

NEXT STEPS

A Guide for Families New
to Autism Spectrum Disorder



 **AUTISM SOCIETY**

Improving the Lives of All Affected by Autism

10th Edition



ACKNOWLEDGEMENTS

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Autism Society of Southeastern Wisconsin

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ABOUT THIS GUIDE

After your child has been diagnosed with Autism Spectrum Disorder, 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 give you enough background on the range of services available to guide you in taking the next steps after an autism diagnosis.

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.

During the development of this guide, we asked the autism community for advice or 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 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're here to share the journey, from diagnosis through the lifespan.

Published in October of 2016.



ABOUT THE AUTISM SOCIETY

Autism Society

The Autism Society is the nation's oldest and largest autism grassroots organization in the United States. In 1965, the Autism Society founders came together to create an organization that enabled parents and individuals impacted by autism to support one another and advocate for services that allow people with ASD to achieve the highest quality of life. Today, the Autism Society is a national system of over 100 state and local affiliates representing thousands of individuals and families affected by autism in communities across the nation. The Autism Society has a long, proud history of promoting autism awareness and helping families and individuals navigate the autism journey.

Our Mission

Improving the lives of all affected by autism.

Our Vision

The Autism Society envisions a world where individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued.



A group of dedicated Autism Society volunteers and staff from across the nation gathered in New Orleans in July, 2016.



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.

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



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 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.



Family Voices compiled a list of organizational tools that may be helpful as you begin:

www.familyvoices.org/work/caring?id=0052



Learning About Autism

Learning about autism will help you make informed decisions for your child and your family. It may also help you understand why your child acts a certain way. As you learn more about the characteristics of autism, some of your child's challenges and behaviors may make more sense to you.

Autism Spectrum Disorder (ASD) is a developmental disability caused by a difference in the brain. Autism can impact a person differently, 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 others. The thinking and learning abilities of people with autism can vary – from gifted to severely challenged ([CDC, 2015](#)).

There are two main categories that the characteristics of ASD fall into. These characteristics are described in the Diagnostic and Statistical Manual, fifth edition (DSM -5). Professionals use this manual as a tool to diagnose mental health conditions based on a set of observable behaviors.

The first category in the diagnostic criteria for ASD is a deficit in social communication and social interactions. This includes lack of social reciprocity, nonverbal communication skills, and difficulty with relationships. Examples of what you might see:

- Not responding to their name being called or not responding when a question is asked
- Difficulty having a back-and-forth conversation
- Not pointing to objects
- Difficulty with eye contact
- Limited facial expressions, possible lack of a "social" smile in response to your smile
- Disinterest in peers/siblings
- Difficulty with pretend play
- Prefers to play alone
- Difficulty understanding the thoughts and feelings of others
- Difficulty regulating social interactions and emotions

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



The second category is restrictive, repetitive patterns of behavior, interests or activities. This includes behaviors like:

- Repetitive physical movements like rocking back and forth, flapping hands, moving fingers in front of eyes
- Lining up toys
- Repeating speech: repeating what you've said or repeating what they've heard on TV or radio
- Preference of sameness – would like to eat the same thing, follow specific routines and may become upset by changes in routine
- Extreme interest in one particular topic



Some individuals with autism also perceive sensory information such as sounds, smells, textures, tastes and sights differently. Your child may show an over (hyper) reaction or under (hypo) reaction to various sensory input. For example, certain sounds (fire alarms, vacuums, hair dryers, sirens) may be painful. Or perhaps particular smells (perfumes, candles, flowers, foods) may be overwhelming and distracting. Various types of lighting (fluorescent) may be extremely bothersome. On the other hand, your child may show no reaction to painful circumstances such as ear infections, headaches, burns or broken bones. Or your child may seek out sensations like spinning on the swing set, deep pressure or heavy blankets.

Other sensory examples:

- Only eating certain foods because of texture or taste
- Preference of one type of clothing because of how it feels on body
Bothered by clothing tags or seams

Some children with ASD exhibit a wide range of challenging behaviors. These behaviors may include self-injurious behavior (SIB), aggression, self-stimulation, difficulty following directions, and/or withdrawal. Many children on the spectrum also have challenges with sleep and toilet training. Realize that these behaviors may serve a real purpose to your son/daughter or they may be a reflection of other issues in his or her life. Involving professionals who understand autism and how to assess the function of behavior will help alleviate the stress of challenging behaviors for you and your child.

How Common Is Autism?

