

# Care Notebook

Documents and Resources to Support Your Child's Shared Plan of Care

<u>Contents</u>	<u>Page</u>
ntroduction	1
Definitions	2
What is a Medical Home?  Directions to Make a Care Map  Care Map Example  Care Map Template	4 5
Supporting Materials:	7
Creating a Shared Plan of Care	8
Supporting Materials:	9
Maintaining Your Child's Shared Plan of Care  Wisconsin Resources for Families of Children and Youth with Special Health Care Needs	
Supporting Materials:	12

Contents (cont'd)	<u>Page</u>	
Appendix A: Forms		
Health Care Provider contact information	13	
My Medicine Record, an FDA form	15	
Insurance Company contact information	20	
Medical Equipment Supply contact information	22	
Agencies to Support my Family	24	
Appendix B: Fact Sheets		
Finding the Right Doctor	26	
Questions for a Mental Health Agency	28	
<ul> <li>Questions for my Health Plan or Insurance Company</li> </ul>	30	
What are Outcomes?	32	
You are an Advocate for Your Child	34	
Appendix C: Resources		
Finding Your Way, a navigation guide	36	
Shared Plan of Care	37	
<ul> <li>Wisconsin Resources for Families of Children and Youth with</li> </ul>		
Special Health Care Needs (expanded search)	42	

# Introduction

This Care Notebook is intended to support the Care Coordination Curriculum created by Family Voices of Wisconsin and the Wisconsin Medical Home Initiative (WisMHI). Families will find that the forms, fact sheets and resources are valuable for all children and may want to use it independently of this curriculum.

### How do I set up the Care Notebook?

The Care Notebook forms are online. You may download them, print them, and place them into a 3-ring binder format with information organized so you can find it quickly. The Care Notebook has forms that you can fill in to track important information.

### To set up your Care Notebook:

- 1. Gather the information you already have.
- 2. Decide what information is most important to keep in your Care Notebook:
  - a. What do you look up the most?
  - b. What will those caring for your child need?
  - c. Consider storing other information in a file box or drawer where you can find it when needed.
- 3. Read through the information and move things where they will be easiest for you to find.

Put your Care Notebook together for YOU! Everyone has a different way of organizing. The only right way is the way that works for you.

#### How do I use the Care Notebook to help with my child's Shared Plan of Care?

You can use your Care Notebook to help you track important information in your child's Shared Plan of Care, such as contact information for health care providers. It can also help you share information and prepare for appointments.





# **Definitions**

<u>Care Map</u>: A hand-drawn picture showing many of the supports and people involved in the life of a child or youth with special health care needs.

<u>Care Team</u>: This team is made up of your family and your child, along with the doctors, nurses, other health care professionals and other service professionals to make sure that your child is as healthy as possible. The care team can be as big, or as small as it needs to be, depending on your child. Along with your child's doctor and nurses, some other team members might be care coordinators, case managers, family partners, family support groups, community health workers, community group member, school nurses, teachers, social workers, and other education professionals.

<u>Children and Youth with Special Health Care Needs (CYSHCN)</u>: Any child or youth aged 0-21, with a condition expected to last at least a year. Children or youth with special health care needs need more help (in the form of medication, services, therapy and/or equipment) than other kids their age.

<u>Health Care Provider</u>: The medical professional who manages your child's long-term health. This person might be a pediatrician, family physician, physician assistant, or pediatric nurse practitioner.

<u>Medical Home</u>: A medical home is a partnership between parents and the health care professionals caring for your child. Most commonly, these professionals include a primary care doctor (pediatrician, family physician), nurse, and other care team members. Children receiving care within medical homes receive better care overall. Some medical homes use Shared Plans of Care to coordinate care for children with special health care needs.

<u>Medical Summary</u>: A document which has your child's current diagnoses, medicines, allergies and important events like hospitalizations or surgeries. This is part of the Shared Plan of Care.

<u>Negotiated Actions</u>: Goals that are set with your family, your child and his/her care team. These include your child's personal and clinical goals and the activities to reach these goals. Timelines and the person responsible for each activity will also be assigned by the team. This is part of the Shared Plan of Care.

<u>Shared Plan of Care</u>: A form filled out by parents and the health care providers to make sure that everyone caring for your child knows about his or her medical condition and that next steps in his or her care are outlined. A Shared Plan of Care has 3 key parts:

- A medical summary (including diagnoses, medications, and important events, like hospitalizations and surgeries)
- Family strengths and preferences
- Negotiated actions (goals for your child, steps needed to reach these goals and a timeline)
  - O It can also include other important documents like emergency plans or school Individualized Education Plans (IEPs).

# What is a Medical Home?

In this section you can identify many of the people involved in your child's care and life and begin to think about what matters most to your child and family. Both of these activities may help you contribute to the "Negotiated Actions" section of your child's Shared Plan of Care.

#### What's included in this section?

- Directions on how to make a Care Map for your child.
- Care Map example for Gabe, a 7-year old with medical complexities.
- Care Map template to get started on your child's map.
- Supporting Materials

### What is a Care Map?

- It's a way to show health professionals all the different areas that you coordinate for your child's care.
- Care Mapping began with Cristin Lind, a mother, to create a picture of everyone her family relies on to care for her son.

