

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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UPDATED - 2013/2015/2017/2020

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Southern Regional Center
Children and Youth with
Special Health Care Needs

The Children and Youth with Special Health Care Needs Southern Regional Center is supported by the Wisconsin Department of Health Services, Division of Public Health, Children and Youth with Special Health Care Needs Program with funding from the Maternal and Child Health Title V Services Block Grant number B04MC21385. The original publication (2011) was supported by funding from the U.S. Health Resources and Services Administration, Maternal and Child Health Bureau, through grant number H6MMC11063, Wisconsin State Implementation Grants for Improving Services for Children and Youth with ASD.



WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

The Waisman Center, at the University of Wisconsin–Madison, 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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ACKNOWLEDGEMENTS

We are grateful to the members of the Guide Workgroup and the Review Committee who provided invaluable feedback and suggestions. Thank you to the Community Systems Practice Group, Community of Practice on Autism Spectrum Disorder and other Developmental Disabilities, and to the Children and Youth with Special Health Care Needs Network for supporting the development of this Navigation Guide and for their dedication to getting timely and accurate information into the hands of families.

The 2011 guide was written and compiled by Lynn Renner and Joanne Juhnke, edited by Amy Whitehead, Sharon Fleischfresser, and Tim Markle. Subsequent updates by Lynn Havemann, Lisa Koob, Rachael Kramer, Amy Lyle, Liz Hecht, Stacy McCarthy, Sonja Oetzel, Meredith Vitaoli and Tim Markle. The original document was designed by Allison Gritton. Subsequent formatting and design by Cheri Sanders.

Thank you to the following organizations for their assistance:

- ABC for Health
- Autism Society of Southeastern Wisconsin
- Autism Society of Greater Wisconsin
- Family Voices of Wisconsin
- Parent to Parent of Wisconsin
- Regional Centers for Children and Youth with Special Health Care Needs
- Well Badger Resource Center
- Wisconsin Division of Health Services, Department of Public Health
- Wisconsin Department of Public Instruction, Division for Learning Support
- Wisconsin Family Ties

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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.

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 disorder
- 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 throughout the changing landscape of your journey.*

The Wisconsin Children and Youth with Special Health Care Needs Program developed this guide in partnership with the Community of Practice on Autism Spectrum Disorder and other Developmental Disabilities. The Southern Regional Center at the Waisman Center keeps the Navigation Guide available and up-to-date.

This guide's purpose is to assist families who may have concerns or questions about their child's development or have 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.



A SPECIAL NOTE TO FAMILIES

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 their 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

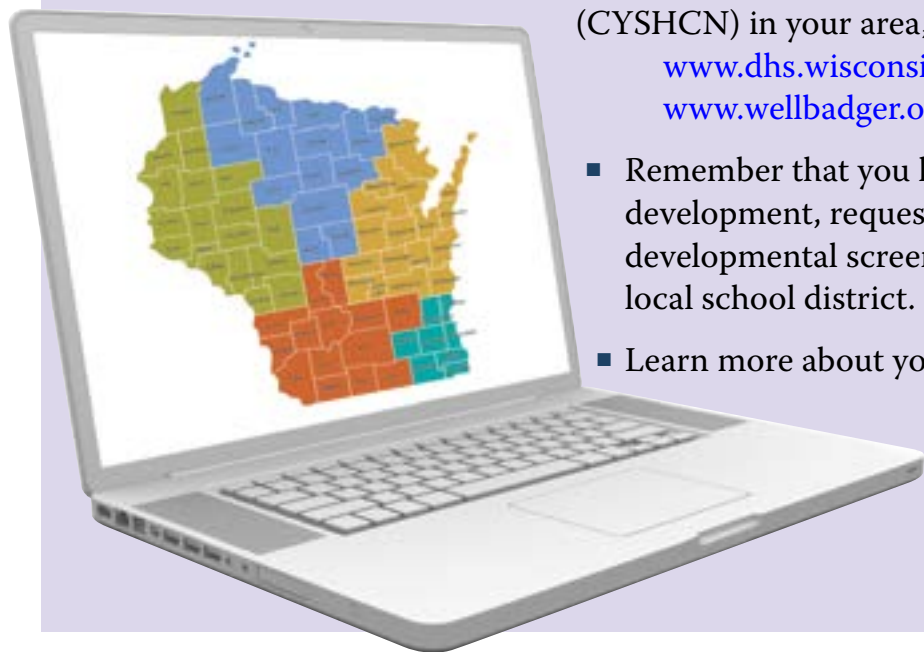
- ■ *The journey of having a child with a special health care need begins in many different ways. For some, the journey begins when their child is born, or even before. For others, it begins a bit later, when parents recognize delays in their child's development, health concerns appear and/or issues 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. Wherever your journey begins, there are many programs described in this Navigation Guide that can assist you in caring for your child with special needs. Think about what you would find most helpful. For some families, access to information and someone who can help them think things through can help. For others it might be talking with another family or group of families with similar experiences. Still others might need help paying for things their child and family needs. The tips below will get you started. While some suggestions may not match your family's immediate needs, others you may find very useful.

Begin with the Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) in your area, or the Well Badger Resource Center.

www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm
www.wellbadger.org

- Remember that you know your child best. If you have concerns about your child's development, request that their doctor (primary care provider) complete a developmental screening and 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 Parent to Parent of Wisconsin (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, the Children's Community Options Program (CCOP), or the Children's Long-Term Support (CLTS) Waiver Program.
- Keep moving forward and remember there are people available to help you.

WHERE TO ASK QUESTIONS

The Well Badger Resource Center offers health-related information and referral services to individuals, families, and professionals. Services are free, confidential, and available to anyone in Wisconsin. Well Badger specializes in referrals for children and youth with special health care needs, pregnant and postpartum women, and low-income families.

Well Badger Specialists are available Monday – Friday, 7 AM – 6 PM. To reach them:

- Call: 1-800-642-7837
- Text: 608-360-9328
- Email: help@wellbadger.org
- Facebook Messenger: www.facebook.com/wellbadger
- Live Chat: www.wellbadger.org
- You can also visit www.wellbadger.org to search an online directory of thousands of free/low-cost services and programs in Wisconsin.



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.

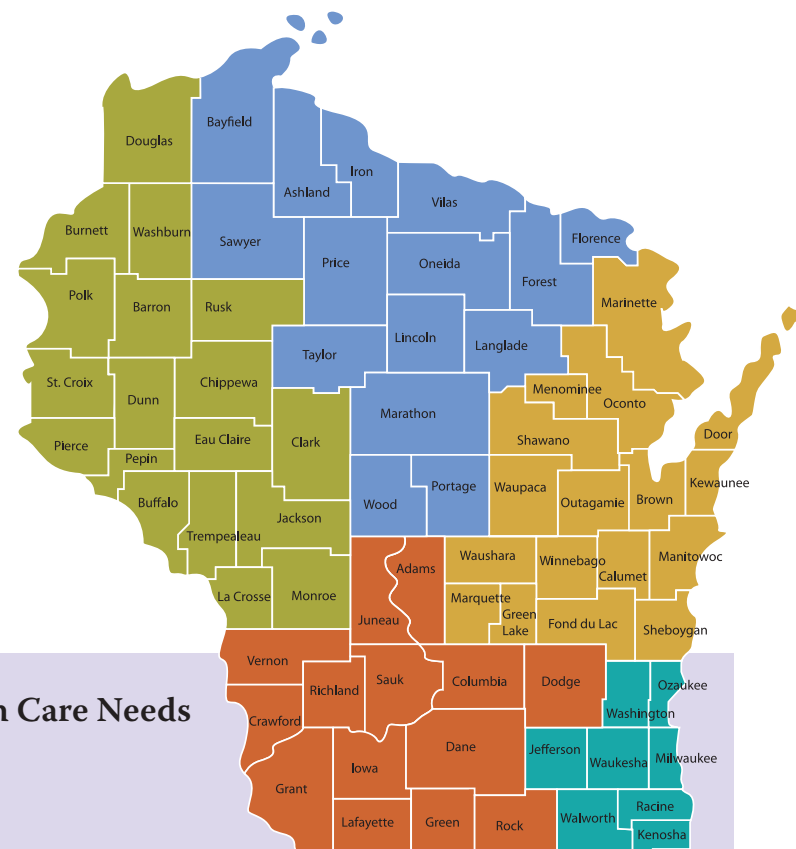
Each Regional Center is staffed during business hours by specialists who can help find answers, provide support in family leadership and advocacy, find services and connect you to community resources.

