

# FINDING YOUR WAY.



A Navigation Guide for Wisconsin  
Families Who Have Children and  
Youth with Special Health Care  
Needs and Disabilities

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The University of Wisconsin–Madison, Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It is one of 9 national centers that encompass both an Intellectual and Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) designated by the Administration on Developmental Disabilities.

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- Regional Centers for Children and Youth with Special Health Care Needs
- Wisconsin Department of Health Services, Division of Long Term Care, Bureau of Long Term Support, Division of Health Care Access and Accountability
- Wisconsin Department of Public Instruction, Division for Learning Support
- Wisconsin Family Ties
- Wisconsin First Step

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## DEFINITION

### Who are Children and Youth with Special Health Care Needs (CYSHCN)?

Anyone from birth to age 21, with a long term physical, developmental, behavioral or emotional illness or condition.

Some examples include:

- Asthma, diabetes, sickle cell anemia, cystic fibrosis, childhood cancers and heart disease
- Attention Deficit Hyperactivity Disorder (ADHD) and mental health conditions
- Down syndrome, cerebral palsy and autism spectrum disorders
- Hearing and vision impairments
- Spina bifida, muscular dystrophy
- ...and many other health conditions

# About this Guide

- ■ *Raising a child with a special health care need or disability can be challenging and you cannot know everything there is to know right away. We hope this Navigation Guide will assist you now and also in the future when the landscape of your journey changes.*

The Wisconsin Children and Youth with Special Health Care Needs Program developed this guide in partnership with the Community of Practice on Autism Spectrum Disorders and other Developmental Disabilities to assist families who may have concerns or questions about their child's development or have recently received a diagnosis of a special health care need or disability. It provides brief descriptions of programs, services and systems of support and gives contact information to learn more about these and other resources.

## FOR FAMILIES WHO HAVE A CHILD WITH SPECIAL HEALTH CARE NEEDS

Hearing or suspecting that your child has a special need is not easy. Most of us expect parenting to go as planned and never expect that our child will have delays or be different from other children. This guide provides a starting point to discover the services and resources available in Wisconsin. Remember, your child and your journey are unique. Finding the health care, educational, and community services to help your child reach his or her greatest potential will take time, but there are resources available in Wisconsin and professionals and parents who are eager to help you and your child.





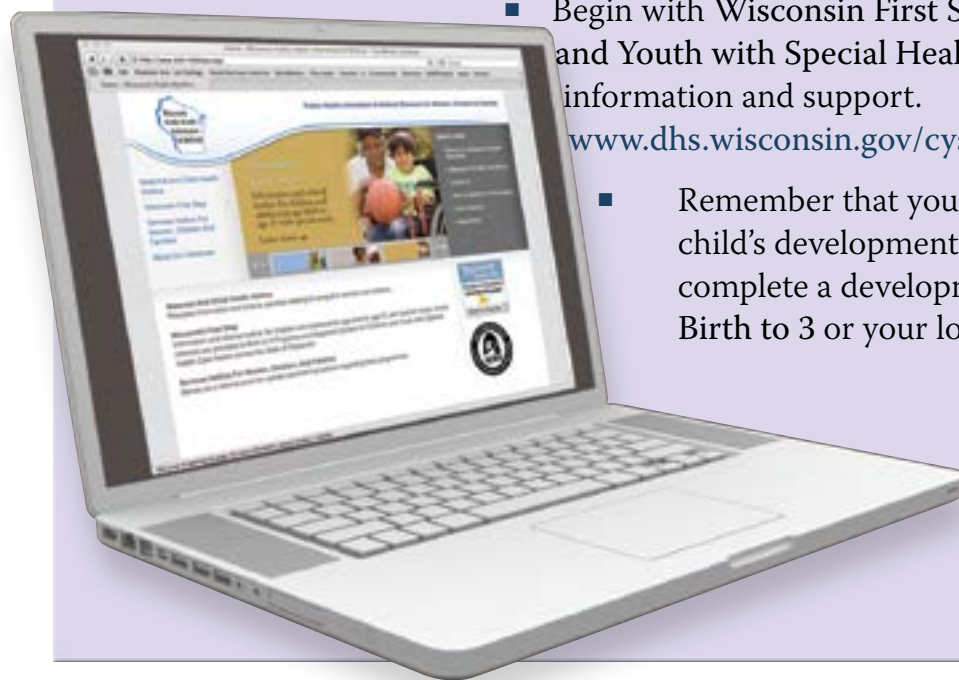


# Getting Started

- ■ *The journey of having a child with a special health care need begins in many different ways. For some the journey begins when their child is born, or even before. For others it begins a bit later, when parents recognize delays in their child's development, health concerns appear and/or issues arise at school.*

