and workshops, are a great way to network with other families while learning more about autism. The Autism Society of Wisconsin offers an annual statewide spring conference and other workshops throughout the year for families, individuals on the autism spectrum, educators and other professionals. For more information about conferences offered through the Autism Society of Wisconsin, please visit our conference webpage at [www.asw4autism.org/conferences\\_workshops.html](http://www.asw4autism.org/conferences_workshops.html)

Local Autism Society Affiliates also offer workshops and trainings for families. Some workshops are offered in conjunction with parent support group meetings and others are separate. To find local workshop opportunities, please contact your local Autism Society affiliate.

“We were able to learn about personal stories, positive outcomes, diet, medications, music therapy, small businesses for individuals on the spectrum, and more. We came home with a few new books, some great handouts and info from vendors, great ideas, and new hopes for our family's future.”

-2013 Autism Society of Wisconsin Conference Attendee

“Attend conferences on autism. It is a great way to get the most current autism information, identify resources and form contacts within the autism community in a short period of time. Also read multiple publications by adults with autism. Their writings provide an excellent window into the different world your child is likely experiencing.”

Nancy  
Cottage Grove, WI

In addition to workshops about autism, you may be interested in attending some leadership trainings to help you advocate for your child. Here are some leadership training opportunities in Wisconsin:

- Parents As Leaders: Leadership for parents of children birth to 6. [www.waisman.wisc.edu/pals](http://www.waisman.wisc.edu/pals)
- Parents in Partnership: Leadership for parents of children ages 6 to 14. <http://wspei.org/families/pip.php>

# FINDING SUPPORT

## Family & Parent Support

Some of the best advice families 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 many services available. There are several ways you can connect with other parents in Wisconsin.

The Autism Society of Wisconsin offers a peer support listserv through a Yahoo Group. With over 900 parents, educators, and other professionals on the listserv, it can be a great place to ask for advice and/or find resources and support. To join the listserv, follow this link: <http://groups.yahoo.com/neo/groups/ASW-Autism/info>.

"After meeting other moms and seeing them with their kids, autism didn't seem so scary"

- Amy

The local affiliates of the Autism Society offer in person support group meetings. They may also offer play or social groups for your child. Call your local affiliate to find out more about parent support group dates, times, and locations. Contact information for



Parent to Parent of Wisconsin provides support for parents of children with special needs, including autism. They provide a one-to-one connection with another parent who has had a similar experience and who knows firsthand about the feelings and realities that come with having a child with autism. Call Parent to Parent to get matched with another parent.

Parent to Parent of Wisconsin

[www.p2pwi.org](http://www.p2pwi.org)

866-266-0028

## Sibling & Grandparent Support

An autism diagnosis will affect all 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 to those who share similar joys and concerns. There are also more and more emerging resources for grandparents. See the resources listed below.

"I had no idea there was a community of people willing to love and accept my son *as he is*. The Autism Society rocks."

-Autism parent

### Resources for Siblings:

- Sibling Support Network: Offers Sibshops, which are best described as opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. To find a Sibshop near you, visit this link: [www.siblingsupport.org](http://www.siblingsupport.org)
- Autism Society: Sibling Perspectives: Guidelines for Parents  
[www.asw4autism.org/pdf/LWA\\_Siblings.pdf](http://www.asw4autism.org/pdf/LWA_Siblings.pdf)
- Autism Speaks: A Sibling's Guide to Autism  
[www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits](http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits)

### Resources for Grandparents:

- Wisconsin Grandparents' Network  
[www.waisman.wisc.edu/grandparents.htm](http://www.waisman.wisc.edu/grandparents.htm)
- Autism Speaks: A Grandparent's Guide to Autism  
[www.autismspeaks.org/family-services/community-connections/celebrating-grandparents](http://www.autismspeaks.org/family-services/community-connections/celebrating-grandparents)



## 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, contact your county for more information.

Respite Care Association of Wisconsin  
608-222-2033  
[www.respitecarewi.org](http://www.respitecarewi.org)

## Recreation

Finding fun community activities is important for every child, including children with autism. Many children can participate in any children's activity when given appropriate support. Although your child may require some preparation and accommodations, most sponsoring organizations can find a way to work with you so that he or she can fully participate.

Autism Society affiliates offer recreational opportunities such as football camps, family outings, bike camps, and more, which are designed specifically for children with autism and their families. Call your local affiliate to find out what is happening in your area.

