# 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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- 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
- 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

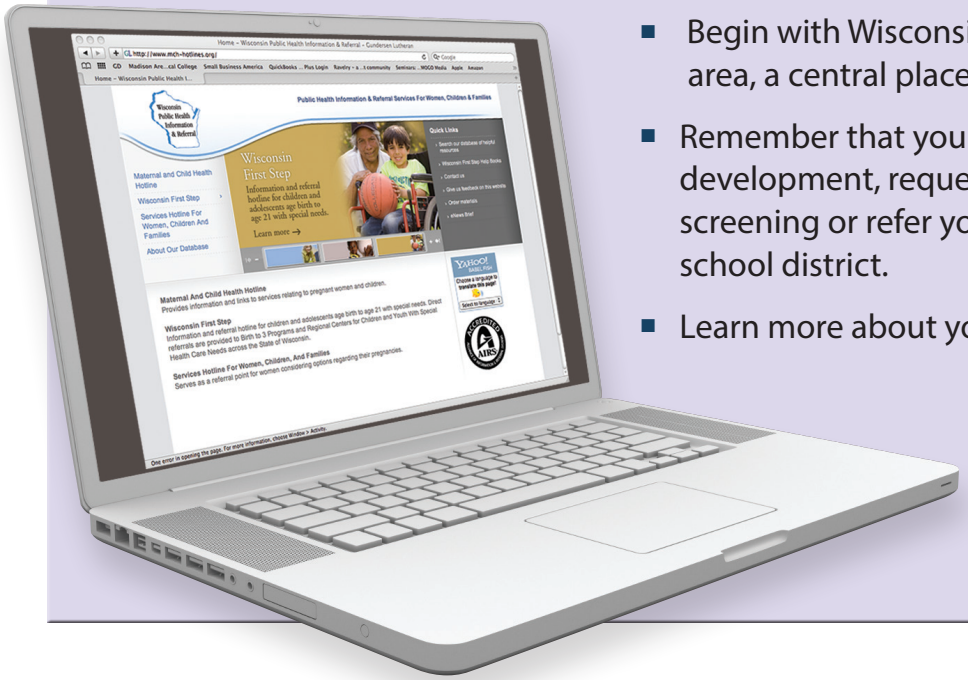
Hearing or suspecting that your child has a special need is not easy. Most of us expect parenting to go as planned and never expect that our child will have delays or be different from other children. This guide provides a starting point to discover the services and resources available in Wisconsin. 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 Center in your area, a central place for information and support.
- Remember that you know your child best. If you have concerns about your child's development, request that his/her 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 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:

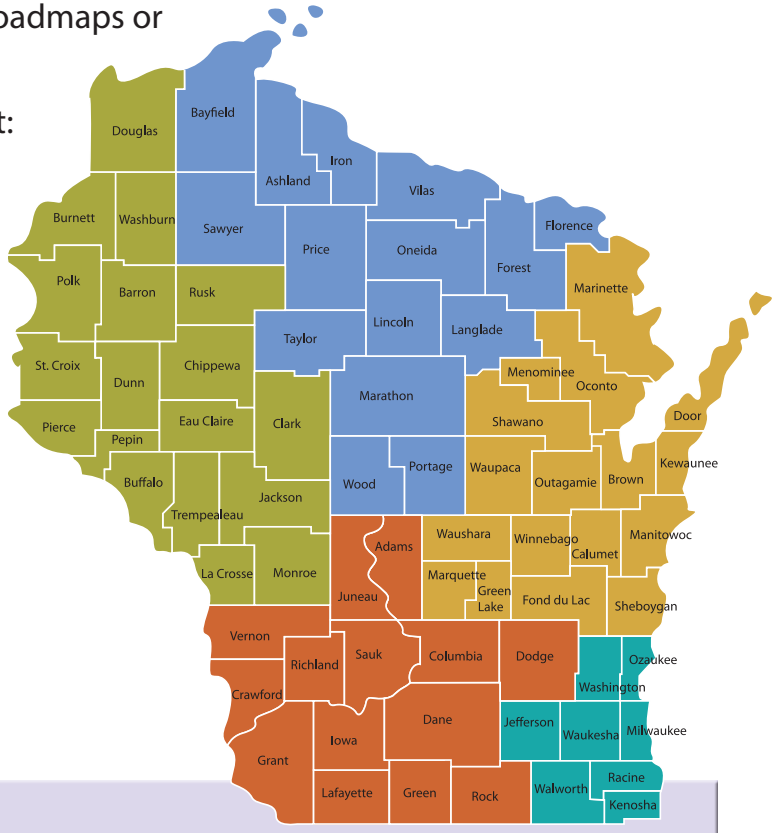
800-642-7837
www.mch-hotlines.org

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/health/children
- 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
- 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/ltcare/adrc




- Northern Regional Center
  www.co.marathon.wi.us/cyshcn.asp
  866-640-4106
- Southeast Regional Center
  www.southeastregionalcenter.org
  800-234-5437
- Northeast Regional Center
  www.northeastregionalcenter.org
  877-568-5205
- Southern Regional Center
  www.waisman.wisc.edu/cshcn
  800-532-3321
- Western Regional Center
  www.co.chippewa.wi.us/ccdph/CSHCN
  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:

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

## LEARN MORE – SCREENING FOR DEVELOPMENTAL DELAYS

- Tracking Your Child's Developmental Milestones
  www.ActEarly.wisc.edu
  www.cdc.gov/ncbddd/actearly/pdf/parents/MilestoneMomentsEng508.pdf
- Developmental Screening Fact Sheet
  www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/DevelopmentalScreening.pdf

Screening Tools for Autism Spectrum Disorders (ASD) and other Developmental Disabilities:

- First Signs Hallmark Developmental Milestones
  www.firstsigns.org/healthydev/milestones.htm
- Centers for Disease Control and Prevention Screening Recommendations
  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) 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
  www.aap.org/topics.html
- Genetics Home Reference
  www.ghr.nlm.nih.gov
- Kids Health Medical Problems
  www.kidshealth.org/parent/medical
- National Center of Birth Defects and Developmental Disabilities (Centers for Disease Control and Prevention)
  www.cdc.gov/ncbddd
- National Dissemination Center for Children with Disabilities
  www.nichcy.org

There are also diagnosis-specific organizations:

- Interactive Autism Network
  www.iancommunity.org/cs/newly_diagnosed/
- American Diabetes Association
  www.diabetes.org/living-with-diabetes/recently-diagnosed/
- Epilepsy Foundation
  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/
- Medical Home portal
  www.medicalhomeportal.org
- Wisconsin Medical Home Toolkit
  www.wimedicalhometoolkit.aap.org
- Partnering with Your Doctor – The Medical Home Approach
  www.region4genetics.org/Resources/Resources.aspx

## 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

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 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 Association of Wisconsin (414-607-9061).
- Finding the Right Doctor: A "Did You Know? Now You Know!" Fact Sheet
  www.fvofwi.org/publications/fact-sheets/
- Department of Health Services
  The Consumer Guide to Health Care: Finding and Choosing a Doctor
  www.dhs.wisconsin.gov/guide/find/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/localhealth

## 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:

- Free or Low Cost Health Clinics in Wisconsin
  www.dhs.wisconsin.gov/forwardhealth/clinics.htm
- Free or Reduced Fee Medical Services
  www.dhs.wisconsin.gov/guide/spec/freemed.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 – visit the oral health resources page.
- 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/tab/public

## LEARN MORE

- Oral Health Toolkit for Children with Autism
  www.autismspeaks.org/community/family_services/dental.php
- My Healthy Smile – Social Scripts CDs and Apps
  www.fraser.org/products/CDs.html

DEFINITION

What is Mental Health?

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

Source: What is mental health? World Health Organizations Online Q&A; September, 2007; http://www.who.int/features/qa/62/en/index.html

## 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:

- Federation of Families for Children's Mental Health
  www.ffcmh.org
- National Institute of Mental Health
  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

## 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:

PDR Health
www.pdrhealth.com/drugs/rx/rx-a-z.aspx

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.