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

Aging and Disability Resource Centers (ADRCs) provide support to youth age 17 ½ and older and their family. Each county has an ADRC. 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



Wisconsin's five Regional Centers for Children and Youth with Special Health Care Needs

■ Southeast Regional Center
www.southeastregionalcenter.org
800-234-5437
Email: serc@chw.org

■ Northeast Regional Center
www.northeastregionalcenter.org
877-568-5205
Email: infonerc@chw.org

■ Southern Regional Center
cyshcn.waisman.wisc.edu
800-532-3321
Email: cyshcn@waisman.wisc.edu

■ Northern Regional Center
www.northernregionalcenter.org
866-640-4106
Email: specialneedsinfo@co.marathon.wi.us

■ Western Regional Center
www.co.chippewa.wi.us/government/public-health/children-with-special-health-care-needs
800-400-3678
Email: wrccyshcn@co.chippewa.wi.us



Image of ForwardHealth
Identification Card

ELIGIBILITY, ENROLLMENT AND ENTITLEMENT

If you are looking for help paying for things your child and family needs, here are two questions to consider:

Are there eligibility and enrollment criteria?

Most programs and services have criteria or guidelines for admitting a child into a program. To enroll in a program, you might have to fill out the right paperwork by a certain date. To be eligible for a program, you or your child may need to meet a certain level of disability or financial need.

What is an entitlement?

Some benefits or programs are legally required to provide supports and services to all eligible children. Eligible children are entitled to receive them.

The Birth to 3 Program and school special education programs are examples of this type of program.

Other programs, like the Children's Long-Term Support (CLTS) Waiver Program and the Children's Community Options Program (CCOP), are not required to serve all eligible children. These programs sometimes do not have enough money. They can have a "wait list" and will serve children once funding becomes available. Even programs that require all eligible children be served sometimes have a delay in services or a limited number of available providers.

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 if 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 from their primary care provider or from a Head Start/Early Head Start Program. Remember, noticing a child needs help early and having that child receive help 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:

- Well Badger Resource Center
800-642-7837 – ask for the Birth to 3 Program contact in your county.
www.wellbadger.org
- Birth to 3 (for children under age 3)
www.dhs.wisconsin.gov/birthto3/index.htm
- Early Childhood Special Education Programs (for children ages 3 to 6)
apps6.dpi.wi.gov/SchoolDirectory/Search/PublicDistrictsSearch – 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





LEARN MORE – DEVELOPMENTAL MONITORING AND SCREENING FOR DEVELOPMENTAL DELAYS



■ Developmental Monitoring--Tracking Your Child's Developmental Milestones

Act Early Wisconsin

actearly.wisc.edu

Center for Disease Control and Prevention (CDC) Milestone Moments Booklet

www.cdc.gov/ncbddd/actearly/milestones/index.html

CDC Milestone Moments Tracker App

www.cdc.gov/ncbddd/actearly/milestones-app.html

Developmental Monitoring and Screening

www.cdc.gov/ncbddd/childdevelopment/screening.html

■ Screening for Autism Spectrum Disorder (ASD)

CDC Screening Recommendations

www.cdc.gov/ncbddd/autism/screening.html

Modified Checklist for Autism in Toddlers (M-CHAT)

m-chat.org

About the Autism Diagnostic Observation Schedule (ADOS)

www.appliedbehavioranalysisprograms.com/faq/

[what-is-the-autism-diagnostic-observation-schedule/](http://www.appliedbehavioranalysisprograms.com/faq/what-is-the-autism-diagnostic-observation-schedule/)

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, their 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 CYSHCN 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. In addition, talking to other families who have a child with a similar disability or health condition may be helpful.



Online starting points include:

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

There are also diagnosis-specific organizations. Examples include:

- Autism Society
www.autism-society.org
- American Diabetes Association
www.diabetes.org/living-with-diabetes/recently-diagnosed
- Epilepsy Foundation
www.epilepsy.com/article/2013/2/newly-diagnosed-seizures-or-epilepsy-where-do-i-find-information



LEARN MORE

“Coordinating Your Child’s Health Care”

To learn more about a medical home and tools families can use to partner with their child’s providers to coordinate their child’s health care go to:

- familyvoiceswi.org/learn/coordinating-your-childs-health-care/

MEDICAL HOME

Your relationship with your primary care provider can be a “home base” which helps you think about all the needs of your child and family. This is sometimes called a *Medical Home*. It is a way to know what a primary care clinic can do and how you can work with your doctor.

You know that you have a Medical Home when your primary clinic:

- knows you and helps you with your child’s special needs
- listens to you and works with you as a partner
- helps plan your child’s care and helps connect you to community resources
- offers staff reachable when you need them and accepts your insurance
- helps with other visits and talks with other doctors and caregivers who work with your child
- works with your family to transition (move) to adult health care services when your child becomes an adult

For more information on Medical Home, go to:

- National Resource Center for Patient/Family-Centered Medical Home
medicalhomeinfo.aap.org/Pages/default.aspx
- Medical Home Portal
www.medicalhomeportal.org
- Wisconsin Medical Home Initiative
www.wismhi.org/initiatives/medical-home
- National Alliance to Advance Adolescent Health
www.thenationalalliance.org/adolescent

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
- med-peds – (Combined Internal Medicine and Pediatrics) physician
- nurse practitioner – a registered nurse who can perform examinations, deliver a diagnosis, write prescriptions and provide referrals
- physician assistant – a medical professional who can perform examinations, deliver a diagnoses, write prescriptions and provide referrals

Your child's primary care provider will see your child for well-child visits, give immunizations and is the first one you should consult for diagnosis and treatment of health concerns and developmental delays. The primary care provider can conduct developmental screenings to check whether your child is learning and moving as other children their 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 specialists on the following web site:

www.health.harvard.edu/staying-healthy/specialists

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 check out:

- Your CYSHCN Regional Center or Well Badger Resource Center– they cannot recommend a doctor, but can share other families' experiences and give you a list of options
- A diagnosis-specific organization such as the Down Syndrome Association of Wisconsin (www.dsaw.org or 414-327-3729) or Spina Bifida Wisconsin (www.sbwis.org or 414-607-9061)
- A "Medical Home" – *What Should I Expect From My Doctor* (A Family Voices of Wisconsin Fact Sheet) familyvoiceswi.org/resource-library/a-medical-home-what-should-i-expect-from-my-doctor-2
- WI Department of Health Services: Finding and Choosing a Doctor www.dhs.wisconsin.gov/guide/doctor.htm





LOCAL PUBLIC HEALTH DEPARTMENTS

Your county's local public health department may be a good resource for your family. Services vary by county, but may include immunization clinics and information on health care services. Find out what services and resources your county's local public health department can offer you at:

www.dhs.wisconsin.gov/lh-depts/counties.htm

CLINICS FOR THE UNINSURED OR UNDER-INSURED

Families who do not have private health insurance or public benefits (such as BadgerCare Plus or Medicaid) or do not have a regular source of health care may not have a primary care provider. There are clinics and programs in Wisconsin that see families without insurance and/or who have low income. There are many free clinics, Federally Qualified Health Centers, Rural Health Centers, and Tribal Health Centers; any of which may become your Medical Home and help you find a primary care provider. They may also be able to help you and your family explore options to better connect with health insurance coverage.