Maybe your child already has a diagnosis, or recently you have had a concern about your child's development or health and want to learn more.

Whenever your journey begins, this *Navigation Guide* will help you navigate the many Wisconsin agencies and organizations prepared to offer support for your child and family. The tips below will get you started. Some of the suggestions you may find useful, while others may not match your family's immediate needs. More information on each of these tips is included on the pages to follow.



- Begin with Wisconsin First Step (800-642-7837) or the Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) in your area, a central place for information and support.

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

- Remember that you know your child best. If you have concerns about your child's development, request that his/her doctor (primary care provider) complete a developmental screening or refer your child for an assessment with Birth to 3 or your local school district.
- Learn more about your child's condition – there are many resources available.
- Seek a support group, online or in person or contact Wisconsin's Parent to Parent Program ([www.p2pwi.org/](http://www.p2pwi.org/)) so they can connect you with a family who has similar experiences.

## GETTING STARTED (CONTINUED)

- Take advantage of the help available from your service coordinator or case manager (if you have one already) to get you connected with resources, services and supports in your community.
- Create a way to organize and keep track of all medical, school and other records and to log all appointments, notes and provider contact information.
- Explore educational opportunities and services:
  - Younger than age three: Birth to 3 Early Intervention.
  - Ages 3 to 21: Public School Special Education services.
- Learn about ways to pay for the care your child needs. Find out what your private insurance covers or look into the Wisconsin Medicaid Program and Family Support Program.
- Keep moving forward and remember there are people available to help you.



## WHERE TO ASK QUESTIONS

Families of children with special needs often say that getting accurate and timely information is one of their greatest needs.

Wisconsin First Step is an Information and Referral hotline for families of children, age birth to 21, with special needs and their providers. Staff is available 24/7 to listen and help identify needs, explore options and provide information about available services to meet your child's needs. Between 8:00 am-4:00 pm Monday through Friday calls are answered by a Parent Specialist, a professional who also has a child with special needs. Calls are free and confidential. You can also search the Wisconsin First Step website for special needs resources:

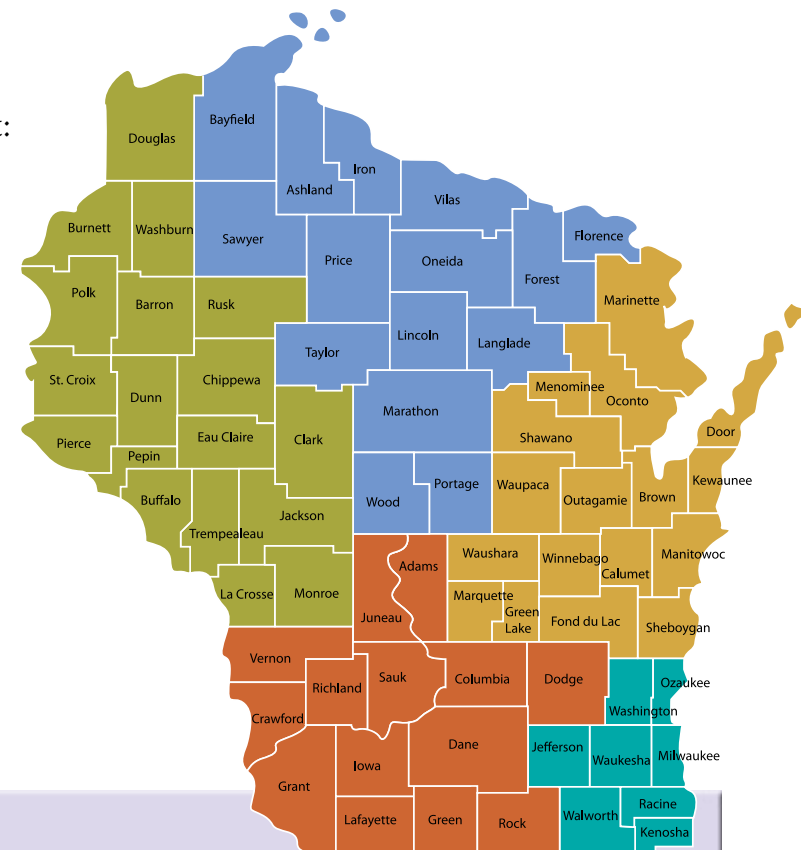
- 800-642-7837  
[www.mch-hotlines.org](http://www.mch-hotlines.org)