### 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
- 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

To learn more about therapy services available through the public school system, contact:

Wisconsin Department of Public Instruction
800-441-4533
www.sped.dpi.wi.gov/sped_hmprograms

What is Applied Behavior Analysis?

"Behavior analysis is a scientific approach to understanding behavior and how it is affected by the environment. The science of behavior analysis focuses on 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 be harmful or that interfere with learning."

Source: www.autismspeaks.org/whattodo/what_is_aba.php

## 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 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
- Autism Speaks
  www.autismspeaks.org/whattodo/index.php

## 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:

- Wisconsin's Assistive Technology Program
  www.dhs.wisconsin.gov/disabilities/wistech/
- ABLEdata: database of assistive technology products
  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

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.

Two good sources of information are:

- Consumer Guide to Health Care
  www.dhs.wisconsin.gov/guide/info/quality.htm
- National Institute of Mental Health
  www.nimh.nih.gov/health/index.shtml

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/info/web.htm

# 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

- 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.fvofwi.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

For more information on natural supports:
www.waisman.wisc.edu/naturalsupports/ec.php

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

- Wisconsin Families for Hands and Voices and Wisconsin Educational Services Program for Deaf and Hard of Hearing (WESP-DHH) have a parent-to-parent matching program called Guide by Your Side – the program matches parents of children who are deaf, hard of hearing or deafblind with other parents to provide support and resources.

  888-656-8556
  www.wesp-dhh.wi.gov/wesp

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)
  www.asw4autism.org and Autism Society chapters
  (go to "chapters" on the ASW website for contact information)
- Center for Blind and Visually Impaired
  www.wcbvi.k12.wi.us
- Down Syndrome Association of Wisconsin
  www.dsaw.org
- Epilepsy Foundation
  www.epilepsywisconsin.org
- Muscular Dystrophy Association (MDA)
  www.mdausa.org/supportgroups.html

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

- Family Resource Centers
  www.wichildrenstrustfund.org/index.php?section=ourwork~frcns
- Grandparenting Today
  www.fyi.uwex.edu/grandparenting/

If a support group does not exist to meet your needs, consider starting your own. More information is available from:

- Family Village
  www.familyvillage.wisc.edu/general/selfhelp.html
- Parent-to-Parent of Pennsylvania
  www.parenttoparent.org – and go to parent support.

## 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 that in order to best care for 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:

The Family Caregiver Alliance – Taking Care of YOU: Self-Care for Family Caregivers
800-445-8106
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=847

### Brothers and Sisters

Siblings of children with special needs sometimes need additional support. There are groups that can connect siblings from different families so they can share their experiences. For a listing of groups in Wisconsin go to:

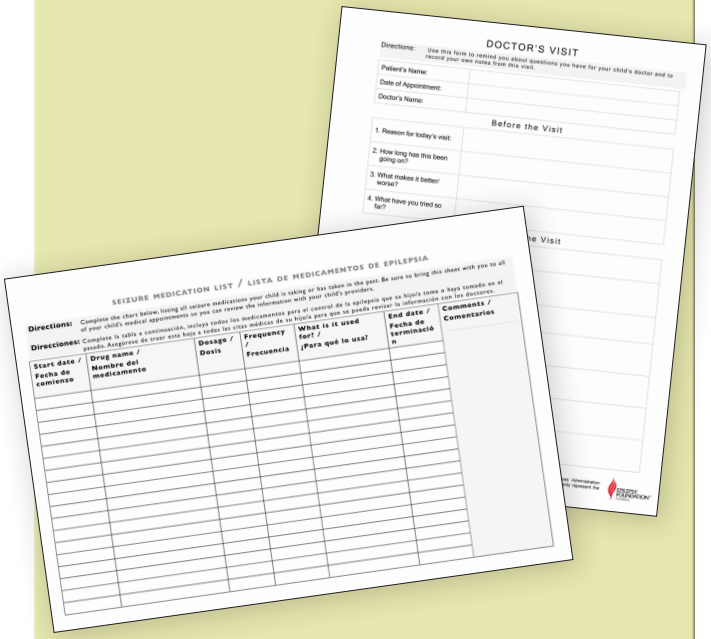
Sibling Support Network Sibshops
206-297-6368
www.siblingsupport.org/sibshops/find-a-sibshop

## 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


DOCTOR'S VISIT

Directions: Use this form to remind you about questions you have for your child's doctor and to record your own notes from this visit.