A list of clinics, services and other resources can be found at:

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

www.dhs.wisconsin.gov/guide/special-cond.htm

- Well Badger Resource Center

www.wellbadger.org

1-800-642-7837

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.

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

- 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/reduced-rate-dental-clinics



LEARN MORE

- Dental Toolkit for Children with Autism
www.autismspeaks.org/tool-kit/dental-tool-kit
- Access Community Health Centers - Dental
accesscommunityhealthcenters.org/services/dental/



DEFINITION

What is **Mental Health**?

“Mental health is not just the absence of mental disorders. It is defined as a state of well-being in which every individual realizes their own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to their community.”

Source: Mental Health: strengthening our response www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

MENTAL HEALTH

When your child is struggling with their mental health, you may have 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, ongoing treatment at school or in the community may be recommended. To learn more about diagnosis, treatment and support for children mental health challenges, go to:

- National Federation of Families for Children's Mental Health
www.ffcmh.org
- National Institute of Mental Health
www.nimh.nih.gov/health/topics/index.shtml

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

- Wisconsin Family Ties
800-422-7145
www.wifamilyties.org
- National Alliance on Mental Illness (NAMI) Wisconsin
800-236-2988
namiwisconsin.org
- Parent to Parent
833-361-6300
www.p2pwi.org
- Mental Health America of Wisconsin
866-948-6483
www.mhawisconsin.org
- WI Office of Children's Mental Health
children.wi.gov/pages/home.aspx
- Well Badger Resource Center
800-642-7837
www.wellbadger.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 is right for your child. Families should avoid options that might not be needed, could be harmful or could be a waste of money. You may want to research, talk with your primary care provider and check with your insurance coverage before you agree to some options.

Sources of information are:

- Consumer Guide to Health Care
www.dhs.wisconsin.gov/guide/index.htm
- A Guide to Quackery, Health Fraud, and Intelligent Decisions
www.quackwatch.com

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

- Does my insurance cover this?
- 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.

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 and pharmacist about any drug allergies your child has, other medications your child is taking, (including vitamins and other supplements), and any special diets your child may be trying.

For information on prescription drugs:

- Prescribers' Digital Reference
www.pdr.net/browse-by-drug-name

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.healthline.com/health/speech-therapy
- What is occupational therapy?
www.uwhealth.org/health/topic/special/occupational-therapy/tp23082spec.html
- What is physical therapy?
www.uwhealth.org/health/topic/special/physical-therapy/zt1045.html

School services are designed to help students learn in school. Parents may want to consider seeking additional therapies outside of the collaborative consultative services provided in public schools if they feel the needs extend beyond the school setting. To learn more about schools and collaborative consultative with speech, occupational and physical therapies:

Wisconsin Department of Public Instruction

School Based Speech Therapy: dpi.wi.gov/sped/program/speech-language

School Based Occupational Therapy: dpi.wi.gov/sped/educators/consultation/occupational-therapy

School Based Physical Therapy: dpi.wi.gov/sped/educators/consultation/physical-therapy



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.

DEFINITION



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/applied-behavior-analysis-aba-0

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/

Children with a diagnosis of Autism Spectrum Disorder (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 CYSHCN 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/more_information/resources
- Autism Speaks
www.autismspeaks.org/applied-behavior-analysis-aba-0

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. You may be able to “borrow” a device from your Independent Living Center.

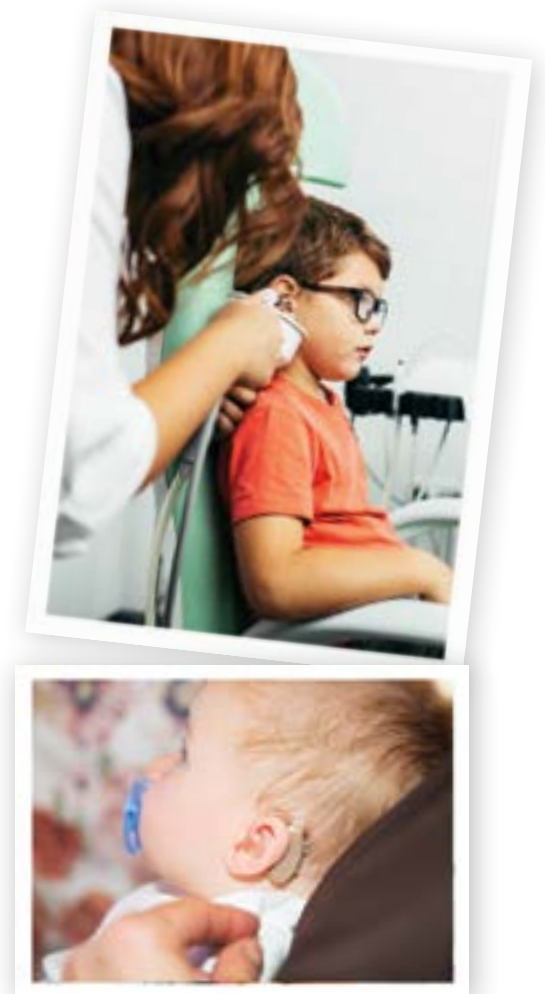
More information on Assistive Technology is available from:

- Wisconsin’s Assistive Technology Program
www.dhs.wisconsin.gov/disabilities/wistech/index.htm
- Independent Living Centers in Wisconsin
www.dhs.wisconsin.gov/disabilities/physical/ilcs.htm
- WisTech Assistive Technology Program
www.wisconsinat4all.com
- Assistive Technology Lending Center (for schools)
www.atclibrary.org
- Wisconsin Assistive Technology Initiative (for schools)
www.wati.org
- Abledata: database of assistive technology products
health.gov/node/114

Complementary Health Approaches

Complementary Health Approaches refer to the use of non-mainstream approaches together with conventional medical 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 therapies you are considering for your child. For more in-depth information, go to:

- National Institutes of Health, National Center for Complementary and Integrative Health
www.nccih.nih.gov/health/be-an-informed-consumer



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 to get to know other families who have children with similar health issues. Hospitals, clinics and family resource centers sometimes host parent support groups. Contact your CYSHCN Regional Center to find out if there are support groups meeting in your area. Below are some family-to-family organizations that can help:

- Parent to Parent of Wisconsin is a statewide network of families who support each other on the journey of parenting children with special needs by providing a one-to-one connection with another parent who has a similar experience. Trainings are provided for parents who feel ready to become Support Parents.
833-361-6300
p2pwi.org
- Family Voices of Wisconsin provides information, training and leadership opportunities so that families can be informed and effective partners in their child's care and in influencing the systems that support them.
608-220-9598
familyvoiceswi.org

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

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:

- school-based programs
- clinic or hospital based programs
- state or county administered programs



FAMILIES HELPING FAMILIES (CONTINUED)

Wisconsin Family Ties is a statewide, parent-run nonprofit serving families that include children with social, emotional and behavioral needs. Wisconsin Family Ties provides advocacy, information, training, and support for families and professionals through parent peer specialists who are available throughout the state.

www.wifamilyties.org

800-422-7145

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 Greater Wisconsin (ASGW)
888-428-8476
www.autismgreaterwi.org and Get Started (go here to find your local affiliate)
- Down Syndrome Association of Wisconsin (DSAW)
866-327-DSAW
www.dsaw.org
- Epilepsy Foundation
800-693-2287
www.epilepsywisconsin.org
- Muscular Dystrophy Association (MDA)
800-572-1717
www.mda.org/services/supportgroup



LEARN MORE

Families with children who are deaf/hard of hearing/deafplus:

- | | |
|---|---|
| <ul style="list-style-type: none">■ Under three years old--Wisconsin Sound Beginnings Parents Reaching Out
608-577-3895 (Voice/Text/Facetime) | <ul style="list-style-type: none">■ Three years and older--WESP Parent Mentor Program
262-728-7112
wesp-dhh.wi.gov |
|---|---|

There are also organizations that support families who care for children with and without special needs.