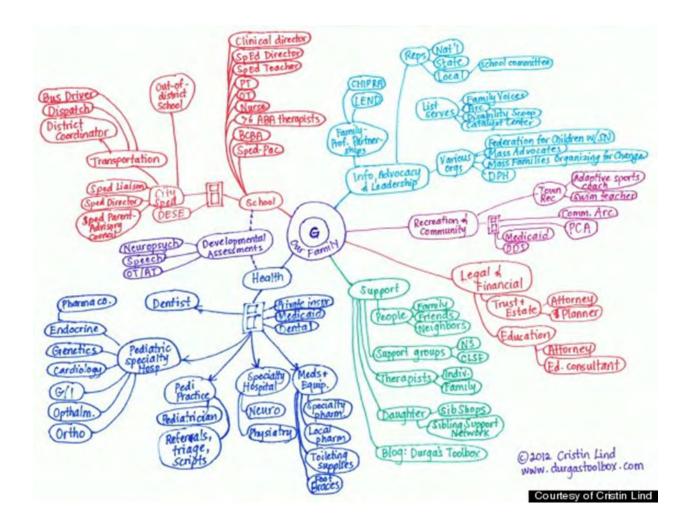
# **Directions to Make a Care Map**

- 1. You can use the template in this notebook or you can start with a blank piece of paper and a pencil, draw a circle in the middle of the paper and write your child's name. Then draw a ring around your child and label it "family." You can use a picture of your child or family in the center.
- 2. Outside the center circle for your child and family, draw circles for the people or organizations that are part of your child's team. Place the large groups first and then break them down into smaller groups farther from the center. The most important thing is that it makes sense to you. It may take several tries before it feels complete. Don't worry about getting it 100% right.
- 3. You may need to use different colors, symbols and line shapes to show things like barriers, support or unmet needs. It's best to keep your process simple. Include your children in the care mapping process. They may even be able to make their own. You might consider making an appointment with a member of your child's care team to help you make the Care Map. By working with someone from the team, you'll both learn a lot.
- 4. Lastly, make copies of your care map and/or scan it. Having an electronic version will allow you to share it by email. The most important step will be to share this information with your child's team.

# Care Map Example:

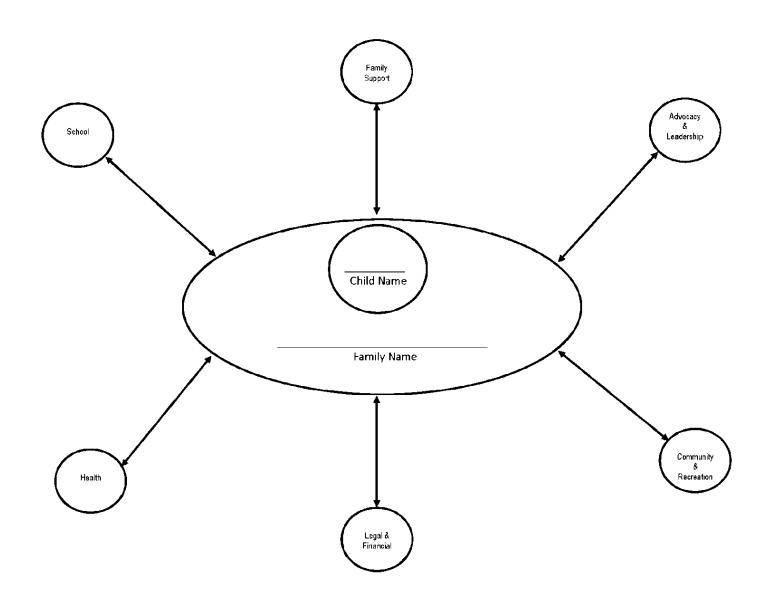
Below is a care map for Gabe. He is a 7-year old with complex medical needs.

Cristin Lind couldn't find the words, so she drew a picture. It shows the scaffolding in our lives, which is usually unseen. We are surrounded by a web we don't always know is there, but every so often, usually in crisis or its aftermath, makes itself visible. By the time Ms. Lind finished drawing, there were 70 labeled ovals on her page, which she calls "Gabe's Care Map."



5

# Care Map Template



# **Supporting Materials**

## Forms (Appendix A)

**Health Care Provider Contact Information**: A template to manage the contact information for the different health care providers on your child's care team.

## Fact Sheets (Appendix B)

**Finding the Right Doctor:** The right doctor will partner with you to create and maintain coordinated care within a medical home. This fact sheet will gives ideas and questions to ask to make sure the doctor is the right fit for your child and family.

Questions for a Mental Health Agency: This fact sheet will help families who have a child with mental health or behavioral health challenges as they look for therapy or counseling services for their child.

Questions for my Health Plan or Insurance Company: This fact sheet will help families find out how much services will cost and the paperwork required when looking for medical care, therapy services or other treatment for a child with special needs.

# Resources (Appendix C)

**Finding Your Way:** A navigation guide for Wisconsin families who have children and youth with special health care needs and disabilities. This guide will assist you now and also in the future when the landscape of your journey changes.

# **Creating a Shared Plan of Care**

#### What's included in this section?

- Shared Plan of Care
- Supporting Materials

#### What is a Shared Plan of Care?

- A living document that includes important information about your child's health.
- A plan made together by health care teams and families.
- Some pieces are:
  - A Medical Summary, (including diagnoses, medications, and important events, like hospitalizations and surgeries)
  - o Family Strengths and Preferences
  - Negotiated Actions (goals for your child, steps needed to reach these goals and a timeline)
    - Other important documents like emergency plans or school IEPs

#### Directions to make a Shared Plan of Care

The key to a useful Shared Plan of Care is to make sure that the care team has the most up to date information. Set a calendar reminder to make sure everything is current.

Why Should My Child Have a Shared Plan of Care?

 Having a Shared Plan of Care for your child can make communicating with health care providers and other professionals easier.

Where can I see an example of a Shared Plan of Care\*?

- See next page and also in Appendix C
- Examples are available at <a href="http://www.wismhi.org/wismhi/About-Us/System-">http://www.wismhi.org/wismhi/About-Us/System-</a> Integration/Shared-Plan-of-Care-Project
  - o If your child already has a Shared Plan of Care keep it in this section.
    - Do NOT switch to using the template if your child's care team has a version it's currently using.

\*Shared Plan of Care example from Indiana University of School of Medicine, Riley Children's Hospital Care Coordination Program Team, Director Jeanne W. McAllister, BSN, MS, MHA

# **Supporting Materials**

### Forms (Appendix A)

**Insurance Company Contact Information:** A template to manage the contact information for your health insurance providers.

**Medical Equipment Supply Information:** A template to manage the supply company information for any health care equipment that your child may need.

**My Medicine Record:** A form, created by the FDA, to track your child's medicines, doses, dates, allergies and other important information.

## Fact Sheets (Appendix B)

What are Outcomes?: This fact sheet provides information on creating outcomes which can be used for developing a Shared Plan of Care and is very useful for any child as you and your family partner with schools, health care providers and community services and supports.

### Resources (Appendix C)

**Shared Plan of Care:** A template to make communicating with care team members easier by ensuring that every member has the same, most current information. An example of a Shared Plan of Care can be found on pg.17 or in Appendix.