As of March 2016, 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 Disorders are almost five 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

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. Regardless of the cause, we know that autism is neurologically-based. Most importantly, parents do not cause their child(ren) to have autism. Autism cannot be caused by lack of discipline, or “cold” parenting.

Read more:

www.cdc.gov/ncbddd/autism/research.html#risk



RESOURCES

Autism Society of America | www.autism-society.org

American Psychiatric Association – DSM 5 Development | www.dsm5.org

National Center of Birth Defects and Developmental Disabilities: | www.cdc.gov/ncbddd/autism/index.html



Conferences & Workshops

Attending conferences and workshops is a great way to learn more about autism while networking with other families. Many Autism Society affiliates in Wisconsin offer educational opportunities for parents, educators and other interested community members.

The Autism Society of Wisconsin offers an annual conference in the spring 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, visit our conference webpage at www.asw4autism.org/conferences_workshops.html.

The Autism Society of Wisconsin also hosts a free webinar series for families and professionals in Wisconsin. You can sign up to attend upcoming webinars live or watch archived webinars at your convenience at www.asw4autism.org/webinars.html.

Local affiliates 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.

In addition to workshops about autism, you may be interested in attending some leadership training to help you advocate for your child. The box below includes two leadership training opportunities in Wisconsin.

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

Parents in Partnership | Leadership for parents of children ages 6 to 14 |

<http://wspei.org/families/pip.php>

Family Voices of Wisconsin | *Did You Know, Now You Know* training |

<http://fvofwi.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 local affiliates of the Autism Society offer in-person support group meetings. Attending a support group meeting with other parents of children with autism can reduce feelings of isolation. You may also gain valuable information about local resources and tips on handling specific situations. Call your local affiliate to find out more about parent support group dates, times and locations.

For online support, the Autism Society of Wisconsin offers a peer support listserv through a Yahoo Group. With over 1,000 parents, educators and other professionals on the listserv, it can be a great place to ask for advice and find resources and support. To join the listserv, visit <http://groups.yahoo.com/neo/groups/ASW-Autism/info>.

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. Contact Parent to Parent to get matched with another parent.

Parent to Parent of Wisconsin | www.p2pwi.org | 888-266-0028

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



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 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 | www.wisconsibs.org

Autism Society: Sibling Perspectives | www.asw4autism.org/pdf/LWA_Siblings.pdf

Organization for Autism Research (OAR) |

www.researchautism.org/family/familysupport/SiblingSupportInitiative.asp

Autism Speaks: A Sibling's Guide to Autism |

www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits

RESOURCES FOR GRANDPARENTS

Wisconsin Grandparents' Network | www.waisman.wisc.edu/grandparents.htm

Autism Speaks: A Grandparent's Guide to Autism |

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.

Respite Care Association of Wisconsin
608-222-2033 | www.respitecarewi.org

Take time for yourself. It's really easy to get lost going to and from therapy and doctor's 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

Recreation

Finding fun community activities is important for every child, including children with autism. Although it may require some preparation and accommodations, most children can participate in any children's activity when given appropriate support. Don't be afraid to contact sponsoring organizations to find a way to include your child with autism.

At times you may prefer groups designed especially for children with autism and/or other special needs. 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 recreational opportunities designed for children with special needs.



Special Olympics | 800-552-1324
www.specialolympicswisconsin.org

Miracle Leagues | 770-760-1933
www.miracleleague.com

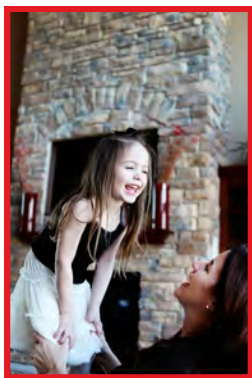
Reel Movies for Real Needs with Marcus Theatres
www.marcustheatres.com/marcus-specials/sensory-specific-films

Sensory Friendly Films with AMC Theatres
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. But with the range of different treatment options and variety of treatment providers, it can be difficult to know where to start.



Remember that you, as a parent, are the best expert on your child. Each child with autism is different and each family and child will have different needs. While evaluations and assessments may focus on your child's deficits, it's also important to identify what your child does well. The information gained through evaluations can add to what you already know about your child to help you identify treatment priorities. Ultimately treatment programs should capitalize on areas of strength and use areas of interest to motivate and reinforce.

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.

Once you've chosen a treatment approach, you will need to decide on a treatment provider. Available services/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. Ask trusted professionals and friends for recommendations.