Examples include:

- Family Resource Centers
preventionboard.wi.gov/Pages/ForFamilies/FamilyResourceCenters.aspx
- Grandparenting Today
fyi.extension.wisc.edu/grandparenting

TIME FOR YOURSELF AND YOUR RELATIONSHIPS

Having a child with special needs can take a lot of time and energy and have an impact on the whole family. Remember, in order to take the best care of your child, you need to take time for yourself!

Taking time for your spouse, your partner, your other children and friends is also important. Carving out time to get away (e.g., taking a walk or going to see a movie) can create balance in your life and positively impact your ability to care for those you love. Information on caring for yourself as a caregiver can be found at:

- Family Caregiver
800-445-8106
www.caregiver.org/taking-care-you-self-care-family-caregivers

SIBLINGS

Siblings of children with special needs sometimes need additional support. There are groups that can connect siblings to siblings from different families and to helpful information.

WisconSibs

920-968-1742

Email: info@WisconSibs.org
WisconSibs.org

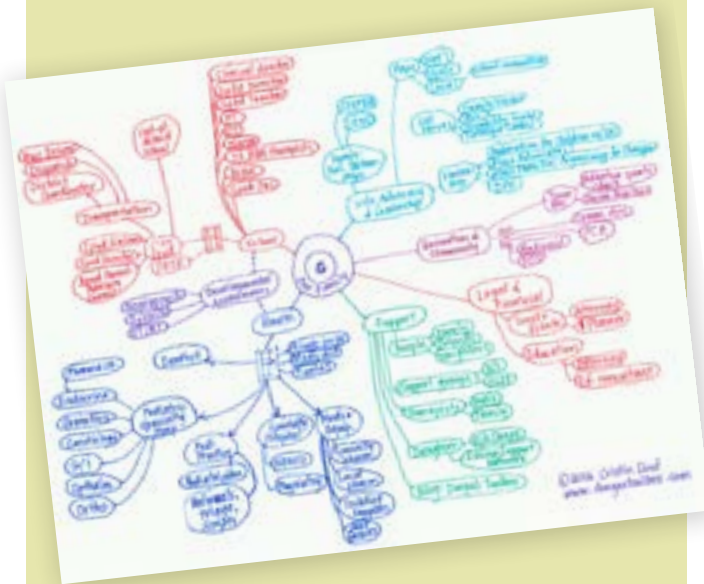


DEFINITION

What is Care Coordination?

“Care coordination is a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.”

*American Academy of Pediatrics Policy Statement
November 2005*



SERVICE AND CARE COORDINATION

Some programs provide care coordination. In these programs, a case manager or service coordinator will assist you to identify and connect with community supports. Examples include the Birth to 3 and the Children’s Long-Term Support (CLTS) Waiver programs. Your child’s doctor or other clinic staff may also assist your family in coordinating your child’s services and supports.

While some families have this type of help, it is common for parents to provide care coordination for their own child. This can be an intimidating and overwhelming experience for families; however, resources exist to help minimize these feelings.

One way to stay organized is to start a care notebook. A care notebook is a system for organizing medical, school and other records, appointments, providers and notes.

An example of a care notebook is available at:

- medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx

Some families find it helpful to prioritize their next steps or goals. The GPS (Getting Parents Started) Form in Appendix A is a simple tool to help families work on their goals.

CARE MAPPING

Care Mapping is a family-centered process that visualizes a family’s strengths and communicates both the big picture and the small details of all the resources needed to support a child and their family. Your CYSHCN Regional Center offers trainings on the importance of creating a care map for your family and on “how-to” create a care map.

To find your Regional Center:

- www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm

CONFERENCES AND TRAININGS

We all help ourselves by learning more. Conferences and trainings allow you to meet other families and provide an opportunity to learn new information that can help your child. Several of these organizations offer scholarships or provide trainings at no cost to participants. There are several good online resources to keep families updated on trainings and other learning opportunities. One example is the monthly Family Engagement Newsletter.

For the latest issue go to:

- servingongroups.org/resources

Below are some examples of conferences and training opportunities:

- **Waisman Center Days with the Experts** are six annual educational events focused on autism, cerebral palsy, cochlear implants, Down syndrome, Augmentative and Alternative Communication (AAC), and Fragile X syndrome that feature advances in research, clinical services and self-advocate/family panels.
www.waisman.wisc.edu/outreach/waisman-center-day-with-experts/
- **Autism Society of Greater Wisconsin (ASGW)** has an annual statewide conference and local affiliates have workshops and training for parents and families.
www.autismgreaterwi.org/conferences
- The **Circles of Life Conference** is for families of children with disabilities and special health care needs and the professionals who support them.
www.circlesoflifeconference.com
- **Did You Know? Now You Know!** trainings from Family Voices of Wisconsin and the CYSHCN Regional Centers provide information on how to navigate health care and community supports.
www.familyvoiceswi.org/learn
- **Children Come First Conference** is an annual conference for families and providers caring for or working with children with mental, emotional or behavioral needs.
www.ccfconference.org





WHERE FAMILIES CAN LEARN MORE

- Waisman Center is a University Center for Excellence in Developmental Disabilities and includes the Southern Regional Center for CYSHCN for families and providers.
800-532-3321 or cyshcn.waisman.wisc.edu
- Wisconsin Board for People with Developmental Disabilities advocates for the independence and inclusion of people with developmental disabilities. To learn about the Board's legislative and state budget priorities, grant opportunities and their advocacy network:
608-266-7826 or wi-bpdd.org
- Wisconsin Family Assistance Center for Education, Training and Support (WI FACETS) holds both in-person and telephone trainings for families about a variety of educational issues.
www.wifacets.org/training

LEADERSHIP TRAINING

Leadership training can help you get more involved in your community and can assist you to become a more effective advocate for your child and other children as well. Some leadership training opportunities in Wisconsin include:

- Parents in Partnership (for parents of children ages 6 to 21).
www.wspei.org/families/pip.php
- Youth in Partnership with Parents for Empowerment (for youth together with their parents).
www.wspei.org/families/yippe.php
- Partners in Policymaking (a multiple weekend training for individuals with disabilities and parents who have children up to age 21).
wi-bpdd.org/index.php/partners-in-policymaking/
- Advocacy for Change is a one-day advocacy skills and strategies training for parents/family members.
www.familyvoiceswi.org/advocacy-for-change



RESPITE CARE

Respite is a service which provides relief from caregiving responsibilities. In most cases families will either have to pay for the services or have another source of funding, which could include the Children's Community Options Program (CCOP) or Children's Long-Term Support (CLTS) Waiver.

For information about respite care in Wisconsin, contact:

- County Contact Information for Programs for Children with Delays and Disabilities

www.dhs.wisconsin.gov/clts/contact.htm

Respite Care Association of Wisconsin has funding/caregiving grants if you are waiting for county funds or don't qualify for county funding. They also provide a searchable database to help locate respite and on-line training for family or friends to learn how to provide respite.