Wisconsin has five Regional Centers that support families of children and youth with special health care needs and the providers who serve them. Their services are free and confidential.

Each Regional Center is staffed during business hours by specialists who can help get answers, find services and connect you to community resources, and many have county roadmaps or local resource guides that provide listings of services available in your area.

Additional information, including links to programs and services, can be found at:

- Wisconsin Department of Health Services,  
Children and Youth with Special Health Care Needs Program  
[www.dhs.wisconsin.gov/cyshcn/index.htm](http://www.dhs.wisconsin.gov/cyshcn/index.htm)
- The Great Lakes Inter-Tribal Council's Children/Youth with Special Health Care Needs Program – provides information, resources, professional support, and assistance to Native American families of children with disabilities.  
715-588-1011  
[www.glitc.org/programs/cyshcn/](http://www.glitc.org/programs/cyshcn/)
- Aging and Disability Resource Centers (ADRCs) provide support to youth age 17 ½ and older and their family in most counties in Wisconsin. An ADRC provides information on programs and long-term care services available in your area, and assists individuals to apply for programs and benefits.  
[www.dhs.wisconsin.gov/adrc/consumer/index.htm](http://www.dhs.wisconsin.gov/adrc/consumer/index.htm)



■ Northern Regional Center  
[www.northernregionalcenter.org/](http://www.northernregionalcenter.org/)  
866-640-4106

■ Northeast Regional Center  
[www.northeastregionalcenter.org](http://www.northeastregionalcenter.org)  
877-568-5205

■ Southeast Regional Center  
[www.southeastregionalcenter.org](http://www.southeastregionalcenter.org)  
800-234-5437

■ Southern Regional Center  
[www.waisman.wisc.edu/cshcn](http://www.waisman.wisc.edu/cshcn)  
800-532-3321

■ Western Regional Center  
[www.co.chippewa.wi.us/CYSHCN](http://www.co.chippewa.wi.us/CYSHCN)  
800-400-3678



*If your child is not currently eligible for a service or program but you still have concerns, contact the agency or school and schedule a follow up screening or evaluation.*

## ELIGIBILITY, ENROLLMENT AND ENTITLEMENT

There are many programs described in this *Navigation Guide* that can assist you in caring for your child with special needs. Two questions to consider are:

### **Are there eligibility and enrollment criteria?**

Most programs and services have criteria or guidelines for admitting a child into a program. Enrollment requirements could include filling out appropriate paperwork or applying to the program by a certain date. Eligibility criteria may include meeting a certain level of disability or financial need.

### **Is this an entitlement?**

A benefit or program that is an entitlement is one where the individual has a legal right to that benefit or program if eligibility criteria are met. The Birth to 3 Program and school special education programs are examples of entitlement programs. If your child meets eligibility criteria he or she cannot be denied services. Other programs, like the Family Support Program, are not entitlement programs. Funding levels may vary and waiting lists may exist.

# Finding Out Early

## SCREENING FOR DEVELOPMENTAL DELAYS

■ ■ ■ *As children grow, they gain new skills: a first smile, word, and step. They develop skills in playing, learning, speaking, moving and interacting with others. When a child does not gain skills at a particular age or acquires skills much later than their same-age peers, it is called a developmental delay.*

Routine developmental screenings can help determine whether your child is reaching important developmental milestones. Parents are often the first to sense a concern about their child's development. Tell your child's doctor about your concerns. If developmental concerns are suspected the doctor may refer your child for additional evaluation with the Birth to 3 Program or your local school district's Special Education Program. Your child may receive developmental screenings by his or her primary care provider or from a Head Start/Early Head Start Program. Remember, early intervention has a positive and lasting impact.

If you are concerned about your child's development and would like to talk with someone about screening and evaluation, talk to your child's doctor or contact:

- Wisconsin First Step  
800-642-7837 – ask for the Birth to 3 phone number in your county.  
[www.mch-hotlines.org](http://www.mch-hotlines.org)
- Birth to 3 (for children under age 3)  
[www.dhs.wisconsin.gov/birthto3/index.htm](http://www.dhs.wisconsin.gov/birthto3/index.htm)
- Early Childhood Special Education Programs (for children ages 3 to 6)  
[apps4.dpi.wi.gov/SchoolDirectory/Search/PublicSchoolsSearch](http://apps4.dpi.wi.gov/SchoolDirectory/Search/PublicSchoolsSearch) – search for your local school district and call to get the early childhood special education program contact information.
- Wisconsin Head Start Association  
608-442-6879  
[whsaonline.org/wisconsin-head-start-map/](http://whsaonline.org/wisconsin-head-start-map/)







## LEARN MORE – SCREENING FOR DEVELOPMENTAL DELAYS



- Tracking Your Child's Developmental Milestones:  
Act Early Wisconsin  
[www.ActEarly.wisc.edu](http://www.ActEarly.wisc.edu)  
Milestone Moments Booklet  
[www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/MilestoneMomentsEng508.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/MilestoneMomentsEng508.pdf)
- Developmental Screening Fact Sheet  
[www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/DevelopmentalScreening.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/DevelopmentalScreening.pdf)  
Screening Tools for Autism Spectrum Disorders (ASD) and other  
Developmental Disabilities:
- Autism Society  
[www.autism-society.org/what-is/diagnosis/screening-instruments/](http://www.autism-society.org/what-is/diagnosis/screening-instruments/)
- Centers for Disease Control and Prevention Screening Recommendations  
[www.cdc.gov/ncbddd/autism/hcp-screening.html](http://www.cdc.gov/ncbddd/autism/hcp-screening.html)

# Taking Care of Health

## YOUR CHILD'S CONDITION

- *You are a partner with your child's doctor and health care team. In order to be effective, it is important that you learn about your child's condition. This is not a one-time activity! As your child grows and matures his or her health, behavioral and emotional needs will change and new questions will come up. In addition, new treatments and therapies may become available.*

There is a wealth of information online and your Regional Center will be able to guide you to resources. Your clinic, local health care system or hospital may have information or fact sheets on medical conditions. For example, Children's Hospital of Wisconsin ([www.chw.org](http://www.chw.org)) has a section on their website called *Caring For My Child* with brief descriptions of many medical conditions. In addition, talking to other families who have a child with a similar disability or health condition may be a helpful.



Online starting points include:

- American Academy of Pediatricians Children's Health Topics  
[healthychildren.org/english/health-issues/conditions/pages/default.aspx](http://healthychildren.org/english/health-issues/conditions/pages/default.aspx)
- Genetics Home Reference  
[www.ghr.nlm.nih.gov](http://www.ghr.nlm.nih.gov)
- Kids Health Medical Problems  
[www.kidshealth.org/parent/medical](http://www.kidshealth.org/parent/medical)
- National Center on Birth Defects and Developmental Disabilities (Centers for Disease Control and Prevention)  
[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

There are also diagnosis specific organizations. Examples include:

- Interactive Autism Network  
[www.iancommunity.org/cs/newly\\_diagnosed/](http://www.iancommunity.org/cs/newly_diagnosed/)
- American Diabetes Association  
[www.diabetes.org/living-with-diabetes/recently-diagnosed/](http://www.diabetes.org/living-with-diabetes/recently-diagnosed/)
- Epilepsy Foundation  
[www.epilepsyfoundation.org/about/quickstart/newlydiagnosed/](http://www.epilepsyfoundation.org/about/quickstart/newlydiagnosed/)



## MEDICAL HOME

Your relationship with your primary care provider can be a “home base” designed to consider all the needs of your child and family. This is sometimes called a *Medical Home*, and it is another way of describing what to expect from a primary care provider’s office and your role as an important partner with the provider.

When your doctor and his or her care team provide a Medical Home they will:

- know you, help you and address your child’s special needs
- listen to you and work with you as a partner
- help plan your child’s care and help connect you to community resources
- be available when you need them and accept your insurance
- help coordinate visits and communicate with other doctors and caregivers who work with your child
- work with your family to transition to adult health care services when your child becomes an adult

For more information on Medical Home go to:

- National Center for Medical Home Implementation  
[www.medicalhomeinfo.org/](http://www.medicalhomeinfo.org/)
- Medical Home Portal  
[www.medicalhomeportal.org](http://www.medicalhomeportal.org)
- Wisconsin Statewide Medical Home Initiative  
[www.wismhi.org/WiSMHI-home](http://www.wismhi.org/WiSMHI-home)
- Partnering with Your Doctor – The Medical Home Approach  
[www.region4genetics.org/education/families/](http://www.region4genetics.org/education/families/)
- National Alliance to Advance Adolescent Health  
[www.gottransition.org/](http://www.gottransition.org/)



## HEALTH CARE PROVIDERS

A child's health care should start with a primary care provider and your insurance may require you to choose one. Your child's primary care provider could be a:

- pediatrician – a children's doctor
- family physician – a doctor for both children and adults
- nurse practitioner – a registered nurse with advanced training who can provide some of the same services as a doctor and works closely with physicians

Your child's primary care provider will see your child for well-child visits, give immunizations and is the first one to consult for diagnosis and treatment of health concerns and developmental delays. The primary care provider can conduct developmental screening to check whether your child is learning and moving as other children his or her age usually do.

When health care needs are more complex, the primary care provider may recommend that you visit a physician who is a **specialist**. A specialist is a doctor who is an expert in one area of medicine (e.g., a heart doctor or cardiologist). You can find short descriptions of many medical specialties on the following web site:

[www.health.harvard.edu/fhg/specialists.shtml](http://www.health.harvard.edu/fhg/specialists.shtml)

To find the health care providers you need, you can ask doctors you already see, other families you may know through a support group or online, or contact:

- your Regional Center or Wisconsin First Step ([www.mch-hotlines.org](http://www.mch-hotlines.org) or 800-642-7837) – they cannot recommend a doctor, but can share other family's experiences and give you a list of options.
- a diagnosis specific organization such as the Down Syndrome Association of Wisconsin (414-327-3729) or the Spina Bifida Wisconsin ([sbwis.org](http://sbwis.org) or 414-607-9061).
- Finding the Right Doctor: A "Did You Know? Now You Know!" Fact Sheet  
[www.familyvoicesofwisconsin.com/?page\\_id=691](http://www.familyvoicesofwisconsin.com/?page_id=691)
- Department of Health Services  
The Consumer Guide to Health Care: Finding and Choosing a Doctor  
[www.dhs.wisconsin.gov/guide/doctor.htm](http://www.dhs.wisconsin.gov/guide/doctor.htm)





## LOCAL PUBLIC HEALTH DEPARTMENTS

Your local public health department may be a good resource for your family. Services vary by county, but may include immunization clinics, a nurse on-call to help answer questions and information on health care services in your community. To find out what services and resources are available in your county, visit the following web site:

[www.dhs.wisconsin.gov/lh-depts/counties/index.htm](http://www.dhs.wisconsin.gov/lh-depts/counties/index.htm)

## CLINICS FOR THE UNINSURED

Families who do not have public or private insurance or do not have a regular source of health care may not have a primary care provider. There are clinics and programs around Wisconsin that see families who do not have insurance and/or are low income. Many of these clinics, including free clinics, Federally Qualified Health Centers, Rural Health Centers, and Tribal Health Centers, will assign each patient a primary care provider and follow a Medical Home model of care.

Listings of clinics and services can be found at:

- Consumer Guide to Health Care - Dealing with Special Health Care Needs Situations

[www.dhs.wisconsin.gov/guide/special-cond.htm](http://www.dhs.wisconsin.gov/guide/special-cond.htm)

## ORAL HEALTH

Regular visits to the dentist and good oral hygiene at home are important for all children, but may be challenging for a child with special needs. Starting a relationship with a dentist early in your child's life will promote good oral health and can help your dentist get to know your child and be sensitive to his or her special needs.

For many families paying for dental care is a barrier. To learn about options and find a dentist in your area, you can contact:

- Children's Health Alliance of Wisconsin  
414-292-4000  
[www.chawisconsin.org/oral-health.php?pg=34](http://www.chawisconsin.org/oral-health.php?pg=34)
- Wisconsin Dental Association to learn about reduced rate dental practices who see patients who are uninsured or low income.  
414-276-4520  
[www.wda.org/your-oral-health/community-activities/community-dental-clinics](http://www.wda.org/your-oral-health/community-activities/community-dental-clinics)



LEARN MORE



- Oral Health Toolkit for Children with Autism  
[www.autismspeaks.org/community/family\\_services/dental.php](http://www.autismspeaks.org/community/family_services/dental.php)
- My Healthy Smile – Social Scripts CDs and Apps  
[www.fraser.org/products/CDs.html](http://www.fraser.org/products/CDs.html)



## DEFINITION

### What is **Mental Health**?

"... mental health is more than just the absence of mental disorders or disabilities. Mental health is a state of well-being in which every individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community."

Source: [www.who.int/mediacentre/factsheets/fs220/en/](http://www.who.int/mediacentre/factsheets/fs220/en/)

## MENTAL HEALTH

When your child is struggling with his or her mental health, you may have many questions and not know where to turn.

A first step to connecting with needed resources is to talk with your child's primary care provider about your concerns. They can recommend further evaluation by a mental health professional, which could include a psychiatrist, psychologist, behavioral therapist or social worker.

Depending on your child's diagnosis, therapy, or medications and/or other needs, on-going treatment at school or in the community may be recommended. To learn more about diagnosis, treatment and support for children with mental health challenges go to:

- National Federation of Families for Children's Mental Health  
[www.ffcmh.org](http://www.ffcmh.org)
- National Institute of Mental Health  
[www.nimh.nih.gov/health/publications/treatment-of-children-with-mental-illness-fact-sheet/index.shtml](http://www.nimh.nih.gov/health/publications/treatment-of-children-with-mental-illness-fact-sheet/index.shtml)

To connect with other families who have a child with an emotional, behavioral or mental disorder and to learn about resources and support, contact:

- Wisconsin Family Ties  
800-422-7145  
[www.wifamilyties.org](http://www.wifamilyties.org)



## DEFINITION

One term that you may hear when talking to your provider or learning about different therapy or treatment options is evidence based practice (EBP).

### What is Evidence-based Practice?

Evidence-based practice means using the best available research evidence to help guide health care and education services. Using the best research evidence helps providers give top-quality care that works well and is right for your child. The Institute of Medicine defines EBP as “the integration of best-researched evidence and clinical expertise with patient values.”

## QUALITY HEALTH CARE

While many therapy and treatment options are available, not every option will be beneficial for your child. Taking the time to become an informed consumer of health care will help you to avoid potentially unnecessary or harmful interventions or wasted resources.

Sources of information are:

- Consumer Guide to Health Care  
[www.dhs.wisconsin.gov/guide/index.htm](http://www.dhs.wisconsin.gov/guide/index.htm)
- A Guide to Quackery, Health Fraud, and Intelligent Decisions  
[www.quackwatch.com/](http://www.quackwatch.com/)
- Making Wise Health Decisions  
[www.webmd.com/a-to-z-guides/making-wise-health-decisions-topic-overview](http://www.webmd.com/a-to-z-guides/making-wise-health-decisions-topic-overview)

When you consider therapies and treatments, you may want to ask providers questions like these:

- Are there risks to this therapy or treatment? If so, what are they?
- What is the evidence that this treatment is effective?
- How will failure of the therapy or treatment affect my child and family?
- What is the cost, time commitment and location of the therapy?
- Could I talk with another family about their experience with this treatment or therapy?