Patient's Name:
Date of Appointment:
Doctor's Name:

Before the Visit

1. Reason for today's visit:
2. How long has this been going on?
3. What makes it better/ worse?
4. What have you tried so far?

SEIZURE MEDICATION LIST / LISTA DE MEDICAMENTOS DE EPILEPSIA

Directions: Complete the chart below, listing all seizure medications your child is taking or has taken in the past. Be sure to bring this sheet with you to all of your child's medical appointments so you can review the information with your child's providers.

Direcciones: Complete la tabla a continuación, incluya todos los medicamentos para el control de la epilepsia que su hijo/a toma o haya tomado en el pasado. Asegúrese de traer esta hoja a todas las citas médicas de su hijo/a para que se pueda revisar la información con los doctores.

| Start date / Fecha de comienzo | Drug name / Nombre del medicamento | Dosage / Dosis | Frequency / Frecuencia | What is it used for? / ¿Para qué lo usa? | End date / Fecha de terminación | Comments / Comentarios |
|---|---|---|---|---|---|---|

Downloadable pages for starting a Care Notebook are available online at: www.medicalhomeinfo.org/for_families/care_notebook

## CARE COORDINATION

Some programs available to families who have children with special needs provide one-on-one care coordination. In these programs, a case manager or service coordinator will assist you to identify and contact appropriate community supports. Examples include the Birth to 3 Program and the Family Support Program. Your child's doctor or other clinic staff may also be able to assist your family in coordinating your child's services and supports. Take advantage of your service coordinator's knowledge and expertise. He or she should know about community resources, formal and informal supports.

While some families have this type of one-on-one 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 this feeling.

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:

www.medicalhomeinfo.org/for_families/care_notebook

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

## CONFERENCES AND TRAINING

Families can also help themselves 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 training and other learning opportunities. One example is the monthly Family Engagement Newsletter. For the latest issue go to:

http://www.wsti.org/for-parents/

Below are some examples of conferences and training opportunities:

- Autism Society of Wisconsin (ASW) has an annual statewide conference and ASW chapters have workshops and trainings for parents and families – www.asw4autism.org (go to "chapters" for contact information on regional ASW organizations).
- The annual Circles of Life conference is for families of children with disabilities and special health care needs and the professionals who support them. www.colwisconsin.org
- Did You Know? Now You Know! trainings from Family Voices of Wisconsin, provides information on how to navigate health care and community supports. 608-220-9598
  www.fvofwi.org/training-and-events/
- Wisconsin Family Assistance Center for Education, Training and Support (FACETS) holds both in-person and telephone trainings for families about a variety of educational issues.
  www.wifacets.org/training
- Children Come First/Upper Midwest Behavioral Health Conference is an annual conference for families and providers caring for or working with children with mental, emotional or behavioral disorders.
  www.wifamilyties.org/wifamilyties.org-events.html

## 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
  www.waisman.wisc.edu/wrc

- 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 called DAWN (Disability Advocates: Wisconsin Network):

  888-332-1677
  www.wi-bpdd.org

## 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 as Leaders
  Leadership for parents of children birth to 6.
  www.waisman.wisc.edu/pals

- Parents in Partnership
  Leadership for parents of children ages 6 to 21.
  www.wspei.org/families/pip.php

- Youth in Partnership with Parents for Empowerment
  Leadership for youth together with their parents.
  www.wspei.org/families/yippe.php