- respitecarewi.org

There is also a Medicaid benefit called personal care services. For an eligible child, this service includes a person who comes to the family home and can help with daily chores, such as bathing, dressing, toileting, and feeding. Some families experience this help as a break or respite from caregiving.

- *Medicaid Personal Care Services* (A Family Voices of Wisconsin Fact Sheet)
familyvoiceswi.org/resource-library/medicaid-personal-care-services/

DEFINITION



What is Respite Care?

"Respite is temporary relief for caregivers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses..."

Respite Care Association of Wisconsin



RECREATION/COMMUNITY ACTIVITIES

Participating in recreational and other community activities is important for all children, including children with special needs. While your child may need extra support to take part in an activity, most schools and other sponsoring organizations can work with you to find ways for your child to fully participate.

Examples include:

- play groups
- faith-based groups and activities
- scouts
- clubs and sports at school
- YMCA

There are camps, community programs and activities that are specifically set up for children with special needs. Your CYSHCN Regional Center can provide contact information for programs in your community.

Some examples include:

- Special Olympics
800-552-1324
www.specialolympicswisconsin.org
- Easter Seals Wisconsin
800-422-2324
www.eastersealswisconsin.com

LEGAL ASSISTANCE

Legal questions may come up as you consider care and services for your child. Sometimes your health care benefits or the rights of your child may be unclear and getting legal help may be necessary. Below are organizations available to assist you. There may be a fee associated with this assistance.

- ABC for Health (Advocacy and Benefits Counseling for Health) is a public interest law firm dedicated to ensuring health care access for children and families, particularly those with special needs. They can provide health benefits counseling on health coverage and benefits, and in certain situations, legal representation to families experiencing low income.
800-585-4222
www.safetyweb.org
- Disability Rights Wisconsin is a private non-profit organization that defends the rights of individuals with disabilities throughout the state.
800-928-8778
www.disabilityrightswi.org
- Wisconsin Judicare is a law firm that provides legal assistance to individuals, including those with low income, living in northern Wisconsin and those who are members of the 11 federally recognized Native American tribes.
800-472-1638
www.judicare.org
- Legal Action of Wisconsin is a law firm that provides legal services, through staff and volunteer attorneys, to families having low income. They serve 39 southern Wisconsin counties in the areas of housing, consumer, family, public benefits and drivers' licenses and expungement law.
855-947-2529
www.legalaction.org

Learning About Education

- ■ *Children and youth with special health care needs often require educational support. Some children may need only minimal support for a short period of time and others may need ongoing and/or extensive educational support. Regardless of the frequency or duration of the support, every child and youth has the right to a free, appropriate public education. (This is referred to as FAPE).*

Education for children with disabilities, from birth to age 21, is guided by a U.S. law called the Individuals with Disabilities Education Act (IDEA). Wisconsin also has state statutes that guide special education.

CHILDREN UNDER THREE

Before age three, education for a child with developmental delays is called early intervention. Wisconsin's early intervention program is referred to as the Birth to 3 Program.

The Birth to 3 Program evaluates children with developmental concerns. If the evaluation identifies your child as having a 25% delay in one or more developmental areas, he or she is eligible for the Birth to 3 Program. A child can also be eligible for the Birth to 3 Program based on a diagnosed disability.

All eligible children and families are entitled to receive Birth to 3 Program services regardless of their income. Families determined to have an "ability to pay" through the Parental Cost Share System pay an annual amount to help cover the cost of their child's services while participating in the Birth to 3 Program.





CHILDREN UNDER THREE (CONTINUED)

A service coordinator will work with your family to develop an Individualized Family Service Plan (IFSP) based on your child's strengths and needs. The Birth to 3 Program team, including parents and providers, will determine supports and services to meet the goals on the IFSP. Families receive services that address all areas of a child's development including education and therapy services. All services and supports are provided where your child typically spends their day. This may include a child care setting, the child's home, foster home, Head Start, etc.

Upon turning three, a child is no longer eligible for the Birth to 3 Program. Some children may be eligible for Early Childhood Special Education and will be referred to their local school district.

The following can provide more information on early intervention services:

- Facts About the Birth to 3 Program
www.dhs.wisconsin.gov/birthto3/index.htm
- Birth to 3 in your county
www.dhs.wisconsin.gov/birthto3/contacts/primarycontact.htm

CHILD FIND

"Child Find is a continuous process of public awareness activities, screening and evaluation designed to locate, identify, and refer as early as possible all young children with disabilities and their families who are in need of an Early Intervention Program (Part C) or Early Childhood Special Education (Part B) services of the Individuals with Disabilities Education Act (IDEA)." In Wisconsin we use an Informed Referral Network.

dpi.wi.gov/sped/early-childhood/child-find

INCLUSIVE CHILD CARE

Finding high quality child care and having access to respite care can be essential for the health and well-being of your child and for your entire family.

Child care that is provided for children with and without special needs is called inclusive child care. By law, licensed child care providers in Wisconsin must make “reasonable accommodations” for children with disabilities. In reality, some child care providers are more prepared than others to take care of children with special needs. In certain circumstances, funding is available to help pay for the additional costs of childcare for a child with special health care needs. Here are some resources for finding inclusive child care, and for working with child care providers to create inclusive care:

- YoungStar searchable database to find childcare
dcf.wisconsin.gov/youngstar
- YoungStar Early Childhood Inclusion
dcf.wisconsin.gov/youngstar/eci
- *Together Children Grow*
dcf.wisconsin.gov/files/ccic/pdf/together-children-grow.pdf
- Supporting Families Together Association (SFTA)
www.supportingfamielstoegether.org
- *Inclusive Child Care for Children with Disabilities* (A Family Voices of Wisconsin Fact Sheet)
familyvoiceswi.org/resource-library/finding-quality-child-care-for-a-child-with-special-needs/



CHILDREN THREE AND OLDER

Children with disabilities may qualify for special education and related services from the public school system. These services are detailed in the student's Individualized Education Program (IEP). Public schools must follow U.S. and state laws to decide whether a child has a disability that qualifies for special education.

For more information and an explanation of disability categories:

- Special Education Eligibility
dpi.wi.gov/sped/laws-procedures-bulletins/laws/eligibility

School districts provide Early Childhood Special Education to children age three to five years with disabilities in a wide variety of settings, including preschools, Head Start Programs or in a child's home. Starting at age six, eligible children will receive special education at their local school.

Schools are responsible for identifying children with disabilities living in their school district. Professionals such as doctors, teachers, and social workers should let the school know if they think a child has a disability. Parents should contact the school in writing if they think their child has a disability. The school must then evaluate the child to determine whether the child meets special education eligibility criteria. For more information, contact your local school district or the Department of Public Instruction.

- Finding your Local School District
www.dpi.wi.gov/directories
- Department of Public Instruction
800-441-4563
www.dpi.wi.gov





CHILDREN THREE AND OLDER (CONTINUED)

The services that a child needs for their education are written each year in a plan called an Individualized Education Program (IEP). The team that writes the IEP includes parents, teachers, therapists and school administrators. Children are encouraged to participate in their IEP meetings. An IEP is a plan that: identifies a student's educational needs, contains learning based goals based on the student's needs, and describes the services a student will receive in order to progress toward learning goals.

dpi.wi.gov/sped/college-and-career-ready-ieps



CHILDREN THREE AND OLDER – LEARN MORE

- An Introduction to Special Education
dpi.wi.gov/sites/default/files/imce/families-students/intro-se.pdf
- Special Education in Plain Language
www.wsems.us/special-education-in-plain-language/introduction

504 PLANS

Some students with special health care needs are best supported with a 504 Plan, especially if they have been found not to qualify for an Individualized Education Program (IEP). This support is guided by Section 504 of a US law called the Rehabilitation Act of 1973.

A 504 plan is a written plan that describes what the school will do for the student in order to meet individual medical, physical, or emotional needs. Any student who has an IEP automatically has Section 504 protections.

A 504 plan might include services like:

- tutoring
- reduced homework
- extra test-taking time
- other accommodations or services



The Department of Education Office of Civil Rights (OCR) is responsible for enforcement of Section 504.

For more information:

- Frequently Asked Questions about Section 504
www2.ed.gov/about/offices/list/ocr/504faq.html
- The OCR office for Wisconsin is located in Chicago
312-730-1560
Email: OCR.Chicago@ed.gov

PRIVATE SCHOOLS

Parents sometimes choose to send their children with special needs to private school and pay the tuition cost themselves. Keep in mind that private schools can choose the students who attend the school and may not be required to follow IDEA or provide special education services.

The following bulletin from DPI can provide more information:

- Wisconsin Department of Public Instruction – *Information Update Bulletin: Parentally Placed Private School Children with Disabilities* dpi.wi.gov/sped/laws-procedures-bulletins/bulletins/06-03

HOME SCHOOLING

Some families choose to teach their children at home instead of sending them to school. Families who homeschool in Wisconsin must file a form with the Department of Public Instruction.

- Wisconsin Homeschooling Parents Association www.homeschooling-wpa.org Telephone 608-283-3131
- Department of Public Instruction Home-Based Private Education Program (Homeschooling) dpi.wi.gov/sms/home-based

OTHER PUBLIC SCHOOL OPTIONS

The Wisconsin Center for the Blind and Visually Impaired (WCBVI) is located in Janesville, WI. Services include the Wisconsin School for the Blind and Visually Impaired as well as statewide outreach services.

The Wisconsin Educational Service Program for the Deaf and Hard of Hearing (WESP-DHH) is located in Delevan, WI. Services include the Wisconsin School for the Deaf (WSD) statewide outreach services.

- To learn more about WSBVI: www.wcbvi.k12.i.us/school
- To learn more about placement options available to IEP teams: dpi.wi.gov/sped/laws-procedures-bulletins/bulletins/11-01
- To learn more about statewide WCBVI Outreach Services: www.wcbvi.k12.wi.us/outreach/ Telephone: 1-800-832-9784
- To learn more about WESP-DHH: wesp-dhh.wi.gov
- To learn more about WSD: wesp-dhh.wi.gov/wsd
- To learn more about outreach services: wesp-dhh.wi.gov/outreach/

There may be other placement options. **Contact your IEP team to discuss what options might be available to you and your child.**

SPECIAL EDUCATION HELP FOR FAMILIES

There are two primary organizations in Wisconsin that work with families and special education:

- Wisconsin Family Assistance Center for Education, Training and Support (WI FACETS) is a statewide organization that supports families and others with training, information and referral, and individual assistance related to children with disabilities.
877-374-0511
www.wifacets.org
- The Wisconsin Statewide Parent-Educator Initiative (WSPEI) is an organization that provides services for parents, educators, and others interested in parent-educator partnerships for children with disabilities. WSPEI coordinators are located in each of Wisconsin's 12 Cooperative Educational Service Agencies (CESA). WSPEI strives to develop strong relationships and build effective partnerships with families and schools.
833-879-7734
www.wspei.org



COOPERATIVE EDUCATIONAL SERVICE AGENCY (CESA)

Help and assistance can also be found through your CESA. CESAs act as the link between school districts and the state. CESAs facilitate communication and cooperation among public and private schools, agencies, and organizations that provide services to students.

To find the CESA in your area go to:

- CESA Directory
608-266-3584
dpi.wi.gov/cesa



Paying For What You Need

- ■ *It's important to find out what services and supports can best meet your child's needs. Figuring out how to pay for services can be a big question as well.*

PRIVATE HEALTH INSURANCE

Many families have private health insurance, often through an employer. Private health insurance plans can be very different from one another in terms of:

- what conditions and treatments are included
- how much the plan will pay
- co-pays (how much you have to pay yourself for each appointment or treatment)

To learn what your plan covers, how much you are expected to pay and to get a copy of your benefit plan, you will need to call your insurance carrier.

Private insurance must follow certain U.S. and state laws. The Wisconsin Office of the Commissioner of Insurance (OCI) monitors and enforces state insurance laws and can answer your questions about how these laws impact private health plans.

OCI has developed WisCovered.com to help Wisconsin residents learn about health insurance options and connect to experts who can assist in finding quality, affordable health coverage, as well as file insurance complaints. Contact OCI at:

- wiscovered.com



PRIVATE HEALTH INSURANCE – LEARN MORE

- Need help navigating the healthcare financing system (private and public health insurance)? Contact ABC for Health at 800-261-6939 or www.safetyweb.org



PRIVATE HEALTH INSURANCE (CONTINUED)

During 2009 and 2010, changes in state law had an impact on Wisconsin-based private insurance coverage for children with special health care needs. This includes mandatory coverage for intensive therapy for autism, and cochlear implants. It also extended the age up to which a son or daughter may be covered on their parent's insurance plan to age 26.

The following provides more information on these changes:

- OCI Frequently Asked Questions on Mandated Coverage of Autism Services
oci.wi.gov/Documents/Consumers/PI-234.pdf

Affordable Care Act (ACA)

The ACA is a federal resource that provides a Marketplace to purchase affordable health insurance coverage for a family or individual.

Wisconsin Resources:

- Covering Wisconsin
www.coveringwi.org
- Kids Forward
kidsforward.org

National Resources:

- HealthCare.gov
www.healthcare.gov
or call 800-318-2596



PUBLIC HEALTH CARE COVERAGE

Katie Beckett Program

The Katie Beckett Program uses a special eligibility process to allow certain children with long term disabilities or complex medical needs to receive Wisconsin Medicaid. Children who are not eligible for other Medicaid programs because the income of their parents is too high may be eligible for Medicaid through the Katie Beckett Program.

- Katie Beckett Program
www.dhs.wisconsin.gov/kbp/index.htm
- *What is the Katie Beckett Program?*
(A Family Voices of Wisconsin Fact Sheet)
www.familyvoiceswi.org/resource-library/what-is-the-katie-beckett-program

HealthCheck Other Services

HealthCheck Other Services (HCOS) is a source of Medicaid reimbursement for children under age 21 who already qualify for Medicaid. HCOS may cover medically necessary goods and services not typically covered by Medicaid, such as over the counter medication. For more information, contact Well Badger Resource Center or contact your CYSHCN Regional Center.

- *What is HealthCheck “Other Services” (HCOS)?*
(A Family Voices of Wisconsin Fact Sheet)
www.familyvoiceswi.org/resources-library/medicaid-healthcheck-other-services
- HealthCheck: Preventive Health Care for Children and Young Adults Through Age 20
www.dhs.wisconsin.gov/forwardhealth/healthcheck.htm



Health Coverage Help:

- ACCESS – a quick and easy way to see if you might qualify for Wisconsin's health, nutrition and other programs.
www.access.wisconsin.gov
- ABC for Health – provides health benefits counseling and limited legal services to help families navigate health coverage options and overturn inappropriate denials of eligibility and covered services.
800-261-6939
www.safetyweb.org

Saving for the Future:

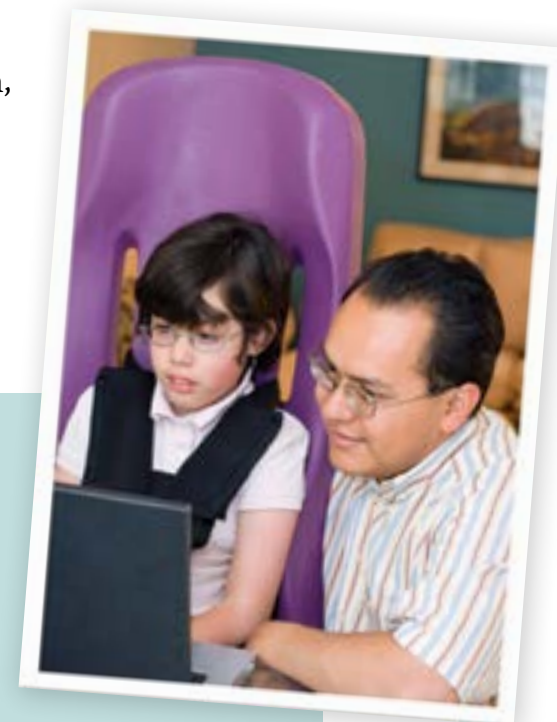
Families want to be able to care for their children now and in the future. There are some special tools available to help.

- Achieving a Better Life Experience (ABLE) Accounts
www.revenue.wi.gov/Pages/FAQS/ise-ABLEAccounts.aspx
- Special Needs Trusts
www.snp-llc.com/special-needs-trust

PUBLIC HEALTH CARE COVERAGE (CONTINUED)

Wisconsin Medicaid/ForwardHealth

Wisconsin Medicaid is funded by both the federal government and the state of Wisconsin, Department of Health Services (DHS). It provides high-quality health care coverage, long-term care, and other services to Wisconsin residents and has a set of benefits associated with it. In Wisconsin, the program is also referred to as: BadgerCare Plus, Medical Assistance (MA), Title XIX and/or Title 19. Medicaid eligibility can be based on the family's income and/or the child's level of disability.



BadgerCare Plus

The BadgerCare Plus program offers assistance to families and individuals with low income. A person does not need to have a disability to be covered by BadgerCare Plus. Eligibility is based on family size and income.

To learn more:

- Covering Wisconsin
www.coveringwi.org
- ForwardHealth
www.dhs.wisconsin.gov/forwardhealth/index.htm

To learn more about and apply for public benefits: access.wisconsin.gov/access

Medicaid may cover services or products that private insurance does not cover. Some examples include diapers for children age four or older and home health care like personal care services.

In some families, a child is covered both by private health insurance and by Medicaid. If your child is covered by both, private insurance will always be billed first. If private insurance does not pay, then Medicaid may be billed or Medicaid may pay your deductible or any remaining charges.

CHILDREN'S LONG-TERM SUPPORT (CLTS) WAIVER AND OTHER PROGRAMS

The Children's Long-Term Support (CLTS) Waiver Program provides funding and support for families who have children with disabilities, who are Medicaid eligible, so they can care for their children at home and participate in their communities.

To learn more, go to:

- Children's Long-Term Support Waivers
www.dhs.wisconsin.gov/children/clts/waiver/family/index.htm
- *What is the Children's Long-Term Support (CLTS) Waiver Program?*
(A Family Voices of Wisconsin Fact Sheet)
familyvoiceswi.org/resource-library/introduction-and-overview/

Children's Community Options Program (CCOP)

The Children's Community Options Program (CCOP) is a state program administered at the county level that offers services and supports to families of children with severe disabilities. The program provides a case manager who helps connect a family with information and resources.

CCOP can be used when individuals are eligible for CCOP but not CLTS and as a complement to services provided under CLTS. CCOP funding can be more flexible and may be used to pay for goods and services not allowed under the waiver. Eligibility for CCOP is based on age, level of care from the CLTS functional screen, and allowable setting.

For information on eligibility and contacts:

- www.dhs.wisconsin.gov/ccop

Comprehensive Community Services (CCS)

The CCS program helps individuals live their life by providing supports that address their unique needs related to mental health and substance abuse.

For information on eligibility and contacts:

- www.dhs.wisconsin.gov/ccs/index.htm



SOCIAL SECURITY BENEFITS

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



- 800-772-1213
www.dhs.wisconsin.gov/ssi
- *Supplemental Security Income (SSI) and Children with Disabilities*
(A Family Voices of Wisconsin Fact Sheet)
www.familyvoiceswi.org/resource-library/supplemental-security-income-ssi-and-children-with-disabilities

If the child (with or without a disability) has a parent who is retired or disabled and receiving Social Security, or is deceased, they may be eligible for survivor benefits. These benefits are based on the parent's work record until the child turns 18, or 19, if still in school.

- 800-772-1213
www.ssa.gov/planners/survivors/ifyou.html

The Social Security Disability Insurance (SSDI) program pays benefits to adults who have a disability that began before they became 22 years old. We consider this SSDI benefit as a “child” benefit because it's paid on a parent's Social Security earnings record.

- www.ssa.gov/ssi/text-child-ussi.htm
- www.ssa.gov/pubs/EN-05-10026.pdf



Community Resources

Your CYSHCN Regional Center may be able to help you find other ways to pay for what your child needs, other than the statewide programs listed above. Organizations in your community might have ways to help. Examples include:

- civic groups like Elks, Lions Club or Kiwanis
- charitable groups like the Children's Miracle Network
- faith-based groups
- grants
- equipment lending agencies

Transition to Adulthood

SCHOOLS

- ■ *The purpose of school-based transition planning is to assist students and their families for life after high school. In Wisconsin, students with disabilities turning 14 years of age are required to have a Postsecondary Transition Plan (PTP). The student must be invited to their IEP meeting at this time, and the IEP team develops the transition plan together. It is important for the student to take the lead as much as possible in their IEP meetings. All IEPs are designed to help the student become college and career ready (CCR IEP).*



The transition plan must include measurable postsecondary goals written for when the student exits high school. This applies to the areas of employment (ie., working full or part-time), education/training (ie., attending college, a short-term certificate program, receiving on the job training) and when appropriate, independent living (ie., caring for one's own health and medical needs, living away from home and finding recreational opportunities). To decide these goals, transition assessments are conducted on an ongoing basis to explore the student's strengths and needs. This is also a time when families and the student need to start thinking about the age of consent. When the student turns 18, they will have more legal rights, so exploring options such as Supported Decision-Making and/or guardianship prior to age 18 is important.

Once the goals are decided, the IEP team will plan transition services and activities the student will participate in while in high school. The team will also help the student choose classes that will help them reach their goals. To assist with meeting these goals, adult agencies are often invited to provide additional support.

A student with a disability has the right to attend school until they graduate with a regular diploma or until the age of 21. If a student, with their family, decide to stay in school until age 21, the school district is responsible for providing transition programming like vocational skills, life skills training and other community programming. The programming will likely be provided outside of the school building. The following resources can assist a family with the transition process:

- WiTransition App
witig.org/self-advocacy-tools/witransition-app/
- Wisconsin Transition Improvement Grant
www.witig.org
- Department of Public Instruction
transition services for students with disabilities
dpi.wi.gov/sped/topics/transition

HEALTH CARE

Moving from pediatrics into the adult health care system is called Health Care Transition (HCT). HCT can involve finding new doctors, going to a new hospital, deciding who makes decisions, learning how to stay healthy, using the health care system and so much more. Starting at age 12, youth and families can stay a step ahead by filling out a transition readiness assessment and by building skills needed to be successful in the adult health care system. Families need to be aware that changes in privacy and the ability to consent to some treatments may start as early as 12 years old. Find more resources:

- Health Transition Wisconsin: Supporting Youth to Adult Health Care Transition
healthtransitionwi.org
- Got Transition
gottransition.org
- Your Regional Center offers trainings for families as they prepare for transitioning health care. [Find your Regional Center on page 9.](#)

INDEPENDENT LIVING

- Aging and Disability Resource Centers
www.dhs.wisconsin.gov/adrc/index.htm

Wisconsin Independent Living Centers (ILCs) are regional, non-profit organizations that help people with disabilities achieve and maintain productive lives in their communities.

The Wisconsin Independent Living Centers provide 5 core services:

- 1) Information & Referral
- 2) Independent Living Skills Training
- 3) Peer Support
- 4) Advocacy
- 5) Transition Services

Transition services offered by ILCs include facilitating the transition of youth with disabilities as they enter adulthood and focus on goals related to education, employment and independent living.

To locate your local ILC and to learn which specific services they offer, visit
www.ilresources.org



LEGAL CONSIDERATIONS

As your child reaches adulthood, there may be new legal considerations. These could include Supported Decision-Making Agreements, Guardianship, Power of Attorney for Health Care, special needs trusts, and others. It is important that the individual with the special need/disability has a say in their own future. No matter the tool used to help the individual be safe, the individual's preferences should be taken into account. The best decisions are made together. The person with a special need/disability should have as much decision-making power as possible.

More information on these and other legal tools can be found at:

- Supported Decision Making
wi-bpdd.org/index.php/supporteddecision-making/
- Advance Directives forms from the state of Wisconsin
www.dhs.wisconsin.gov/forms/advdirectives/index.htm
- *What is a Special Needs or Disability Trust?*
www.wispact.org/what-is-a-trust
- Special Needs Trusts
www.snp-llc.com/special-needs-trust

Greater Wisconsin Agency on Aging Resources (GWAAR) Guardianship Support Center. To utilize GWAAR service, you must be 17 and half or older. GWAAR provides legal information about adult guardianships only and/or people transitioning into adulthood.

- Helpline 855-409-9410
Email: guardian@gwaar.org
gwaar.org/guardianship-resources



OTHER CONSIDERATIONS

- Your county Aging and Disability Resource Center (ADRC) provides information on a broad range of programs and services, helps people understand the various long-term care options available to them, helps people apply for programs and benefits, and serves as the access point for publicly funded long-term care. They will help with Medicaid, Long-Term Supports, transportation, home modifications and more.
Find your ADRC at:
www.dhs.wisconsin.gov/adrc/consumer/index.htm
- The Division of Vocational Rehabilitation (DVR) works with students with disabilities who are transitioning from high school to employment and training. DVR works with the Department of Public Instruction (DPI) and the Department of Health Services (DHS) to help students have a smooth transition from school to work and community services.
Find more information at:
dwd.wisconsin.gov/dvr/job-seekers/transition/transition-students.htm

There are also resources to help you look at the big picture of transition:

- *What's After High School?* Training on Transition (online and live training for families)
www.familyvoiceswi.org/learn
- Wisconsin Transition Resource Guide
promisewi.com/transition-guide



Thank You for Reading this Guide!

- ■ We hope this Navigation Guide is informative and provides you with the needed resources to answer many of your questions as you travel on your journey as a parent of a child with special health care needs. We encourage you to keep this guide and review it again in the future as your journey takes new paths or goes in new directions. Having a child with special needs can be challenging and there may be bumps along the way, but services and supports exist in Wisconsin and many organizations and individuals are available to assist you! And remember that you can always contact your CYSHCN Regional Center or Well Badger Resource Center about any of the material included in this guide.

GPS

getting parents started



What do you need to know? Where do you want to go? We can help you get there!

Family/child name _____

Guided by _____

■ GOAL 1

Contact _____

Phone _____

Email _____

Results _____

Next Steps _____

■ GOAL 2

Contact _____

Phone _____

Email _____

Results _____

Next Steps _____

■ GOAL 3

Contact _____

Phone _____

Email _____

Results _____

Next Steps _____

■ GOAL 4

Contact _____

Phone _____

Email _____

Results _____

Next Steps _____

GLOSSARY OF ABBREVIATIONS AND ACRONYMS

AAC	Augmentative and Alternative Communication	HCT	Health Care Transition
ABLE	Achieving a Better Life Experience	IDEA	Individuals with Disabilities Education Act
ACA	Affordable Care Act	IEP	Individualized Education Program
ADA	Americans with Disabilities Act	IFSP	Individualized Family Service Plan
ADHD	Attention Deficit Hyperactivity Disorder	ILC	Independent Living Centers
ADRC	Aging and Disability Resource Center	LPHD	Local Public Health Department
ASD	Autism Spectrum Disorder	MA	Medical Assistance (also referred to as Medicaid, Title XIX or Title 19)
ASC	Autism Society of South Central Wisconsin	MDA	Muscular Dystrophy Association
ASGW	Autism Society of Greater Wisconsin	NAMI	National Alliance on Mental Illness
ASSEW	Autism Society of Southeastern Wisconsin	OCI	Office of the Commissioner of Insurance
BCBA	Board Certified Behavior Analyst	OCR	U. S. Department of Education Office of Civil Rights
BPDD	Board for People with Developmental Disabilities	OT	Occupational Therapist
CAM	Complementary and Alternative Medicine	PCP	Primary Care Provider
CCOP	Children's Community Option Program	PT	Physical Therapist
CCR IEP	College Career Ready	PTP	Postsecondary Transition Plan
CCS	Comprehensive Community Services	SFTA	Supporting Families Together Association
CESA	Cooperative Educational Service Agency	SLP	Speech and Language Pathologist
CLTS	Children's Long-Term Support	SSDI	Social Security Disability Insurance
CYSHCN	Children and Youth with Special Health Care Needs	SSI	Supplemental Security Income
DHS	Department of Health Services	WATI	Wisconsin Assistive Technology Initiative
DPI	Department of Public Instruction	WCBVI	Wisconsin Center for the Blind and Visually Impaired
DSAW	Down Syndrome Association of Wisconsin	WESP-DHH	Wisconsin Educational Service Program for the Deaf and Hard of Hearing
EBP	Evidence-Based Practice	WI FACETS	Wisconsin Family Assistance Center for Education, Training and Support
FAPE	Free Appropriate Public Education	WSD	Wisconsin School for the Deaf
GPS	Getting Parents Started	WSPEI	Wisconsin Statewide Parent Educator Initiative
HCOS	HealthCheck Other Services		

**IN ADDITION TO THE ORIGINAL WORK DEVELOPED FOR THIS GUIDE,
THE FOLLOWING SOURCES WERE USED WITH PERMISSION:**

Barbara Katz and Elizabeth Hecht, “*Did You Know? Now You Know!*” Training,
Family Voices of Wisconsin, Madison, Wisconsin (Updated 2019).

familyvoiceswi.org/learn/did-you-know-now-you-know

Identifying Resources for Children/Youth and Families – Appreciating the Big Picture, Making a Unique Journey, a presentation developed by the Southern Regional Center for Children and Youth with Special Health Care Needs and Connections Community Training Team, Madison, Wisconsin (Updated 2019).

Next Steps – A guide for families new to autism spectrum disorders, 7th edition,
Autism Society of Wisconsin and CESA 7, 2008/2009.

Wisconsin Department of Health Services website (www.dhs.wisconsin.gov)
and other websites listed throughout the Guide.

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

“ 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



Southern Regional Center
Children and Youth with
Special Health Care Needs



WAIMAN CENTER
University Center for Excellence in Developmental Disabilities

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