# Maintaining Your Child's Shared Plan of Care

#### What's included in this section?

- Wisconsin Resources for Families of Children and Youth with Special Health Care Needs
- Supporting Materials

#### What is the Resources tab?

- Contact information for people or agencies that help you solve problems.
- A place to store important contacts, to cut down on repeated Internet searches.

### Resources to keep in this section

- Resource Information: Keep contact information for the agencies or people who can guide you to the next step for your child or can direct you to available services.
- Family Support Information: Keep information for community supports and family advocacy groups.
  - It gives ideas for advocating for your child's health.
  - o It's the information that you need when you think that there are gaps in your child's care.

# Wisconsin Resources for Families of Children and Youth with Special Health Care Needs

Family Voices of Wisconsin- is a statewide network of families who have children with special health care needs and disabilities and those who work on their behalf. FVW 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.

www.familyvoicesofwisconsin.com 608-220-9598

Regional Centers for Children and Youth with Special Health Care Needs- Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them. Free and confidential services include information, referral and problem solving, parent support, help understanding insurance coverage and applications, transition planning and connections to community resources.

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

Northern Regional Center: 866-640-4106
Northeast Regional Center: 877-568-5205
Southern Regional Center: 800-532-3321
Southeast Regional Center: 800-234-5437

• Western Regional Center: 800-400-3678

**Well Badger**- is a statewide information and referral hotline to assist Wisconsin families and providers working with children and youth with special needs. The line is operational 24 hours/day, 7 days a week. Parent Specialists, who have disability expertise and a child with a special need, answer the line Monday through Friday 8 a.m. to 4 p.m. https://wellbadger.org/800-642-7837

# **Supporting Materials**

### Forms (Appendix A)

**Agencies to Support My Family:** A Template to keep information for community supports and family advocacy groups that give ideas for advocating for your child's health.

# Fact Sheets (Appendix B)

You are an Advocate for Your Child: A fact sheet with tips about advocacy that you can use in all types of settings to improve your child's health care.

# Resources (Appendix C)

Wisconsin Resources for Families of Children and Youth with Special Health Care Needs (expanded search): Contact information for the agencies or people who can guide you to the next step for your child, or can direct you to available services.

# Appendix A

**Forms** 

# Health Care Provider Contact Information

<u>Provider Name</u> :	
True of Comico Duovido d	
Type of Service Provided:	
Clinic/Office Name:	
Clinic Address:	
Clinic Phone:	
Clinic Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Days/Hours:	
- ,	
Durani dan Manas	
<u>Provider Name:</u>	
Type of Service Provided:	
Clinic/Office Name:	
Clinic Address:	
Clinic Phone:	
Clinic Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Days/Hours:	

# Health Care Provider Contact Information

<u>Provider Name:</u>	
Type of Service Provided:	
Clinic/Office Name:	
Clinic Address:	
Clinic Phone:	
Clinic Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Days/Hours:	

<u>Provider Name</u> :	
Type of Service Provided:	
Clinic/Office Name:	
Clinic Address:	
Clinic Phone:	
Clinic Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Days/Hours:	

# My Medicine Record

My Medicine Record is a form to use to track your child's medicines, doses, dates and other important information.

#### **How Families Can Use My Medicine Record**

Page 1 of the form: Complete the chart to track medicine information. If you would like to download the form please use this link:

http://www.fda.gov/downloads/AboutFDA/ReportsManualsForms/Forms/UCM095018.pdf

Page 2 of the form: Complete Allergic Reaction and Medical Conditions boxes.

Pages 3-4 of the form: These pages give directions for using this form. Use pages 3 and 4 only if you need more explanation.

### Be an Active Member of Your Health Care Team

# My Medicine Record

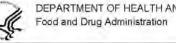


#### DEPARTMENT OF HEALTH AND HUMAN SERVICES Food and Drug Administration FDA

Name	me (Last, First, Middle Initial):				Birth Date (mm/dd/yyyy);		
Ì	What I'm Using Rx – Brand & generic name; OTC – Name & active ingredients	What It Looks Like Color, shape, size, markings, etc.	How Much	How to Use / When to Use	Start / Stop Dates	Why I'm Using / Notes	Who Told Me to Use How to Contact
V	— Enter ALL	prescription (Rx) med	dicine (include	samples), over-the-c	ounter (OTC	) medicine, and dietary sup	olements —
Ex:	XXXX/xxxxxxxxx	20 mg pill; small, white, round	40 mg; use two 20 mg pills	Take orally, 2 times a day, at 8:00 am & 8:00 pm	1-15-11	Lowers blood pressure; check blood pressure once a week; blood test on 4-15-11	Dr. X (800) 555-1212
1							
2		-					
3							
4							
5							
6							
7							
8							
www	.fda.gov/Drugs/Resource	esForYou/ucm079489.h		(888) INFO-FDA www.fda.gov/usemedici	inesafely	These are my medicines as of (Enter date as mm/dd/yyyy)	

#### Be an Active Member of Your Health Care Team

# My Medicine Record



DEPARTMENT OF HEALTH AND HUMAN SERVICES

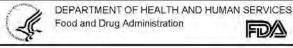
My Personal Contacts		Allergic Reaction or Other Problem I've Had With
My Name (Last, First, Middle Initial)	Birth Date (mm/dd/yyyy)	any medicine, dietary supplement, food, skin cleaner, medical tape
		Describe in space below.
Contact Information		
Emergency Contact		
Name	Relationship	
Contact Information		Mr. Madical Conditions and Operations
Primary Care Physician		My Medical Conditions and Operations  Describe in space below:
and the second s		Describe in space bolow.
Name		
Contact Information		
Pharmacy / Drugstore		
Name		
Contact Information		

#### Questions I Should Ask About Medicines or Dietary Supplements

- Fill in the record for any new medicine, prescription (Rx) or over-the-counter (OTC), or dietary supplement, or ask my doctor or pharmacist to help me fill it in. Make sure I can read what is written on the record.
- When I review the record, or a change is made, ask:
- Can I use a generic form?
- . When should I start to feel differently? When should I report back to the doctor?
- . Will this take the place of anything else I am using?
- · Are there any special directions for using this?

- · Should I avoid any other medicines, dietary supplements, or treatments while using this?
- . Should I avoid any drinks, foods, other substances, or activities while using this?
- . What are the possible side effects from this? Is there anything I should watch for? What do I do if I get a side effect?
- . Will I need any tests (blood tests, x-rays, other) to make sure it is working as it should? When? How will I get the results?
- . What should I do if I miss a dose? What do I do if I use too much?
- . Where and how can I get more written information about this?

# My Medicine Record



#### How to Use My Medicine Record

- Use this record with the "Be An Active Member of Your Health Care Team" pamphlet, found at: www.fda.gov/Drugs/ResourcesForYou/UCM079529#pamphlet
- Save "My Medicine Record" on your personal computer (PC).
   Type information into the fields with your keyboard. You can also print the record and enter the information with a pencil.
- Enter ALL prescription medicines you use, including any medicine samples you are given.
- Enter ALL over-the-counter medicines and dietary supplements (including vitamins, minerals, and herbals) you use, whether you use them all the time or only some of the time.
- Print and share the record with your doctors, pharmacists, or other health professionals at ALL your visits.
- Keep a printed copy with you all the time. It is a good idea to give a copy to a friend or loved one.

Review this record and update it on your PC or by hand when you:

- · Stop or start a medicine or dietary supplement
- · Make a change in anything you use
- · Visit your doctor, pharmacist, or other health professional

#### What I'm Using

- Prescription (Rx) medicine enter the brand and generic name of the medicine, including any samples you are given
- Over-the-Counter (OTC) medicine enter the name and active ingredient(s), including OTCs you use for allergies, stomach ache, heartburn, nausea; OTC pain relievers you use for minor aches and pains, headache, fever; OTC cold medicines,

laxatives, sleeping pills, and others prescribed by your doctor, such as aspirin

· Dietary supplements, including vitamins, minerals, and herbals

#### What it Looks Like

- Form (pill, tablet, capsule, liquid, injection, suppository, cream, lotion, eye or ear drops, etc.)
- Shape, color, size, and scoring (any lines on the medicine) or other markings

#### How Much

- Dose that you are directed to use either by the doctor or pharmacist or by the directions on the label
- If you are to use a dose which is different than the dose the medicine comes in, note the number you use (for example, you are supposed to use 40 mg, and it comes in 20 mg pills, put "40 mg; use two 20 mg pills" or "2 pills")

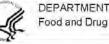
#### How to Use / When to Use

- How to use such as "swallow with water; do not chew" or "take by mouth with food" or "two times a day")
- When to use the time, or time of day, you use it (such as "10:00 pm" or "at bedtime")

#### Start / Stop Dates

- Date you started using it. If you are only supposed to use it for a period of time, put the date you should stop using it
- If it is something you use sometimes, such as an OTC you use only when you have a headache, put "when needed"

# My Medicine Record



DEPARTMENT OF HEALTH AND HUMAN SERVICES
Food and Drug Administration

#### How to Use My Medicine Record

#### Why I'm Using / Notes

- . The reason why you are using it, such as "high blood pressure"
- Any special directions on how to use the medicine, such as whether to take it with or without food
- Any tests that are needed to find out it is working as it should, and dates you need the tests
- . How and where to keep or store it, if not at room temperature

#### Who Told Me to Use / How to Contact

 Name and contact information of the doctor, nurse, or pharmacist (or other) who prescribed or told you to use it

#### My Personal Contacts

 Contact information for you, someone you want contacted in an emergency, your doctor, pharmacy, or pharmacist. Under "Contact Information," enter phone number or e-mail address. An extra space is there for an extra contact person, if needed.

#### Allergic Reaction or Other Problem I've Had With...

 Any medicine, dietary supplement, food, skin cleaner, medical tape with which you have had a problem  Also enter anything that could have an effect on your use, such as pregnancy, breast feeding, trouble swallowing tablets, or trouble remembering to use. Include problems with ingredients, such as colors, flavors, starches, or sugars.

#### My Medical Conditions and Operations

- Any diseases, illnesses, or medical conditions, such as asthma, diabetes, heart disease, high blood pressure, kidney disease, or cancer
- Any conditions or problems you often treat with prescription or over-the-counter medicine or dietary supplements, such as acid stomach or allergies
- · Operations you've had

#### Questions I Should Ask About Medicines or Dietary Supplements

 Fill in the record for any new medicine or dietary supplement, or ask your doctor or pharmacist to help you fill it in. Make sure you can read what is written. If you can't read it, others may have trouble reading it, too. Use these questions when you review the record with your health professionals or when a change is made in something you use.

# **Insurance Company Contact Information**

<u>Primary</u> Insurance Name:	
Identification (ID) Number:	
Group Number:	
Phone:	
Address:	

<u>Primary</u> Insurance Name:
Identification (ID) Number:
Group Number:
Phone:
Address:

# **Insurance Company Contact Information**

condary Insurance Name:	
dentification (ID) Number:	
Group Number:	
Phone:	
Address:	
Other Insurance Name:	
dentification (ID) Number:	
Group Number:	
Phone:	

Address:

# Medical Equipment Supply Information

Supply Company:	
Type of Equipment Supplied:	
Address:	
Phone:	
Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Supply Company:	
Type of Equipment Supplied:	
Type of Equipment copplied.	
Address:	
Address:	
Phone	
Phone:	
F	
Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	

# Medical Equipment Supply Information

Supply Company:	
Type of Equipment Supplied:	
Address:	
Phone:	
1 1101101	
Env	
Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	
Supply Company:	
Type of Equipment Supplied:	
Type of Edolphiem copplica.	
Aulaliana	
Address:	
Phone:	
Fax:	
Key Contact Name (nurse,	
receptionist, etc.):	

# Agencies to Support My Family

Organization:	
Key Contact Name:	
Phone:	
Address:	
Support offered:	
11	
Date Contacted:	
Organization:	
Organizanon.	
Kay Contact Name.	
Key Contact Name:	
Dlama	
Phone:	
A 1.1	
Address:	
Support offered:	
Date Contacted:	

# Agencies to Support My Family

Organization:	
Key Contact Name:	
Phone:	
Address:	
Support offered:	
Date Contacted:	
Organization:	
Key Contact Name:	
Phone:	
Address:	
Support offered:	
Date Contacted:	

# **Appendix B:**

**Fact Sheets** 





# Finding the Right Doctor for Your Child with Special Needs

If you have changed insurance plans, have moved or for other reasons need to find a new primary care doctor for your child with special needs, this fact sheet will give you ideas and questions to ask to make sure the doctor is right for your child and family.