Think about the source of the information you read. Double check things you read on the Internet. For more information:

- Consumer Guide to Health Care: Guide to Using Health Sites on the Web  
[www.dhs.wisconsin.gov/guide/help/web.htm](http://www.dhs.wisconsin.gov/guide/help/web.htm)



## THERAPY AND TREATMENT

Some of the choices that may help your child are provided by health care or educational professionals. Below are examples of therapies and treatments that may be helpful.

### Medications

Your child's doctor may recommend prescription medications to treat your child's condition. Make sure you understand what is being prescribed, including the dose, what the medication is treating and what side effects to look out for. If you are unsure, talk to your doctor, the clinic nurse or the pharmacist. Also be sure to talk with your doctor about other medications your child is taking, including vitamins, other supplements and any drug allergies your child has. For information on prescription drugs:

- Physician's Desk Reference Health  
[www.pdrhealth.com/drugs/rx/rx-a-z.aspx](http://www.pdrhealth.com/drugs/rx/rx-a-z.aspx)

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

Speech, Occupational and Physical therapies may be available through schools, medical clinics or community providers. To learn more about each of these therapies go to:

- What is speech therapy?  
[www.uwhealth.org/health/topic/special/speech-and-language-development/hw265266.html](http://www.uwhealth.org/health/topic/special/speech-and-language-development/hw265266.html)
- What is occupational therapy?  
[www.uwhealth.org/health/topic/special/occupational-therapy/tp23082spec.html](http://www.uwhealth.org/health/topic/special/occupational-therapy/tp23082spec.html)
- What is physical therapy?  
[www.uwhealth.org/health/topic/special/physical-therapy/zt1045.html](http://www.uwhealth.org/health/topic/special/physical-therapy/zt1045.html)

To learn more about therapy services in the community and public schools go to:

- School-Based and Community-Based Therapy Services  
[www.familyvoicesofwisconsin.com/resources/resources-by-topic/](http://www.familyvoicesofwisconsin.com/resources/resources-by-topic/)
- Wisconsin Department of Public Instruction  
800-441-4563  
[www.sped.dpi.wi.gov/sped\\_hmprograms](http://www.sped.dpi.wi.gov/sped_hmprograms)



*You can learn more about prescriptions by talking with your pharmacist and researching medications. Be sure to discuss any concerns you may have with your child's doctor.*



### What is **Applied Behavior Analysis**?

"Behavior analysis focuses on the principles that explain how learning takes place. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning. Applied behavior analysis (ABA) is the use of these techniques and principles to bring about meaningful and positive change in behavior."

Source: [www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba](http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba)

## THERAPY AND TREATMENT (CONTINUED)

### **Psychology and Psychiatry**

Both psychologists and psychiatrists can diagnose and treat mental health issues, including emotional, behavioral and mental disorders. Psychiatrists are medical doctors and can prescribe medication; psychologists use treatments that do not involve medication.

### **Behavioral Therapy**

Children with behavioral issues may need some type of therapy. For general information about behavioral therapy go to:

- Kids Mental Health  
[www.kidsmentalhealth.org/behavioral-therapy-for-children-with-emotional-disorders/](http://www.kidsmentalhealth.org/behavioral-therapy-for-children-with-emotional-disorders/)

Children with a diagnosis of Autism Spectrum Disorders (ASD) will likely have some form of behavioral therapy recommended. A common behavioral therapy is called Applied Behavior Analysis. This therapy may be available through medical clinics and other community providers. Contact your Regional Center or talk to your primary care provider to find out if this or other therapy options are available in your community.

To learn more about behavioral therapy and other therapeutic options for children with ASD go to:

- National Institute of Child Health and Human Development  
[www.nichd.nih.gov/health/topics/autism/resources/Pages/patients-consumers.aspx](http://www.nichd.nih.gov/health/topics/autism/resources/Pages/patients-consumers.aspx)
- Autism Speaks  
[www.autismspeaks.org//what-autism/treatment](http://www.autismspeaks.org//what-autism/treatment)

## Assistive Technology

Assistive Technology (AT) is any product or device that helps people with disabilities improve their independence and quality of life. This can include anything from hearing aids to communication devices. More information on AT is available from:

- Center on Technology and Disability  
[www.ctdinstitute.org/](http://www.ctdinstitute.org/)
- Wisconsin's Assistive Technology Program  
[www.dhs.wisconsin.gov/disabilities/wistech/index.htm](http://www.dhs.wisconsin.gov/disabilities/wistech/index.htm)
- ABLEdata: database of assistive technology products  
[www.abledata.com/](http://www.abledata.com/)

## Complementary and Alternative Medicine (CAM)

Complementary and Alternative Medicine encompasses a wide range of therapies and treatments. Examples include herbal and dietary supplements, massage, chiropractic and osteopathic therapies, homeopathy, deep breathing, meditation, and yoga. Talk to your primary care provider about any CAM therapies you are considering for your child. According to the NIH National Center for Complementary and Alternative Medicine, *"Children are not small adults. Their bodies can react differently from adults' bodies to medical therapies, including CAM."* For more in depth information go to:

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





# Taking Care of the Family

- ■ *In Wisconsin, there are many ways to support families with children with special needs. As you consider your child's needs and what would be a good fit for your family, consider both formal and informal supports available in your community. If a formal support is not available due to a waiting list, consider what informal supports could help you and your child.*

## FAMILIES HELPING FAMILIES

It can be helpful getting to know other families who have children with similar health issues. Contact your Regional Center to find out if there are support groups meeting in your area. Hospitals, clinics and family resource centers sometimes host parent support groups.

Below are some family-to-family organizations that can help:

- Parent to Parent of Wisconsin provides support to parents of children with special needs through a one-to-one connection with another parent who has a similar experience and who knows firsthand about the feelings and realities that come with having a child with special needs.  
888-266-0028  
[www.p2pwi.org](http://www.p2pwi.org)
- Family Voices of Wisconsin is a network of families who have children and youth with special health care needs and/or disabilities and those who work on their behalf. Family Voices provides information, training, and leadership opportunities for families and advocates for public policy and system change to improve the lives of children with special health care needs and/or disabilities.  
608-220-9598  
[www.familyvoicesofwisconsin.com/](http://www.familyvoicesofwisconsin.com/)

## DEFINITION

What are **Informal supports?**  
(also called natural supports)

Informal supports are those supports available through your family or your community that may be available for any child regardless of special need.

Examples include:

- extended family
- friends and neighbors
- faith groups

For more information on natural supports:  
[www.waisman.wisc.edu/naturalsupports/](http://www.waisman.wisc.edu/naturalsupports/)

What are **Formal supports?**  
(also called services)

Formal supports are established programs run by an agency or organization that assist families to care for their child or youth with special needs. Examples include:

- schools
- health insurance
- state or county agencies



## FAMILIES HELPING FAMILIES (CONTINUED)

- Wisconsin Family Ties is an organization run by families for families with children and youth who have emotional, behavioral and mental disorders. Wisconsin Family Ties provides support, advocacy, information, and training for families and professionals through Parent Peer Specialists who are available throughout the state. Information is available on their website and by phone.

800-422-7145

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

There are diagnosis-specific organizations with local or regional chapters. These organizations can connect you to other families and can provide support and resources. Examples include:

- Autism Society of Wisconsin (ASW)  
888-428-8476  
[www.asw4autism.org](http://www.asw4autism.org) and Autism Society chapters (go to “chapters” on the ASW website for contact information)
- Down Syndrome Association of Wisconsin (DSAW) 866-327-DSAW  
[www.dsaw.org](http://www.dsaw.org)
- Epilepsy Foundation  
800-693-2287  
[www.epilepsywisconsin.org](http://www.epilepsywisconsin.org)
- Muscular Dystrophy Association (MDA)  
800-572-1717  
[www.mdausa.org/supportgroups.html](http://www.mdausa.org/supportgroups.html)
- Wisconsin Educational Services Program Deaf and Hard of Hearing – Guide By Your Side  
608-822-3756  
[wespddhh.org/outreach/families/gbys/](http://wespddhh.org/outreach/families/gbys/)

*“ Having a child with special needs is often a life-altering experience – but with the support of another parent we begin to see through the cracks and find joy in places we never could have imagined. Our journey continues, but this time we feel that we will survive because we know another parent who has. ”*



Wisconsin Title V Children  
and Youth with Special  
Health Care Needs Program