Questions to Ask When Choosing a Treatment Provider

- What treatment approach(es) does your company follow?
- What are the goals of the treatment?
- Is there science/research supporting this treatment?
- Is this treatment evidence-based?
- 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?

Many sources of funding (see pages 25-27 for more on potential funding sources) only fund treatment programs consistent with best practice and research on effectiveness for children with autism spectrum disorders. The online resources below can give you more information about research to make informed decisions about your child's care.

ONLINE RESOURCES

Organization for Autism Research (OAR): A Parent's Guide to Research

www.researchautism.org/resources/reading/documents/ParentsGuide.pdf

National Autism Center

www.nationalautismcenter.org/

A Parent's Guide to Evidence Based Practices & Autism

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 techniques 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. This includes Discrete Trial, the Lovaas Method, Applied Verbal Behavioral, Pivotal Response Treatment, and other techniques. By understanding the cause of 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. For children with autism, most early intensive behavioral intervention approaches shown to be effective use ABA.

Early Start Denver Model (ESDM)

ESDM is an evidence-based intervention that uses behavioral and developmental principles to increase rates of development as it simultaneously aims to decrease the symptoms of autism. In particular, this intervention focuses on boosting children's social-emotional, cognitive and language domains, as development in these domains is particularly affected by autism. ESDM also uses a data based approach and empirically supported teaching practices that have been found effective from research in applied behavior analysis. ESDM fuses behavioral, relationship-based, and a developmental, play-based approach into an integrated whole that is completely individualized and yet standardized.

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

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

Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication (AAC) includes all 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.

www.asha.org/public/speech/disorders/AAC/



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

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, or 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

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

Medical Diagnosis versus Educational Determination



A medical diagnosis of autism is 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, or due to 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.

ONLINE RESOURCES

Wisconsin Department of Public Instruction: Services for Children with Autism
<http://dpi.wi.gov/sped/program/autism>

Wisconsin Department of Public Instruction: Special Education Eligibility
<http://dpi.wi.gov/sped/laws-procedures-bulletins/laws/eligibility>



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.

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.

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

www.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. More information on how to make a referral can be found on the Wisconsin Department of Public Instruction's website (www.dpi.wi.gov). 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.

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)

12 regional CESAs serve the special and unique needs of schools and children.

www.cesawi.org/contact/

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 | 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

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

ONLINE RESOURCES

An Introduction to Special Education

<http://dpi.wi.gov/sites/default/files/imce/families-students/intro-se.pdf>

Special Education in Plain Language

<http://dpi.wi.gov/sites/default/files/imce/sped/pdf/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 Disorder. 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

800-236-8517

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. There may be a waiting list for public assistance, be sure to ask how long you can expect to wait for funding.

Children's Long Term Support (CLTS) Waivers

Funding through the Children's Long Term Support waivers 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.

More information about eligibility, allowable services and how to apply:

www.dhs.wisconsin.gov/clts/waiver/family/index.htm



Wisconsin's ForwardHealth Medicaid program

In July 2014, the Centers for Medicare and Medicaid Services (CMS) directed states to provide coverage of autism treatment services as a regular statewide Medicaid benefit. In response, the Department of Health Services (DHS) began transitioning coverage of autism treatment services from the CLTS Waiver Program to a new behavioral treatment benefit under ForwardHealth in 2016.

To qualify for the ForwardHealth behavioral treatment benefit, a child must meet the following conditions:

- He or she must be enrolled in Medicaid, BadgerCare Plus, or the Katie Beckett program
- He or she must have a diagnosed need for behavioral treatment (this includes but is not limited to an autism diagnosis), and
- His or her Medicaid-enrolled behavioral treatment provider must get prior authorization from ForwardHealth for medically necessary behavioral treatment.

The benefit includes two different types of treatment: comprehensive and focused.

Comprehensive: an early intervention treatment approach designed to address multiple aspects of development and behaviors in young children. Typically, this treatment involves more weekly hours and longer duration.

Focused: dedicated to addressing specific behaviors or developmental deficits. Typically this treatment involves fewer weekly hours and shorter duration.

The Forward Health behavioral treatment benefit covers evidence-based treatments, including Applied Behavioral Analysis (ABA) and Early Start Denver Model (ESDM). Services must be prior authorized by ForwardHealth.

www.dhs.wisconsin.gov/medicaid/



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

Katie Beckett Program

The Katie Beckett Program is a special eligibility process that allows certain children with long-term disabilities, mental illness or complex medical needs, living at home with their families, to obtain a Wisconsin [ForwardHealth Medicaid](#) card.