The right doctor will partner with you to create and maintain coordinated care within a medical home. To learn more go to familyvoicesofwisconsin.com/care-coordination/

#### What Steps Should I Take When Choosing a Primary Care Doctor?

- Think about what you want from your health care provider and write it down.
- Make a list of the doctors you want to check out. Talking to family, friends or co-workers, especially if they have children with special needs, may help you create a list of names.
- Call the clinic and request a brief visit with the doctor. Most clinics will set up an
  appointment so that you can interview the doctor in person.
- Come to this visit prepared. You may or may not want to bring your child along to this
  appointment. (see "Interview Questions to Assist You in Choosing A Doctor")
- After your visits compare what you learned and decide who fits your family best.
- Once you have chosen the best doctor, set up an initial appointment and provide information about your child to the doctor and their staff.

#### What is a Medical Home?

A medical home is a trusting partnership between you, your child, and your pediatric primary health care team. A medical home means that your health care team:

- · Knows your child's health history
- Listens to your concerns and needs (as well as your child's)
- Treats your child with compassion
- · Has an understanding of their strength
- Develops a care plan with you and your child when needed
- · Respects and honors your culture and traditions

Your health care team can help you and your child access and coordinate specialty care, other health care and educational services, in and out of home care, family support, and other public/private community services that are important to the overall well-being of you and your child. (Based on AAP's healthychildren.org site - 2016)

#### What is Care Coordination?

Care coordination is the process that links children and their families with needed health care services, along with other supports and services. A child and family's needs, goals, and choices are included in a care plan that is shared with all team members.

Updated September 2016

Family Voices of Wisconsin - www.familyvoicesofwisconsin.com



#### Interview Questions to Assist You in Choosing a Doctor

Below are suggested questions you can ask during a visit with a new doctor or other health care provider.

- Does the doctor have experience working with children with special needs?
- Will the doctor work with you to develop plans of care?
- Does the doctor enjoy working with children who have special needs?
- Does the doctor have time in his or her practice for a child with special needs?
- Is there flexibility in the clinic practice to allow longer appointments?
- Will the doctor sit down with you to review your child's history and diagnosis thoroughly?
- Will you be able to see that doctor when your child needs to be seen on short notice?
- · How are emergencies handled?
- How are urgent messages handled?
- Can you communicate with the doctor by voice mail, e-mail or text messaging and what is the typical response time?
- How will the doctor communicate your child's diagnosis and special needs with partners when your doctor is not on call or is on vacation?
- Can you and the doctor write down protocols for procedures required when your child is ill, which will be available for the doctor's partners in case of emergency room visits?
- How will the doctor feel about you obtaining a second opinion?
- How will the doctor communicate with your child's other medical and non-medical providers (including specialists or non-network providers)?
- Will the doctor help your child transition to adult care providers at the appropriate time?

#### If you have questions or need help finding services contact the following organizations:

- Regional Centers for Children and Youth with Special Health Care Needs is a network of 5 centers dedicated
  to supporting families who have children with special needs at <a href="mailto:dhs.wisconsin.gov/cyshcn/regionalcenters.htm">dhs.wisconsin.gov/cyshcn/regionalcenters.htm</a>
- Wisconsin First Step, a statewide information and referral hotline, can assist families with finding mental health providers and other supports at 1-800-642-STEP (7837) or <a href="www.mch-hotlines.org/wisconsin-first-step">www.mch-hotlines.org/wisconsin-first-step</a>

Adapted with permission from "Working with Doctors: A Parent's Guide to Navigating the Health System" by Carolyn Allshouse, The Pacer Center, Minneapolis, MN, 2001)

Family Voices of Wisconsin - www.familyvoicesofwisconsin.com





# **Questions for a Mental Health Agency**



#### A Resource for Families Who Have Children with Special Health Care Needs

### Getting Started

This fact sheet will help families who have a child with mental health or behavioral health challenges as they look for therapy or counseling services for their child. After working with your child's primary care doctor to get a list of potential agencies, use the questions below to help find the right provider for your child. If you need help finding providers contact Wisconsin First Step at 1-800-642-7837.

When you call a provider agency, you should be prepared to answer a number of *intake* questions. This will include telling them about your child's current diagnoses and behaviors. Then you can ask the following:

### What services does your agency provide?

Agencies offer a range of services which may include: individual therapy, family therapy, group therapy or specialized therapy. Some agencies offer cognitive/behavioral therapy, like Applied Behavioral Analysis or ABA. They may also have support groups or other informal programs.

### Are there any age limits for services?

Some programs serve only adults so make sure you check that the agency serves your child's age group.

# I have \_\_\_\_\_ insurance; does your agency accept that?

This is a <u>critically important question</u> to ask before your first appointment! You do not want to wait for a visit only to find out that the provider does not accept your insurance or is not in your provider network. If your child is covered by Medicaid it is VERY important that you make sure the agency accepts Medicaid.

If your child has both private insurance and Medicaid, you should let the agency know. In most cases private insurance will be billed first and Medicaid will cover the cost of your co-pays or other costs not covered by private insurance.

# Do I need a referral from my child's doctor to be seen?

A referral is an order from a primary care doctor to see a specialist or get certain medical services. If a referral is not in place the health plan may not cover the cost of the visit. To learn about other coverage questions see the fact sheet "Questions for My Health Plan or Insurance Company" at familyvoicesofwisconsin.com/resources/affordable-care-act/family-voices-fact-sheets/

### ❖ Is there a wait list?

The reality is that there aren't enough mental health providers to serve everyone who could benefit from services. There may be a long wait before an initial visit will be scheduled or before ongoing therapy can be provided. This is where a family's advocacy skills and persistence can really help!

#### What can I do if I am on a wait list?

- Ask the agency if you can be put on a cancellation list
- Call back weekly to see where your child is on the wait list
- Ask about other options or group sessions if individual therapy is full
- Contact your child's doctor or school staff to see if they will call and advocate for your child.
- While you are waiting, consider informal supports available in your community such as support groups and school-based or faith-based programs.

If your child is in crisis or is facing out-of-home placement his or her doctor can refer you to treatment services where your child can be served immediately.

### What happens when my child starts being seen?

Most agencies will set up a meeting with you and your child and conduct an assessment. In addition, you may be asked to fill out intake paperwork and sign a "Release of Information" form so that they can share information with your child's doctor. Together with the therapist, you will come up with a care plan, including how long your child will be seen, and decide on goals.

After the first few therapy appointments, if you don't feel comfortable with the provider or are not sure he or she is a good fit for your child, you can ask to meet with one of the other providers at the same agency.

#### ❖ When and where will my child be seen?

Make sure the agency is in a place that is convenient for your family. Keep in mind that you may be going often. Some agencies have multiple locations so find the one that works best. Consider parking, public transportation and other factors that may make it easier or harder to get to appointments. Ask what days and times of day appointments are available. For example, some providers may offer evening appointments.

#### If you have questions or need help finding services contact the following agencies:

- Regional Centers for Children and Youth with Special Health Care Needs, a network of 5 centers dedicated to supporting families who have children with special needs at dhs.wisconsin.gov/cyshcn/regionalcenters.htm
- Wisconsin First Step, a statewide information and referral hotline, can assist families with finding mental health providers and other supports at 1-800-642-STEP (7837) or www.mch-hotlines.org/wisconsin-first-step









A Resource for Families Who Have Children with Special Health Care Needs

This fact sheet will help families find out how much services will cost and the paperwork required when looking for medical care, therapy services or other treatment for a child with special needs.

### 

If your child needs a new medical treatment or service and you are not sure if your insurance will pay for it, call the insurance company or health plan. Before your call, have the following information ready:

- > Your health insurance, HMO member number or plan identification number
- > The name of the medical provider and contact information, including the clinic address and phone number
- The number of visits requested, over what period of time (for example, 6 physical therapy visits, over the next 3 months)

#### Do I have a deductible? How much is it?

A **deductible** is the amount you owe for covered health care services before your insurance begins to pay. For example, if your **deductible** is \$1,000, your plan won't pay anything until you've met your \$1,000 deductible (paid \$1,000 out of pocket) for covered services. The deductible may not be applied to all services, including many preventive health services like immunizations and well-child visits.

## Do I have a co-pay or co-insurance?

A **co-payment** (or **co-pay**) is an amount you may be required to pay as your share of the cost for a medical service or supply, like a doctor's visit or prescription. A **co-pay** is usually a set amount, rather than a percentage. For example, you might pay \$20 each time you visit your doctor or pick up a prescription.

**Co-insurance** is the amount you may be required to pay as your share of the cost for services after you pay any deductibles. Coinsurance is usually a percentage. For example, you will be responsible for paying 20% of the bill for a doctor's visit.

### Is there an out-of-pocket maximum before the plan will pay for my care?

An **out-of-pocket maximum or limit** is the most you pay during a year (1 policy period) before your health plan starts to pay 100% for covered benefits. This limit must include deductibles, coinsurance, copayments or similar charges. This limit does not have to count premiums, amounts for non-network providers and other out-of-network cost sharing.

# Is the provider in my network? If not, who is in the network that offers a similar service?

A **network** is a group of providers that your insurance company or health plan works with most often. Staying within the network can help with coordination of your medical care. However, many health plans will cover the cost of seeing a non-network provider if a similar provider or specialist is not available within the network.

### Do I need a referral or prior authorization for services?

A **referral** is an order from your primary care doctor to see a specialist or get certain medical services. Many health plans require you to get a **referral** before they will cover the cost of care from anyone except your primary care doctor.

A **Prior-Authorization (PA)** is a decision by your health plan that a treatment or service is **medically necessary**. A PA is sometimes called an authorization request or prior approval. A provider will fill out the PA paperwork, have it signed by your primary care doctor and submit it to the health plan. You may ask for a copy and can provide additional information, especially if the PA has been denied and needs to be resubmitted.

### Can I have a copy of my Summary of Benefits and Coverage?

A Summary of Benefits and Coverage (SBC) is the explanation of services that are covered under your plan. It details the cost of care, such as co-payments and deductibles. The summary is the contract between you and your plan. It is not the marketing brochure you might get from your employer.

#### If you have questions or need help finding services contact the following agencies:

- Regional Centers for Children and Youth with Special Health Care Needs, a network of 5 centers dedicated to supporting families who have children with special needs at dhs.wisconsin.gov/cyshcn/regionalcenters.htm
- Wisconsin First Step, a statewide information and referral hotline, can assist families with finding mental health providers and other supports at 1-800-642-STEP (7837) or www.mch-hotlines.org/wisconsin-first-step





#### Updated September 2016

### What Are Outcomes?

# A Tool for Families who Have Children with Special Needs and Disabilities

As a parent or family member of a child with special needs, you might not think about asking your child questions like "What do you want to be when you grow up?" But taking the time to think long term and create "outcomes" can help your child reach the goals that matter most. By creating outcomes, you may learn about new options and resources.

This fact sheet provides information on creating outcomes which can be used for developing an Individual Service Plan (ISP) for the Medicaid Children's Long Term Support Waiver, but it can also be very useful for any child as you and your family partner with schools, health care providers and community services and supports.

#### What is an Outcome?

An outcome is a statement that reflects the values, goals and expectations of your child and family. Outcomes show what is important to your child and family. An outcome might state what your child hopes to achieve, or it may say what you need in order to maintain or improve your child's quality of life. Outcomes are defined by your child and family.

#### Why are Outcomes Important?

Outcomes focus on the concerns and issues that matter most to your child and family. They are centered on your child and family. By deciding on outcomes for your child and including them in your child's Individual Service Plan, you can receive the services and supports you and your family need to achieve these goals.

#### How is an Outcome Written?

Outcomes are written as your child and family members tell them. Your child will be encouraged to share interests, abilities, choices, and hopes for the future. Family members and those close to the child will share information also. The individual outcomes for a child living with family may contain some outcomes for the whole family. An outcome may not be important to your child, but important to the family in providing care for that child. That outcome may be included in the Individual Service Plan. Although an Outcome may support the family as a whole, the Medicaid Children's Long Term Support (CLTS) waiver can pay only for supports and services provided directly to your child.

#### How will the Support and Service Coordinator learn about our Outcomes?

Your Support and Service Coordinator will meet with you and ask you questions about your child and family. The Support and Service Coordinator will observe your child and family, and review written information.



#### Things to consider in defining outcomes:

- · What is going well for your child and family right now?
- · Who are the important people in the life of your child and family?
- Are there family members, friends, or others who are a support to your child and family? How do they help you?
- What is your child currently working on, maintaining, or wanting to change?
- Describe a typical day in the life of your child and family, be specific. What times are difficult for your child or family? What activities cause a problem? What is the best part of your child's day?
- What does your child most like to do?

#### How are outcomes included in the Plan?

Outcomes describe what is most important to you and your child. Outcome statements listed on the Individual Service Plan describe your concerns, desires, goals, solutions, or changes. The plan includes the supports and services that will help to achieve or maintain the Outcomes. It also lists those having a role or responsibility in achieving the outcomes. These statements will be written as you and your child have said them. You should agree to the outcome statements as they are written on the Individual Service Plan.

#### Examples of current child and family outcomes:

- I need to be able to get in and out of my house safely.
- I want John to play safely with his sister.
- I need a break so I can spend time with my other children sometimes.
- I need someone to watch Jill after school while I am at work.
- I want to graduate from High School.
- · I need help keeping our family safe.

#### "What if I don't know if my child's plan includes outcomes?"

If you are not sure whether Outcomes have been included in your child's Individual Service Plan or you would like a copy of the Outcomes, contact your Service Coordinator and ask for a copy.

## "What if things change and I want to have different outcomes included in my child's plan?"

Your child's Service Coordinator can meet with you and your family to talk about the changes in your child's life and can help update the Outcomes included in your child's Plan.

#### If you have questions or need help finding services contact the following organizations:

- Regional Centers for Children and Youth with Special Health Care Needs www.dhs.wisconsin.gov/cyshcn/index.htm
- Wisconsin First Step, a 24-hour hotline and resource database, at 1-800-642-7837



## YOU ARE AN ADVOCATE FOR YOUR CHILD WITH SPECIAL HEALTH CARE NEEDS!

Parenting a child with special health care needs is not easy. The 40,000 members of Family Voices, most of us parents, want you to know you're not alone on this challenging journey. We're there with you! And we've learned that the sooner we become advocates informed, strong voices for our children the smoother life becomes for our child and family. The following advocacy tips, based on years of experience from hundreds of families, focus on health which is the mission of Family Voices. You can use these tips with your child's doctor, hospital, clinic, therapists, preschool, child care center, classroom, community, and with extended family and neighbors. Always begin, of course, with one child...yours.

- 1. Believe with all your heart that your child, like all children, is wonderful --- even when she or he gobbles up so much of your time and energy. Tell all the world about this precious gift!
- 2. As soon as possible, connect with another family who also has a child with special needs. Talking with a parent who also never sleeps, feels inadequate, and is frightened will change your life. Meet the parent sitting next to you at a clinic or school meeting. Most communities have a parent organization, usually listed in the phone book, that brings experienced fathers and mothers together with new parents. They'll be your best teachers in helping you navigate this new, strange world.
- 3. Learn everything you can about your child's diagnosis --- from your pediatrician, early interventionist, therapist, or other parents. Look up the diagnosis on the Internet. If you lack a computer or can't use one, ask another parent, a teacher, or a teenager for help. In every community there is a place, perhaps a library, with free Internet access. Find out about services for your child --- special clinics, pediatric specialists, therapies, equipment, early childhood programs, and state and private agencies. Inquire about financial eligibility, free services, and, most important, where to get the best care.
- 4. Keep records. Of all phone calls, doctor visits, insurance bills, notices, and forms related to your child. Always take notes, including date and person you spoke with. If you're not a good note taker, bring a friend who is, or use a tape-recorder. Request copies of everything. Put this paperwork in one place --- a box in the kitchen, a notebook, and a bedroom drawer.

- 5. Become an expert on your child's health insurance plan, whether private or Medicaid. Know the benefits covered. Read everything from your insurance company, managed care plan, or Medicaid.
- 6. Develop strong partnerships with the professionals in your child's life. Your expertise about your child will help your child's professionals practice family-centered care. Find one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.
- 7. Know that YOU are your child's best advocate. No one else can do the job as well. Use all your information, contacts, friends and skills to advocate with kindness and humor. Teach your child to be an advocate, or prepare a sibling or friend to do so, because you won't be around forever. And please take care of YOU, so that YOU stay healthy.
- 8. Then, help another family. Learn to be a parent-to-parent supporter. Ask a parent group how you can be involved. Work with other families and professionals to improve care for all our children.
- 9. Look to Family Voices for assistance. Visit our website, www.familyvoices.org, or call us toll-free, 1-888-835- 5669, for brochures, books, websites, diagnoses, legislation, state parent groups, information in languages other than English, and training conferences.

NOW, GO FORTH AND ADVOCATE!

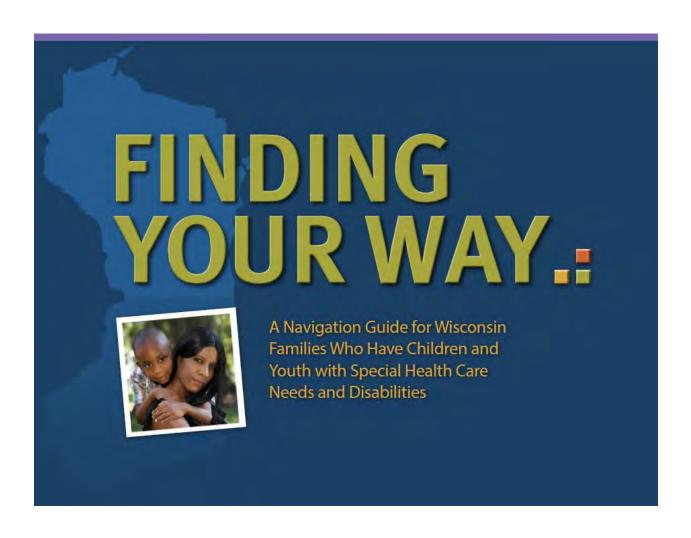
# **Appendix C:**

Resources

### FINDING YOUR WAY: NAVIGATION GUIDE

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.