At times you may prefer groups designed especially for children with special needs. Below is a list of a few recreational opportunities designed specifically for children with special needs:

- Special Olympics  
800-552-1324  
[www.specialolympicswisconsin.org](http://www.specialolympicswisconsin.org)
- Miracle Leagues  
770-760-1933  
[www.miracleleague.com](http://www.miracleleague.com)
- Reel Movie for Real Needs with Marcus Theatres  
[www.marcustheatres.com/Promotion/PromotionDetail/21/](http://www.marcustheatres.com/Promotion/PromotionDetail/21/)
- Sensory Friendly Films with AMC Theatres  
[www.amctheatres.com/programs/sensory-friendly-films](http://www.amctheatres.com/programs/sensory-friendly-films)



# THERAPY & TREATMENT

## Making Decisions about Treatment

Studies have shown that early intervention can significantly improve the quality of life for individuals with autism. Finding an early intervention provider and setting up treatment can seem like a daunting task. How do you know where to begin?

You will come across a lot of information about therapy options for your child. Think about the source of the information. Is the information a personal story, coming from another parent or family? Is the information coming from a provider who is looking to recruit clients? Or is the information research based, coming from a reputable source?

Remember that you, as a parent, are the best expert on your child. Do your research on the different treatment options, talk to other parents and ask questions.

Descriptions of several treatment approaches are included in this guide. Inclusion of a type of therapy or intervention does not imply endorsement by the Autism Society, nor does omission imply disapproval. Treatment providers in Wisconsin each have different treatment philosophies. Some providers may use just one of these approaches while others use a mix of several approaches. The box on the next page includes more questions to ask when choosing a treatment provider for your child.

Many sources of funding (see page 22 for more funding options) only fund treatment programs consistent with best practice and research on effectiveness for children with autism spectrum disorders. The online resources below can help you determine if a particular treatment has been shown to be effective or not.

### Online Resources

- Organization for Autism Research (OAR): A Parent's Guide to Research  
[www.researchautism.org/resources/reading/documents/ParentsGuide.pdf](http://www.researchautism.org/resources/reading/documents/ParentsGuide.pdf)
- National Autism Center  
[www.nationalautismcenter.org/](http://www.nationalautismcenter.org/)
- A Parent's Guide to Evidence Based Practices & Autism  
[www.nationalautismcenter.org/pdf/nac\\_parent\\_manual.pdf](http://www.nationalautismcenter.org/pdf/nac_parent_manual.pdf)

## Early Intensive Behavioral Intervention

Early intensive behavioral intervention usually involves the whole family working closely with a team of professionals to provide therapy based on a child's specific needs. Therapy programs can be set up in the home or at a treatment center.

Of the approaches listed here, research has confirmed the effectiveness of both Applied Behavior Analysis and the Early Start Denver Model. However, families have also reported success with some of the other approaches, especially when used in combination with a proven approach.

These and other approaches are being researched and investigated every day. Many groups are working to develop other approaches and have new techniques that may turn out to be quite effective.

### Applied Behavior Analysis (ABA)

ABA is the use of behavioral and learning principles to shape behaviors. By understanding the cause of those behaviors, applied behavior analysts work to increase behaviors that improve a child's quality of life (such as communication) and decrease behaviors that interfere with a child's life (such as aggression). They influence behavior by changing the child's environment. A key component of applied behavior analysis is a strong focus on measuring observable events and understanding the function of behavior – what that behavior gets for the person who does it.

Applied behavior analysis (ABA) is a branch of psychology that has grown into its own practice, with its own licensing and credentials. For children with autism, most early intensive behavioral intervention approaches shown to be effective use ABA. The most commonly used ABA treatments are Discrete Trial Instruction (DTI) and Applied Verbal Behavior (AVB).

[www.wisaba.org/about-behavior-analysis/](http://www.wisaba.org/about-behavior-analysis/)

### Questions to ask when choosing a treatment approach and/or therapy provider:

What are the goals of this treatment?

Is there science/research supporting this treatment?

Is this treatment evidence based?

How much does this cost?

Is the treatment covered by private or public insurance?

How will I be involved in the treatment?

How is progress measured?

Where does the majority of the treatment take place?



## Early Start Denver Model (ESDM)

The aim of ESDM is to increase the rates of the development in all domains for children with autism as it simultaneously aims to decrease the symptoms of autism. In particular, this intervention focuses on boosting children's social-emotional, cognitive, and language, as development in these domains is particularly affected by autism.

[www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/](http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/)

## Floortime

The Floortime approach is about getting down to the child's level, following the child's lead and building on their strengths and abilities through interactions and relationship building. Parents and therapists engage with the child by doing what the child enjoys.

[www.stanleygreenspan.com](http://www.stanleygreenspan.com)

## Relationship Development Intervention (RDI®)

RDI® uses a parent consultation model where parents are trained to use techniques based on current research in autism, human development and brain based learning. The overall goal of RDI® is to help individuals with autism form personal relationships by working on making social connections.

[www.rdiconnect.com](http://www.rdiconnect.com)

## SCERTS®

The SCERTS® (Social Communication, Emotional Regulation, Transactional Support) model draws from child development and focuses on child-initiated communication in everyday activities. The SCERTS® curriculum provides a systematic method that ensures that specific skills and appropriate supports, stated as educational objectives, are selected and applied in a consistent manner across a child's day.

[www.scerts.com](http://www.scerts.com)



"I don't want people to pity me or my son. I want to be around people who can see his potential, not just his challenges."

- Parent of a child with autism

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

Augmentative and Alternative Communication (AAC) is a term that describes communication methods, besides oral speech. Some children with autism may benefit from using an AAC system to enhance their ability to communicate. AAC systems can range from a paper and pencil, to picture boards, to devices producing voice output. Ipads and ipods can also sometimes be used as AAC systems.

## **Complementary and Alternative Medicine (CAM)**

Complementary and Alternative Medicine (CAM) treatments refer to methods outside of mainstream medicine that may be used in conjunction with proven treatments. Some families affected by autism might consider CAM treatments such as special diets, herbal or dietary supplements with other treatment methods. Because there is little scientific data available on the effectiveness or safety of CAM treatments, it is especially important for you to keep informed when you are considering CAM treatments for your child. We also recommend talking to your health care provider before beginning any complementary health approaches.

National Institutes of Health: National Center for Complementary and Alternative Medicine: [www.nccam.nih.gov/health/decisions](http://www.nccam.nih.gov/health/decisions)

## **Speech, Occupational and Physical Therapy**

Speech/language therapy is helpful for children having difficulty understanding and/or expressing language, and those with difficulty mechanically producing speech (articulation, pitch, volume, etc.). Speech/language therapy may be particularly helpful for children with autism who are not effective verbal communicators, or who have difficulty with conversational language, reading nonverbal cues, and/or other aspects of social language.

Occupational therapy is used to develop functional living skills such as self-care skills and play/social skills. It is also used to help children with autism who have difficulty processing sensory information (touch, movement, sight, etc.) Within the context of occupational therapy, sensory integration therapy identifies issues in sensory processing and creates activities that provide the type of sensory information to address the child's sensory issues.

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

# EDUCATION

## Children Under Three

If your child is younger than 3, accessing early intervention services is a good place to start. Wisconsin's early intervention program is called Birth to 3. No matter where you live in Wisconsin, your county is responsible for providing Birth to 3 services to eligible children and their families. If your child already has an Autism Spectrum Disorder diagnosis, he or she may already be eligible for Birth to 3. If your son or daughter does not yet have a diagnosis, the Birth to 3 program may screen your child for any developmental concerns with moving, learning, seeing, hearing, communicating, or interacting with others. If the screening identifies your child as having a 25% delay in one or more developmental areas, he or she will be eligible.

Services and supports, such as physical therapy, occupational therapy, and/or speech therapy will be based on an Individualized Family Service Plan (IFSP) developed after an assessment of your child's strengths and challenges. All services are provided where your child typically spends his or her day, which may include your home or child care setting.

Children are eligible for Birth to 3 services before turning three. After turning three, some children will be eligible for Special Education Services through their local school districts.

## 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, or anyone else can ask the school to decide if your child needs special education by submitting a referral. More information on how to make a referral can be found on the Wisconsin Department of Public Instruction's website. Once referred, a school must evaluate a child to determine whether or not the child meets special education eligibility criteria.

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



## Medical Diagnosis versus Educational Determination

A medical diagnosis of autism is usually made by a medical or mental health professional using the Diagnostic and Statistical Manual (DSM). A medical diagnosis of an Autism Spectrum Disorder does not mean that a child is automatically eligible for special education under the educational determination of autism. Likewise, a child with an educational determination of autism does not automatically qualify for a medical diagnosis of autism. An educational determination is needed to receive services at school, although your child may also qualify for services based on a delay in a developmental area, emotional, or behavioral concerns. A medical diagnosis is needed to receive services based on insurance or government-funded programs.

To determine eligibility for special education services under an autism determination, an Individualized Educational Program (IEP) team within the school will conduct an evaluation. The IEP team may include teachers, a speech-language pathologist, an occupational therapist, a school psychologist and other school personnel. The team must determine if a child meets educational criteria for impairment under the category of autism using the Wisconsin Department of Public Instruction (DPI) Autism Criteria Checklist. They must also determine that the child needs special education services, meaning that the disability adversely affects his or her educational performance and results in a need for special education services. While a medical diagnosis is not required for a child to receive an educational determination, an IEP team should consider any medical information available during the educational evaluation.

Wisconsin Department of Public Instruction: Services for Children with Autism

[http://sped.dpi.wi.gov/sped\\_autism](http://sped.dpi.wi.gov/sped_autism)

Wisconsin Department of Public Instruction: Special Education Eligibility

[http://sped.dpi.wi.gov/sped\\_eligibility](http://sped.dpi.wi.gov/sped_eligibility)



## 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. Networking with other parents can also be helpful.

The organizations below work with families in Wisconsin about special education issues:

- **Cooperative Educational Service Agencies (CESAs)** – includes 12 regional CESAs that serve the special and unique needs of schools and children. To find your local CESA, visit their website:  
[www.cesawi.org](http://www.cesawi.org)
- **Wisconsin Family Assistance Center for Education, Training and Support (WI FACETS)** – a statewide organization supporting families and others with training, information and referral, and individual assistance related to children with disabilities  
[www.wifacets.org](http://www.wifacets.org)  
877-374-4677
- **Wisconsin Statewide Parent-Educator Initiative (WSPEI)** – an organization that works to create partnerships between parents and educators for students with disabilities.  
<http://wspei.org/>  
877-844-4925



### Online Resources

An Introduction to Special Education

<http://sped.dpi.wi.gov/files/sped/pdf/intro-se.pdf>

Special Education in Plain Language

<http://wspei.org/documents/spec-ed-plain-lang-english.pdf>

# FUNDING

## Private Health Insurance

Wisconsin law mandates that most health insurers cover certain treatments for individuals with Autism Spectrum Disorders. If you have private health insurance, it will be important to understand your benefits. The mandate does not apply to all health insurance plans. 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.

### **Office of the Commissioner of Insurance (OCI):**

Frequently Asked Questions on Mandated Coverage for Autism Services

[www.asw4autism.org/pdf/FAQ\\_12-22-09\\_Autism.pdf](http://www.asw4autism.org/pdf/FAQ_12-22-09_Autism.pdf)

800-236-8517



“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

## Public Health Insurance

If private health insurance doesn't cover treatment, your child may be eligible for public assistance. There are a number of public insurance programs, listed below, that may cover the cost of treatments and services for your child. Many children with autism in Wisconsin are eligible for Early Intensive Behavioral Intervention services through the Children's Long Term Support Waiver. There is often a waiting list for public assistance, be sure to ask how long you can expect to wait for funding.

The Compass Wisconsin Threshold website is a good resource for information about long term support options for children with autism. It provides information about each program, eligibility requirements and how to apply. Families that live in certain counties will also be able to use the website for applying to programs. Below is a list of programs that your child might be eligible for and websites where you can find more information.

Compass Wisconsin Threshold: [www.compasswisconsin.org](http://www.compasswisconsin.org)

## Wisconsin Medicaid

[www.dhs.wisconsin.gov/medicaid/](http://www.dhs.wisconsin.gov/medicaid/)  
<https://access.wisconsin.gov/>

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

Eligibility: [www.dhs.wisconsin.gov/children/clts/waiver/family/autism/eligibility.htm](http://www.dhs.wisconsin.gov/children/clts/waiver/family/autism/eligibility.htm)

How to Apply: [www.dhs.wisconsin.gov/children/clts/waiver/family/apply.htm](http://www.dhs.wisconsin.gov/children/clts/waiver/family/apply.htm)

## Katie Beckett Program

Eligibility: [www.dhs.wisconsin.gov/children/kbp/eligibility.htm](http://www.dhs.wisconsin.gov/children/kbp/eligibility.htm)

How to Apply: [www.dhs.wisconsin.gov/children/kbp/apply.htm](http://www.dhs.wisconsin.gov/children/kbp/apply.htm)

## Supplemental Security Insurance

Eligibility: [www.dhs.wisconsin.gov/ssi/eligibility.htm](http://www.dhs.wisconsin.gov/ssi/eligibility.htm)

How to Apply: [www.dhs.wisconsin.gov/ssi/apply.htm](http://www.dhs.wisconsin.gov/ssi/apply.htm)

*"My advice is don't ever give up, do as much as you can every single day, take every opportunity you can with your child to teach, (if you can count something, count it, read it, spell it, sing it). Always remember, take things day by day, but never lose hope."*

*Betty, Marinette WI*

# ACRONYMS

**AAC:** Augmentative and Alternative Communication

**ABA:** Applied Behavior Analysis

**ADA:** Americans with Disability Act

**ADRC:** Aging and Disability Resource Center

**ASD:** Autism Spectrum Disorder

**ASL:** American Sign Language

**BCBA:** Board Certified Behavioral Analyst

**BIP:** Behavior Intervention Plan

**CAM:** Complementary and Alternative Medicine

**CBI:** Consultative Behavior Intervention

**CESA:** Cooperative Educational Service Agency

**CLTS:** Children's Long Term Support

**DD:** Developmental Disability

**DHS:** Department of Health Services

**DPI:** Department of Public Instruction

**DSM:** Diagnostic and Statistical Manual

**DTI:** Discrete Trial Instruction

**EBD:** Emotional Behavioral Disability

**EC:** Early Childhood

**EIBI:** Early Intensive Behavior Intervention

**ESDM:** Early Start Denver Model

**FAPE:** Free Appropriate Public Education

**FBA:** Functional Behavioral Assessment

**IDEA:** Individuals with Disabilities Education Act

**IEP:** Individualized Education Program

**IFSP:** Individualized Family Service Plan

**LCSW:** Licensed Clinical Social Worker

**LPC:** Licensed Professional Counselor

**LRE:** Least Restrictive Environment

**OHI:** Other Health Impairment

**OT:** Occupational Therapist

**PECS:** Picture Exchange Communication System

**PDD–NOS:** Pervasive Developmental Disorder–Not Otherwise Specified

**PT:** Physical Therapist

**RDI®:** Relationship Development Intervention

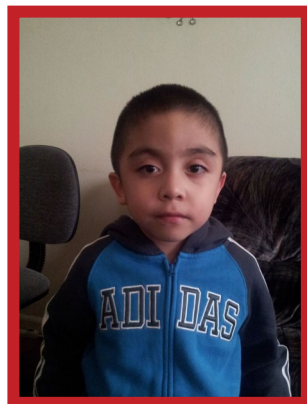
**SCERTS®:** Social Communication, Emotional Regulation, Transactional Support

**SI:** Sensory Integration

**SLD:** Specific Learning Disability

**SLP:** Speech Language Pathologist

**VBТ:** Verbal Behavioral Therapy





# RESOURCES

Below is a list of organizations not already mentioned that may be of further assistance to your family. The inclusion (or exclusion) of any organization or group does not imply endorsement or preference.

## National Resources

### **Autism Internet Modules**

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

### **Autism Source**

Search for services and supports nationwide.  
[www.autismsource.org](http://www.autismsource.org)

### **MyAutismTeam**

Social network site for parents of kids with autism.  
[www.myautismteam.com](http://www.myautismteam.com)

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

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

### **Family Voices of Wisconsin**

Focus on access to resources & community supports.  
608-828-9959  
[www.fvofwi.org](http://www.fvofwi.org)

### **National Alliance on Mental Illness**

Offering education, support & advocacy.  
800-236-2988  
[name@namiwisconsin.org](mailto:name@namiwisconsin.org)  
[www.namiwisconsin.org](http://www.namiwisconsin.org)

### **Navigating Autism, Inc**

General resource information & referral.  
[navigatingautism@gmail.com](mailto:navigatingautism@gmail.com)  
[www.navigatingautism.org](http://www.navigatingautism.org)

### **Wisconsin Board for People with Developmental Disabilities**

Legislative advocacy, community supports.  
608-266-7826  
[bpddhelp@wi-bpdd.org](mailto:bpddhelp@wi-bpdd.org)  
[www.wi-bpdd.org](http://www.wi-bpdd.org)

### **Wisconsin Family Ties**

Children's mental health resources.  
800-422-7145  
[info@wifamilyties.org](mailto:info@wifamilyties.org)  
[www.wifamilyties.org](http://www.wifamilyties.org)



 **AUTISM SOCIETY**

*Improving the Lives of All Affected by Autism*

*Wisconsin*

1477 Kenwood Dr.

Menasha, WI 54952

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

[www.asw4autism.org](http://www.asw4autism.org)