## CHILD CARE AND RESPITE

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

### Inclusive Child Care

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. Here are some resources for finding inclusive child care, and for working with child care providers to create inclusive care:

Child Care Resource and Referral Agencies in Wisconsin
www.supportingfamiliestogether.org/CCR_R.html
888-713-KIDS

*A Thinking Guide to Inclusive Child Care*
www.disabilityrightswi.org/archives/112

### Respite Care

Respite programs provide 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 Family Support Program or Children's Long Term Support waiver. For information about respite care in Wisconsin contact:

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

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 also community programs and activities that are specifically set up for children with special needs. Your Regional Center can provide contact information for programs in your community. Some examples include:

- Special Olympics
  800-552-1324
  www.specialolympicswisconsin.org
- Easter Seals Respite and Recreation Programs
  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 low-income families.
  608-261-6939
  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.
  www.judicare.org
  800-472-1638
- Legal Action of Wisconsin is a law firm that provides legal representation, through staff and volunteer attorneys, for people with low income including assistance with access to health care.
  www.badgerlaw.net/Home/PublicWeb/LAW
  800-236-1127

## LEGAL ASSISTANCE (CONTINUED)

As your child reaches adulthood, there may be new legal considerations. These could include guardianship, Power of Attorney for Health Care and special needs trusts. More information on these and other legal tools can be found at:

- Coalition of Wisconsin Aging Group's Guardianship Support Center
  www.cwagwisconsin.org/elder-law-center/guardianship-support-center
  800-488-2596 ext. 314
- Advance Directives forms from the state of Wisconsin
  www.dhs.wisconsin.gov/forms/advdirectives/index.htm
- The Importance of Special Needs Planning
  www.metlife.com/assets/investments/services/special-needs-children/Issue6-The-Importance-of-Special-Needs-Planning.pdf

# 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.

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 may screen your child to determine whether there are developmental concerns with learning, moving, seeing, hearing, communicating, or interacting with others. 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 Birth to 3 based on a diagnosed disability.

All eligible children and families are entitled to receive Birth to 3 regardless of their income. Some families with higher incomes may be expected to participate in Parent Cost Share – a set monthly fee for participation 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 team, including parents and providers, will determine supports such as physical therapy, occupational therapy, speech therapy and early childhood education. All services and supports are provided where your child typically spends his or her 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 to receive Birth to 3. 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/children/birthto3/familiy/index.htm
- Birth to 3 in Your County
  www.dhs.wisconsin.gov/children/birthto3/contacts/familycountycontacts.asp
- Wisconsin First Step
  800-642-7837) – ask for county Birth to 3 contact information.
  www.mch-hotlines.org

## CHILDREN THREE AND OLDER

Children with disabilities may qualify for special education and related services from the public school system. 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 refer to:

> Guidelines for disabilities and qualifying for special education in Wisconsin
> www.specialed.us/pl-07/pl07-intro.html#who

School districts provide Early Childhood Special Education to children age three to five 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 the school district. Professionals such as doctors, teachers, and social workers should let the school know if they think a child has a disability. Parents can also contact the school 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
  www.dpi.wi.gov/
  800-441-4533

## CHILDREN THREE AND OLDER (CONTINUED)

The services that a child needs for his or her 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 own IEP meetings.

### CHILDREN THREE AND OLDER – LEARN MORE

- An Introduction to Special Education
  www.dpi.wi.gov/files/sped/pdf/spec-ed-plain-lang-english.pdf
- Special Education in Plain Language
  www.specialed.us/pl-07/pl07-index.html

The Wisconsin Department of Public Instruction and the Center for the Blind and Visually Impaired administer the state's school for the blind. Some parents who have a child who is visually impaired choose to send their child to this special school, located in Southern Wisconsin, called the Wisconsin School for Visually Handicapped. For more information go to:

800-832-9784
www.wcbvi.k12.wi.us/wsvh

## TRANSITION TO ADULTHOOD

In Wisconsin, beginning at age 14 the IEP must include plans for a youth's transition to adulthood and the student will be invited to the transition IEP team meetings. Parents can also invite other community providers.

Transition is about preparing for life as an adult, which may include: caring for one's own health and medical needs, attending a university or community college, getting job training and finding a job, living away from home and finding recreational opportunities. Some students are eligible for transition services through the public schools until age 21.

The following resources can assist a family with starting the transition process:

- Department of Public Instruction transition services for students with disabilities
  www.dpi.wi.gov/sped/transition.html
- Wisconsin Statewide Transition Initiative
  www.wsti.org

The Health and the IEP CD and the Transition to Adult Health Care and Transition Health Care Checklist booklets are available from the Waisman Resource Center.

Waisman Resource Center
www.waisman.wisc.edu/wrc/pub.html
800-532-3321

## 504 PLANS

If a student is evaluated for special education and does not qualify, he or she may still be able to get help at school through a "504 plan." This help 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.

A 504 plan might include services like:

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

A 504 plan can help with temporary conditions as well as permanent disabilities. For more information go to:

- Frequently Asked Questions About Section 504
  www2.ed.gov/about/offices/list/ocr/504faq.html

## 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
www.sped.dpi.wi.gov/sped_bul06-03

## HOME SCHOOLING

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

- Wisconsin Parents Association
  608-283-3131
  www.homeschooling-wpa.org
- Department of Public Instruction form for home-based private education programs
  www.dpi.wi.gov/sms/homeb.html

## SPECIAL EDUCATION HELP FOR FAMILIES

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

- Wisconsin FACETS is a statewide organization that supports families and others with training, information and referral, and individual assistance related to children with disabilities.
  877-374-4677
  www.wifacets.org
- 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. There are WSPEI coordinators and parent liaisons in each Cooperative Educational Service Agency (CESA) district.
  877-844-4925
  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 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:

800-441-4563
www.dpi.state.wi.us/cesa.html

# Paying For What You Need

It's important to find out about 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 insurance will pay for, you will need to understand your benefits plan. You can get a copy of your benefits plan from your employer.

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. Contact OCI at:

800-236-8517
www.oci.wi.gov

## PRIVATE HEALTH INSURANCE – LEARN MORE

- Basic Private Health Insurance
  www.fvofwi.org/resources/resources-by-topic/
- Private Insurance Checklist
  www.fvofwi.org/resources/resources-by-topic/

## PRIVATE HEALTH INSURANCE (CONTINUED)

During 2009 and 2010 changes in state law had an impact on private insurance coverage for children with special health care needs. This includes mandatory coverage for intensive therapy for autism, hearing aids 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 27. The following provides more information on these changes:

- OCI Frequently Asked Questions on Mandated Coverage on Autism Services
  www.oci.wi.gov/rules/faq_autism.pdf
- Family Voices of Wisconsin's Fact Sheet on Insurance Changes
  www.fvofwi.org/publications/fact-sheets/

### Health Care Reform

On the federal level, the Affordable Care Act (known as the Health Care Reform Law), adopted in March 2010, will create significant improvements in access to health care and health care benefits for children with disabilities and special health care needs.

For more information go to:

- Office of the Commissioner of Insurance
  www.oci.wi.gov
- National Health Care Reform website:
  www.HealthCare.gov

## PUBLIC HEALTH INSURANCE

### Wisconsin Medicaid/BadgerCare Plus

Medicaid is a public insurance program that pays for health care services, funded by both the federal government and the state of Wisconsin, Department of Health Services (DHS), 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 children with low income. A child does not need to have a disability to be covered by BadgerCare Plus. There are several plans, including the BadgerCare Plus Standard Plan and BadgerCare Plus Benchmark Plan, depending on the family's income.

www.badgercareplus.org
800-362-3002

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.

## PUBLIC HEALTH INSURANCE (CONTINUED)

### 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 or assets of their parents are too high may be eligible for Medicaid through the Katie Beckett Program. Contact Wisconsin First Step (www.mch-hotlines.org or call 800-642-7837) for the Katie Beckett consultant in your region.

Katie Beckett Program
www.dhs.wisconsin.gov/children/kbp/index.htm

### 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. An annual HealthCheck exam, which could be your child's annual physical exam, is required to access HCOS funding. For more information contact Wisconsin First Step (www.mch-hotlines.org or 800-642-7837) or contact your Regional Center. The publication below provides more in-depth information on HCOS:

A Step-by-Step Guide to Accessing Services and Supplies
through the HealthCheck Other Services Component of Medicaid
www.fvofwi.org/publications/fact-sheets/

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

The Children's Long Term Support Waivers provide funding for children living with their families who need a certain level of care in one of three areas of disability: physical disabilities, developmental disabilities, severe emotional disturbance.

The CLTS Waiver Program allows states to use Medicaid funding in more flexible ways. For example, CLTS funds may be used for intensive in-home therapy for autism. To learn more go to:

- Children's Long Term Support Waivers
  www.dhs.wisconsin.gov/children/clts/waiver/family/index.htm
- Information for Families and Providers Regarding Autism Services under CLTS Waivers
  www.dhs.wisconsin.gov/children/clts/waiver/family/autism/eligibility.htm

Supplemental Security Income

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

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
- ForwardHealth (an umbrella term for several DHS programs – Medicaid, BadgerCare Plus, SSI, Health Check) Hotline
  800-362-3002
- 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.

  800-585-4222
  www.safetyweb.org

## FAMILY SUPPORT PROGRAM

The Family Support Program 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 family support coordinator who helps connect a family with information and resources.

Generally, the Family Support Program can provide funding for services that are not covered by private insurance and/or Medicaid (e.g., respite, transportation, home modifications, and specialized equipment). Eligibility for Family Support is based on disability. In most counties, there is a waiting list to receive Family Support services. Keep in mind that each county administers their own program, so there may be differences in funding, services and supports from county to county. To find the Family Support coordinator in your county go to:

www.dhs.wisconsin.gov/children/fsp/index.htm

## OTHER OPTIONS

Your 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
- lending closets

# 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 Regional Center or Wisconsin First Step 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 3

Contact _____

Phone _____

Email _____

Results _____

_____

Next Steps _____

_____

_____

## GOAL 2

Contact _____

Phone _____

Email _____

Results _____

_____

Next Steps _____

_____

_____

## GOAL 4

Contact _____

Phone _____

Email _____

Results _____

_____

Next Steps _____

_____

_____

## GLOSSARY OF ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| ACA | Affordable Care Act (also known as the National Health Care Reform Law) |
| ADA | Americans with Disabilities Act |
| ADRC | Aging and Disability Resource Center |
| AT | Assistive Technology |
| BCBA | Board Certified Behavior Analyst |
| BPDD | Board for People with Developmental Disabilities |
| CAM | Complementary and Alternative Medicine |
| CESA | Cooperative Educational Service Agency |
| CLTS | Children's Long Term Support |
| CYSHCN | Children and Youth with Special Health Care Needs |
| DHS | Department of Health Services |
| DPI | Department of Public Instruction |
| EBP | Evidence-based Practice |
| GLITC | Great Lakes Inter-Tribal Council |
| IDEA | Individuals with Disabilities Education Act |
| IEP | Individualized Education Program |
| IFSP | Individualized Family Service Plan |
| LPHD | Local Public Health Department |
| MA | Medical Assistance (also referred to as Medicaid, Title XIX or Title 19) |
| OCI | Office of the Commissioner of Insurance |
| OT | Occupational Therapist |
| PCP | Primary Care Provider |
| PT | Physical Therapist |
| SLP | Speech and Language Pathologist |
| SSI | Supplemental Security Income |
| WATI | Wisconsin Assistive Technology Initiative |
| WCBVI | Wisconsin Center for Blind and Visually Impaired |
| WSTI | Wisconsin Statewide Transition Initiative |

## 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 (2010). http://fvofwi.org/training-and-events/

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 (2010).

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

> 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.

P-00256 10/11; updated online 4/13