This publication is available at the following link: https://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW e.pdf



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# Wisconsin Resources for Families of Children and Youth with Special Health Care Needs (<u>expanded search</u>)

#### Regional Centers for Children and Youth with Special Health Care Needs-

Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them. Free and confidential services include information, referral and problem solving, parent support, help understanding insurance coverage and applications, transition planning and connections to community resources. <a href="https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm">www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm</a>

Northern Regional Center: 866-640-4106Northeast Regional Center: 877-568-5205

Southern Regional Center: 800-532-3321
Southeast Regional Center: 800-234-5437
Western Regional Center: 800-400-3678

Alianza Latina Aplicando Soluciones- promotes the independence of people with disabilities by providing information and support to them, their families and their service providers in areas related to education and health. In English or Spanish, parents and families are supported with information and connections to community resources.

www.alianzalatinawi.org/ALAS.htm, 414-643-0022

**Birth to Three Program-** is part of the Bureau of Children's Services at the Department of Health Services and is a federally-mandated program providing early intervention services to support families of children with delays or disabilities under the age of three.

www.dhs.wisconsin.gov/health-care-coverage/health-care-coverage/birth-3-program, 800-642-7837

**Disability Rights Wisconsin-** is a private non-profit organization designated by the Governor to ensure the rights of all state citizens with disabilities through individual advocacy and systems change. DRW helps people across Wisconsin gain access to services and opportunities through its advocacy and legal expertise. www.disabilityrightswi.org, Madison 608-267-0368, Milwaukee 414-773-4646, Rice Lake 715-736-1232

Family Voices of Wisconsin- is a statewide network of families who have children with special health care needs and disabilities and those who work on their behalf. FVW 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.

www.familyvoicesofwisconsin.com 608-220-9598

**Great Lakes Inter-Tribal Council, Inc., CYSHCN Project-** provides information, resources and assistance to Native American families of children with special needs. <a href="https://www.glitc.org/programs/cyshcn/">www.glitc.org/programs/cyshcn/</a>, 715-588-1011

**Mental Health America of Wisconsin-** is a community-based network dedicated to helping all Americans live mentally healthier lives through advocacy, education, and the delivery of urgently needed programs and services. <a href="https://www.mhawisconsin.org">www.mhawisconsin.org</a>, 866-948-6483

**NAMI Wisconsin-** works to improve the quality of life of people affected by mental illness and promotes recovery by providing education, advocacy, and support. <a href="www.namiwisconsin.org">www.namiwisconsin.org</a>, 800-236-2988

**Parent 2 Parent of Wisconsin-** provides support to parents of children with special needs through a one-to-one connection with another parent who has similar experience and who knows firsthand about the feelings and realities that come with having a child with special needs. <a href="https://www.p2pwi.org">www.p2pwi.org</a>, 888-266-0028

**Supporting Families Together Association-** is Wisconsin's statewide member association for organizations and individuals committed to making every early childhood a great one. SFTA has ten Child Care Resources and Referral Agencies that assists families in finding child care that meets the needs of each family. <a href="http://supportingfamiliestogether.org">http://supportingfamiliestogether.org</a>, 888-713-KIDS

Waisman Center, University Center for Excellence in Developmental Disabilities-supports the full inclusion and self-determination of people with developmental disabilities and their families. The Waisman Center promotes and strengthens the participation of families with disabilities in partnerships with professionals and providers, community members and elected officials. <a href="www.waisman.wisc.edu/cedd/family.php">www.waisman.wisc.edu/cedd/family.php</a>, 800-532-3321

**Well Badger**- is a statewide information and referral hotline to assist Wisconsin families and providers working with children and youth with special needs. The line is operational 24 hours/day, 7 days a week. Parent Specialists, who have disability expertise and a child with a special need, answer the line Monday through Friday 8 a.m. to 4 p.m. <a href="https://wellbadger.org/">https://wellbadger.org/</a> 800-642-7837

### WI FACETS (Wisconsin Family Assistance Center for Education, Training &

**Support)-** FACETS parent leaders' (parents who have children with disabilities) mission is to provide and broaden opportunities that enhance the quality of life for children and adults with disabilities and their families, with an emphasis on educational support for underserved families in the community. <a href="https://www.wifacets.org">www.wifacets.org</a>, 877-374-0511

Wisconsin Board for People with Development Disabilities- advocates on behalf of individuals with developmental disabilities to foster welcoming and inclusive communities, and improve the disability service system. The Board's mission is to help people with developmental disabilities become independent, productive and included in all facets of community life. <a href="www.wi-bpdd.org">www.wi-bpdd.org</a>, 888-332-1677

**Wisconsin Family Ties-** is a statewide not-for-profit run by families for families that include children with emotional, behavioral and mental disorders. Parent Peer Specialists provide support, education, advocacy, and information and referral for families. Parent representatives are also involved on the local, state and national level to build awareness of family needs. <a href="https://www.wifamilyties.org">www.wifamilyties.org</a>, 800-422-7145

**Wisconsin Foster and Adoptive Parent Association, Inc.-** is a peer and volunteer-based organization that supports and advocates for foster and adoptive parents by offering training, support programs and helps to create and support different legislative measures with our fellow representatives in Madison. <a href="https://www.wfapa.org">www.wfapa.org</a>

**Wisconsin Head Start-** is a Federal program for preschool children from low-income families. Non-profit organizations, schools, community action commissions or other local grantees operate the Head Start program. Head Start supports Parent Affiliates to help guide the work of Wisconsin Head Start. <a href="http://whsaonline.org">http://whsaonline.org</a> 608-442-6879

**Wisconsin Medical Home Initiative -** promotes the concepts of medical home for primary care clinicians, families, and service providers throughout Wisconsin. Training, technical assistance and resources are provided to support medical home implementation with a focus in the areas of early identification of and timely referrals for children with developmental concerns, and behavioral health integration into pediatric primary care. <a href="https://wismhi.org/">https://wismhi.org/</a>

**Wisconsin Statewide Parent-Educator Initiative (WSPEI)-** experienced CESA-based parent liaisons work with families, educators and school districts to promote positive partnerships and provide technical assistance and information to parents in their CESA area. <a href="http://sped.dpi.wi.gov/sped\_parent">http://sped.dpi.wi.gov/sped\_parent</a>, www.wspei.org, 877-844-4925

**Wisconsin Sound Beginnings Program-** is part of the Maternal and Child Health Program at the Department of Health Services, promotes and supports universal newborn hearing screening and follow-up services statewide. Sound Beginnings also helps connect families to Parent Guides through the Wisconsin Guide-By-Your-Side Program.

www.dhs.wisconsin.gov/cyshcn/hearing-screening.htm, www.handsandvoic

es.org/services/guide.htm