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.

More information: www.dhs.wisconsin.gov/kbp/index.htm

Supplemental Security Insurance

Supplemental Security Income (SSI) is a monthly cash benefit paid by the federal Social Security Administration (SSA) and state Department of Health Services (DHS) to people in financial need who are 65 or older or people of any age who are blind or disabled and residents of Wisconsin.

www.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. We can also share information about some limited grant opportunities available to families affected by autism in Wisconsin.

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

www.safetyweb.org

WHAT ELSE CAN I DO?

As a parent, you play a critical role in supporting and teaching your child. Below are a few general words of advice.



Listen to and read about people on the spectrum who may provide insight into your son or daughter's disability.

Work with and build upon your child's interests. Be creative. Realize that these interests and strengths may logically lead to a career in adulthood. Celebrate strengths, interests and accomplishments.

Your child will learn best by being told what to do, rather than what not to do. Provide continual and direct guidance on expected behavior. Minimize negative comments and punishment.

Don't forget to play! Find leisure and recreational activities that all family members can enjoy together. Work with your school or treatment provider to teach skills that will facilitate your child's involvement in social and recreational activities. Join in on those activities that bring your child pleasure, laugh together and enjoy the fun.

Be proud of the accomplishments of your child and yourself whether they are small or large. Small steps may be major accomplishments for your child. Engage, acknowledge and celebrate!

Take care of yourself and your health. You need exercise, rest, laughter and leisure time. Spend quality time with others including your spouse, your other children, family members and friends. It might feel like you don't have time to take care of yourself but your health is a vital piece of the bigger picture.



Do not hesitate to look for outside guidance and support. Lean on your family and faith community, if appropriate. Seek a counselor or therapist if needed. Access parent groups online or in person. Seek out parents who have "walked the walk" and can provide positive support and guidance.

ACRONYMS

AAC Augmentative and Alternative Communication	FAPE Free Appropriate Public Education
ABA Applied Behavior Analysis	FBA Functional Behavioral Assessment
ADA Americans with Disability Act	IDEA Individuals with Disabilities Education Act
ADRC Aging and Disability Resource Center	IEP Individualized Education Program
ASD Autism Spectrum Disorder	IFSP Individualized Family Service Plan
ASL American Sign Language	LCSW Licensed Clinical Social Worker
BCBA Board Certified Behavioral Analyst	LPC Licensed Professional Counselor
BIP Behavior Intervention Plan	LRE Least Restrictive Environment
CAM Complementary and Alternative Medicine	OHI Other Health Impairment
CBI Consultative Behavior Intervention	OT Occupational Therapist
CESA Cooperative Educational Service Agency	PECS Picture Exchange Communication System
CLTS Children's Long Term Support	PDD-NOS Pervasive Developmental Disorder—Not Otherwise Specified
DD Developmental Disability	PT Physical Therapist
DHS Department of Health Services	RDI® Relationship Development Intervention
DPI Department of Public Instruction	SCERTS® Social Communication, Emotional Regulation, Transactional Support
DSM Diagnostic and Statistical Manual	SI Sensory Integration
DTI Discrete Trial Instruction	SLD Specific Learning Disability
EBD Emotional Behavioral Disability	SLP Speech Language Pathologist
EC Early Childhood	VBT Verbal Behavioral Therapy
EIBI Early Intensive Behavior Intervention	
ESDM Early Start Denver Model	

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



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

Autism Source

Search for services and supports nationwide.
www.autismsource.org

MyAutismTeam

Social network site for parents of kids with autism.
www.myautismteam.com

Organization for Autism Research (OAR)

Focus on applied research.
www.researchautism.org

Statewide Resources

Disability Rights Wisconsin

Focus on access to services and legal rights.
800-928-8778
info@drwi.org
www.disabilityrightswi.org

Family Voices of Wisconsin

Focus on access to resources & community supports.
608-828-9959
www.fvofwi.org

National Alliance on Mental Illness

Offering education, support & advocacy.
800-236-2988
name@namiwisconsin.org
www.namiwisconsin.org

Wisconsin Board for People with Developmental Disabilities

Legislative advocacy, community supports.
608-266-7826
bpddhelp@wi-bpdd.org
www.wi-bpdd.org

Wisconsin Family Ties

Children's mental health resources.
800-422-7145
info@wifamilyties.org
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



Contact your Local Affiliate at: