

A thick, solid red wavy line that starts low on the left, rises to a peak in the middle, and then falls back down on the right, spanning across the upper half of the slide.

Promoting Family Understanding of Care Coordination

2019 QI Projects Summit

Presenter: Brigit Frank

Each family has a voice • Together, our voices will be heard

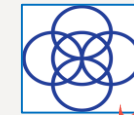
familyvoiceswi.org

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Family Voices of Wisconsin

Newsletters

Spring 2018

Family Voices of Wisconsin

The Home of Wisconsin's Family to Family Health Information Center
in Partnership with the Wisconsin Children and Youth with Special Health Care Needs

Storytelling with a Purpose

Families are often asked to share their stories because of the powerful impact that these stories carry. Many times, though, as much as families are interested in telling their story, they are unsure if they will be meaningful to others.

They may not know where to begin or how to wrap up their stories. And they might wonder what difference it would really make to share their family stories.

The Power of Family Stories
Stories are the things that people remember. When families share their "lived experience" with others, it makes their involvement with programs and systems real.

Stories paint pictures of family life and deepen the listener's understanding of the issues faced by children and families.

How to Share Your Story
When sharing your story, think about your audience and the impact that you want to make. Choose a "slice of life" to illustrate your point.

The hardest part may be deciding what pieces of your story to focus on and what details can be left out. Being brief and to the point with your story is usually best.

Where to Share Your Story
There are lots of opportunities to share family story. When you share stories with family and neighbors, you give them an opportunity to better understand your problem.

When you share your story and your end with the media, policy makers or elected your family story can explain an issue that concerns you and may offer a solution to the problem.

Remember, families offer unique and valuable perspectives. We know what works and what doesn't work, because we live the system, see inconsistencies, and sometimes have remedy inefficiencies in systems that policymakers may not see.

The newsletter insert provides a guide to personal or family story can be used to communicate with legislators or other officials. For more resources see the Family website under "Family Leadership."

Why Tell Your Family Story?

- Stories are what people remember.
- Makes problems real
- Deepens listeners understanding of children and families
- Helps policy makers make decisions to more supportive and responsive

Trainings

Training for Families Who Have Children with Disabilities or Special Health Care Needs

"Did You Know? Now You Know!" explains resources and services for children with disabilities and special health care needs from birth through young adulthood. Learn about health insurance and how to best use your benefits, Medicaid and long-term supports. **This training is free. Dinner and a resource binder will be provided.**

Topics include: Medicaid; Children's Long-Term Supports; prior authorization appealing a Medicaid denial; respite; partnering with your doctor; and more.

When: 5:00p.m.—Tuesday, August 21, 2018

Where: Waisman Center (8th floor), 1500 Highland Ave., Madison, WI

Register: Contact your Southern Regional Center at (800) 234-5437

Cost: **NO cost** to participants. Includes a light meal and resource binder. **Child care will be available on sight.**

Want to Learn More? Visit the Family Voices of Wisconsin website, familyvoicesofwisconsin.com.

This training is co-sponsored by the (Fill in Name) Regional Center for Children and Youth with Special Health Care Needs, Family Voices of Wisconsin and the Southern Regional Center.

Fact Sheets

Seguro de ingresos suplementario y niños con discapacidad

Esta hoja informativa le explicará el Supplemental Security Income (SSI) para niños con discapacidad y cómo se determina la elegibilidad. También proveerá recursos para aprender más sobre el proceso de solicitud de beneficios para su hijo/a.

Por favor tenga en mente – esta hoja será útil si usted está buscando beneficios de SSI para su hijo/a debido a su discapacidad y, como su padre o tutor, no recibe SSI o Seguro de discapacidad del seguro social (Social Security Disability Insurance - SSDI).

¿Qué es SSI?
El Supplemental Security Income (SSI) / Seguro de Ingresos Suplementario es un programa financiado con fondos públicos y gestionado por la Administración de Seguro Social Federal (SSA por sus siglas en inglés), que proporciona ingresos mensuales a un niño o un adulto que tiene ingresos, bienes o recursos limitados y que tiene una discapacidad, es ciego o es un adulto mayor.

¿Hay una edad mínima o edad máxima para que un niño sea elegible para el SSI?
No hay ninguna edad mínima, así que un niño puede ser elegible a partir de su fecha de nacimiento. Puede seguir siendo elegible hasta que cumpla 18 años de edad. Cuando un niño cumple 18, una nueva revisión médica tendrá que ser realizada y se debe cumplir con el criterio médico de adultos para seguir siendo elegible para el SSI.

¿Qué ingresos o recursos son considerados para determinar si un niño es elegible para el SSI?
Si un niño/a vive en casa con los padres, los cuales no reciben beneficios de SSI, el niño/a puede ser elegible para beneficios de SSI (ingreso mensual) dependiendo del ingreso de su hijo/a y una porción de los ingresos de sus padres y otros recursos. La Seguridad Social llama a la porción de los ingresos de los padres "ingresos estimados". Algunos de los recursos de la familia no cuentan para propósitos de los beneficios, incluyendo un auto y su casa. Hay más información disponible sobre ingresos y recursos en el sitio web de la Seguridad Social en www.ssa.gov/ssi/text-resource-ssi.htm

¿Qué criterios utiliza la Seguridad Social para decidir si mi hijo es elegible?

- Un niño debe tener un impedimento físico o mental (o una combinación de ambos) que resulte en una **marcada y severa limitación** en el funcionamiento y
- La condición debe haber durado (o se prevé que dure) por un año completo o que termine en la muerte.
- Si un niño es ciego, debe atenerse a definición legal de ceguera - ver los detalles completos en www.socialsecurity.gov/ssi/text-eligibility-ssi.htm#blind

Family Voices of Wisconsin - www.familyvoicesofwisconsin.com

We're a network of families who have children and youth with disabilities and/or special health care needs. Our work focuses on health care and community supports, education and information.

Listserv
fan@list.wisc.edu



familyvoiceswi.org



Overview of this Session

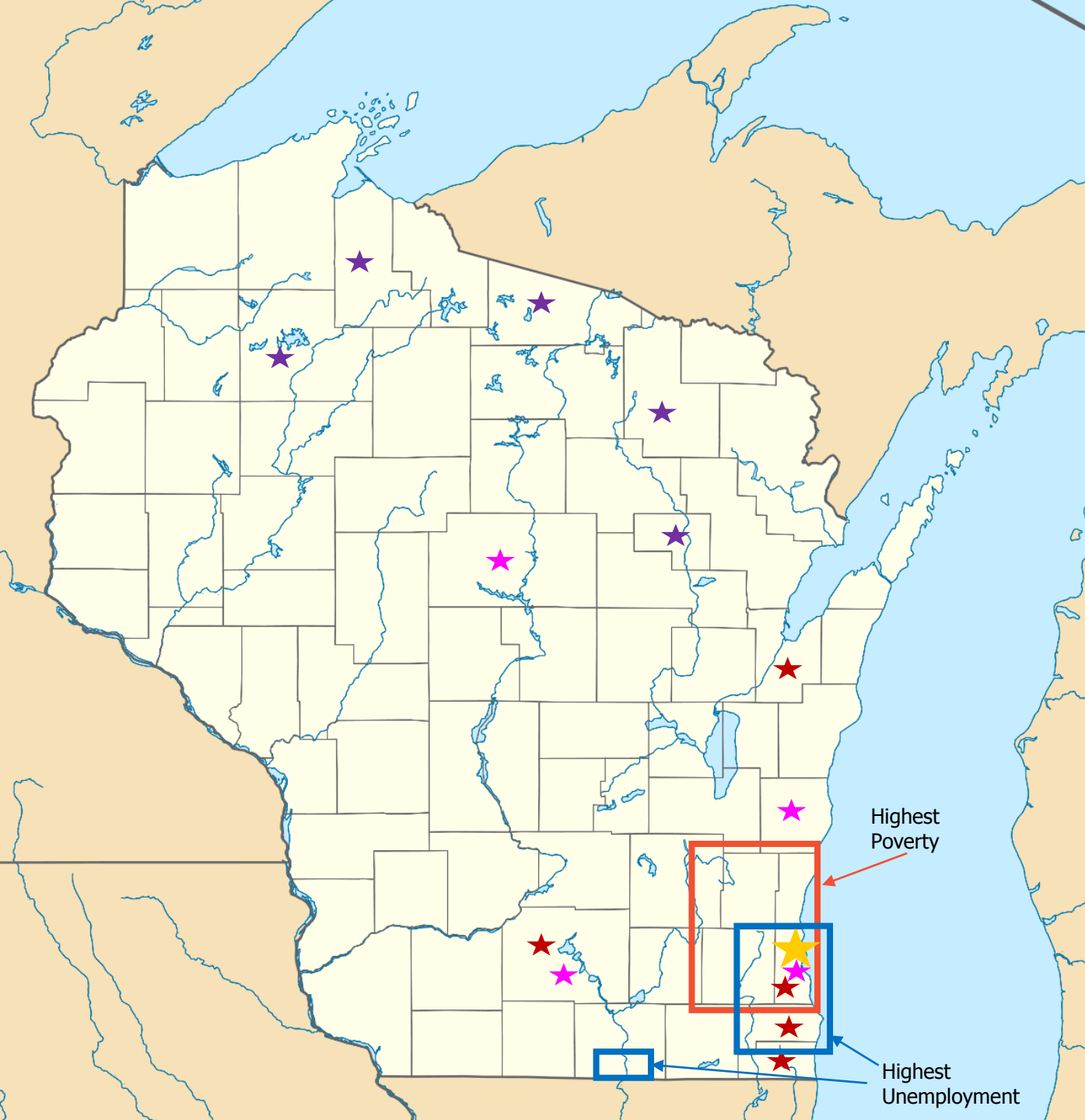
- Wisconsin Data
- Available Tools
- Including Families in the Care Team through Advocacy
- Lessons Learned in Pilot Program
- Final Thoughts and Questions

Wisconsin



- 91.5% of Wisconsin children were in excellent or very good health
- Wisconsin ranked 14th overall based on 30 measures of physical and social determinants of health
- Wisconsin ranked 12th overall for child well being





- Children in minority populations and those with special health care needs are at higher risk of not having a medical home
- Wisconsin ranks 44th in adequate health insurance for children, 39th in well-baby checks, and 50th in excessive drinking among women ages 18-44
- Black/white infant mortality ratio of 3.0 is one of the largest disparities in the nation

★ African American
 ★ Hispanic
 ★ Asian
 ★ Native American

Care Coordination: Why do we want it for Wisconsin Children?

Measure	Wisconsin %	Nation %
CSHCN with 11 or more days of school absences due to illness:	16.5	15.5
CSHCN with any unmet need for specific health care services:	24.5	23.6
CSHCN with any unmet need for family support services	8.0	7.2
CSHCN without a usual source of care when sick (or who rely on the emergency room):	11.2	9.5
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child:	24.4	22.1
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care:	11.0	13.1

Why Build this Home?

Families that have a Medical Home have:

- Children who get a higher quality care overall
- Greater access to community services
- Understanding of how to navigate the medical system
- Improved self-advocacy skills
- The opportunity to connect with other families
- Knowledge to maintain health and living

This content has been adapted from:

Antonelli RC, Browning DM, Hackett-Hunter P, McAllister J, Risko W.
Pediatric Care Coordination Curriculum. Boston Children's Hospital, 2012.

Comprehensive Care Coordination in a Medical Home Leads to:

- Greater access to community services
- Improved skills for self-advocacy
- Opportunity to connect with other families
- Knowledge to maintain health and living
- Greater capacity to navigate the system

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Antonelli RC, Browning DM, Hackett-Hunter P, McAllister J, Risko W.

Pediatric Care Coordination Curriculum. Boston Children's Hospital, 2012.

*Using Tools to
Engage Families*



We Have the Tools to Engage Families

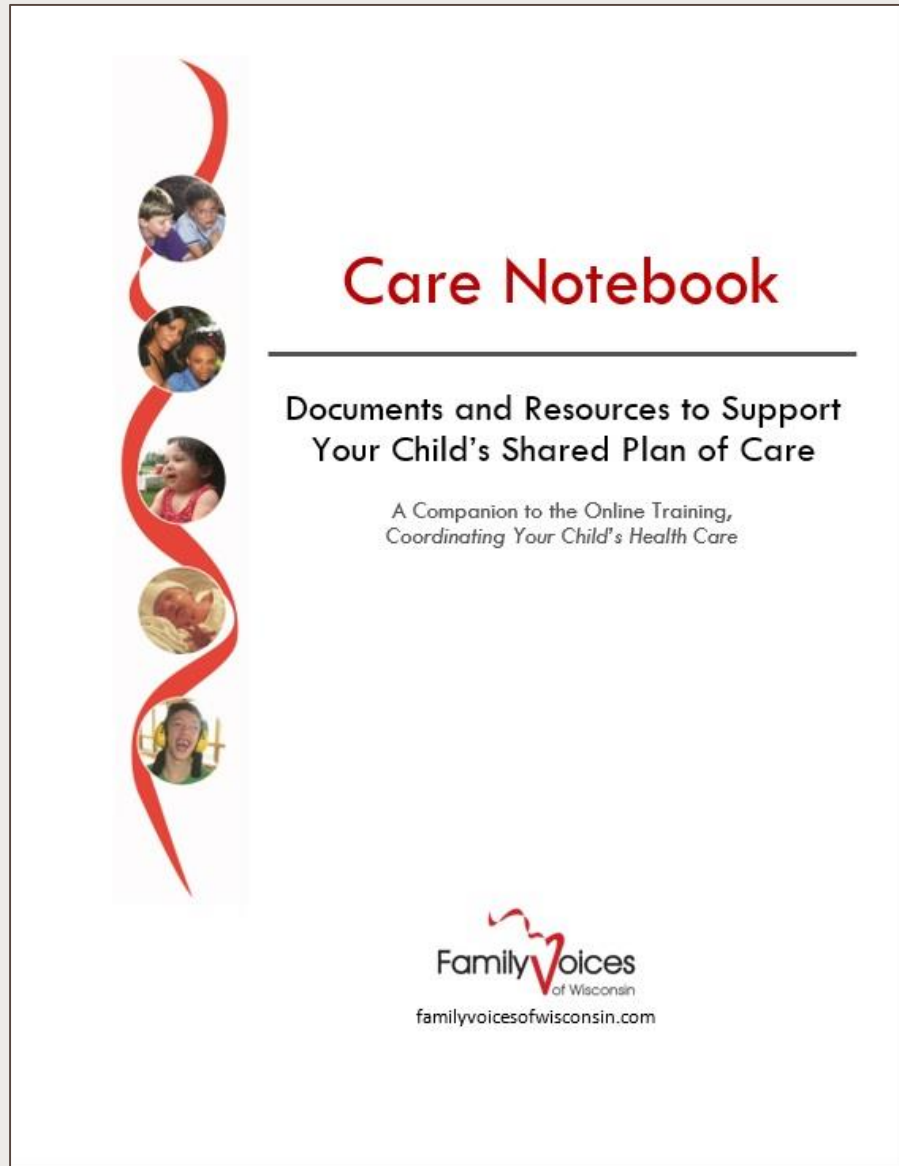
Coordinating Your Child's Healthcare

- 40-minute online training
- On the Family Voices of Wisconsin website, familyvoiceswi.org
- Spanish language available
 - Old version
 - Written materials will be translated soon
 - Contact Family Voices for Spanish language materials

Our Team



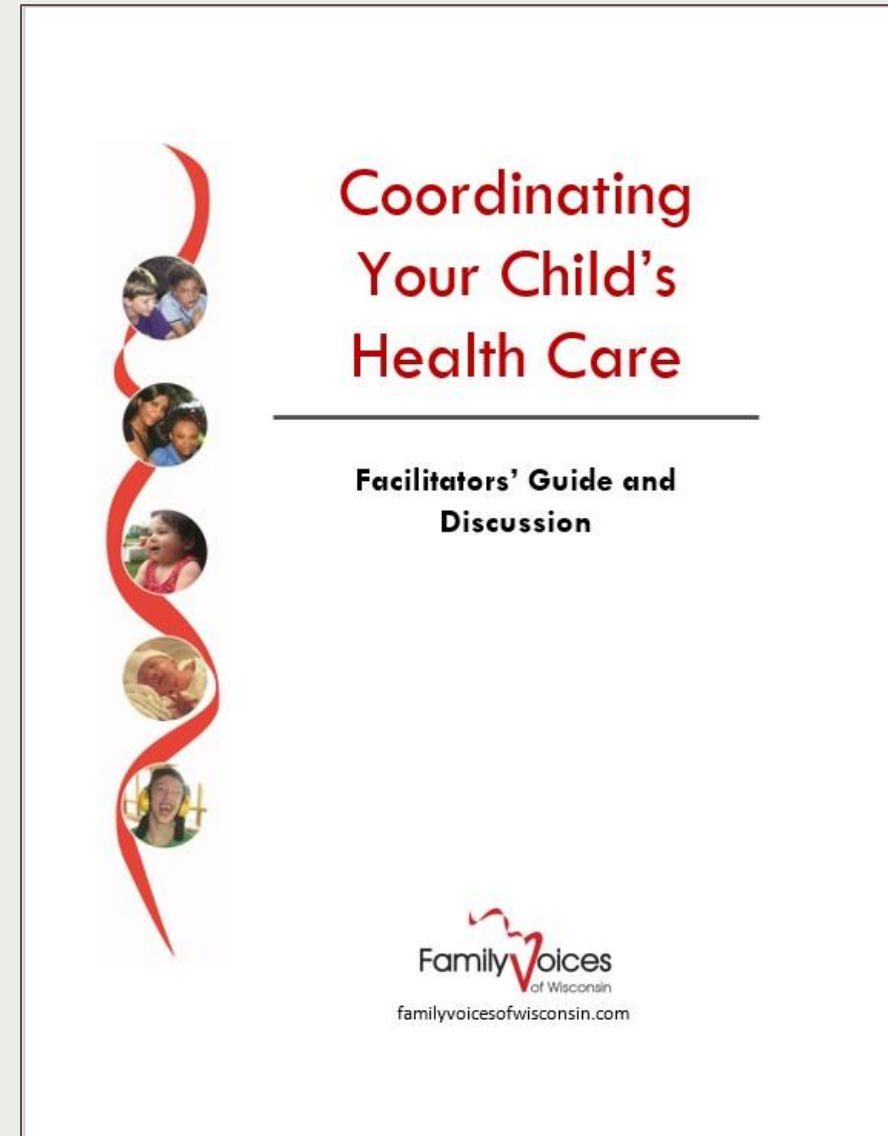
The Need for a Care Notebook



- Definitions
- Care Mapping Directions and Template
- Start Building a Medical Home Materials
- Creating a Shared Plan of Care Directions and Example
- Wisconsin Resources for CYSHCN
- Health Care Provider Contact Information Form
- FDA's My Medicine Record
- Insurance Company Contact Information Form
- Medical Equipment Supply Information Form
- Agencies to Support my Family Form
- Family Voices of Wisconsin Fact Sheets
- A Navigation Guide for Families who have CYSHCN and Disabilities

Facilitators' Guide

- Training Overview Preparedness
- Tips for Facilitators—Before, During and After
- Discussion Questions
- Training Flyer
- Potential Community Partners for Outreach
- Evaluation Form
- Materials Needed Check List
- Training Sign-In Sheet



Mental Health and Behavioral Health Services for My Child

Where Do I Begin?

When to Get Help

Parents are usually the first ones to be concerned about their child's behavior or emotions. Sometimes it is hard to know when to act on your concerns, or whether the behavior is just part of typical development. But when the challenges are causing disruption for your child and family over time and are getting in the way of age-appropriate activity, it may be time to seek help.

Some examples of behavior that may indicate your child needs help include: feeling sad or withdrawn for weeks at a time, severe mood swings, major changes in behavior or personality, extreme over-eating or dieting, not being able to sit still or pay attention, intense worries that get in the way of daily life, or any behavior that is harmful to themselves or others.

Where to Start

Don't be afraid or embarrassed to reach out and seek help for your child. *Did you know that one in five people struggle with mental illness and half of all mental illness starts by age 14?* With treatment and support, most children and teens can learn to cope with challenging behaviors, can develop close relationships and can gain the skills to lead successful lives. (NAMI - www.nami.org).

◆ Talk to your Child's Doctor

For most families, the first step is to make an appointment with your child's primary care doctor and talk about your concerns. Your child's doctor can help recognize behavior that is outside the typical range, and can make referrals for further diagnosis or evaluation. You may want to write down your thoughts and keep track of when you first noticed the concerning behavior, how often you see it and what seems to trigger that behavior.

◆ Talk to Family-Support Agencies

Connecting with family support organizations can be a critically important part of helping families on their journey. **Wisconsin Family Ties (WFT)** at 1-800-422-7145 is staffed by parents who have children with mental health challenges. They will talk to families about where to begin, how to find help and how to partner with your child's school. **NAMI Wisconsin** (namiwisconsin.org) at 1-800-236-2988 and **Mental Health America of WI** (www.mhawisconsin.org) at 1-866-948-6483 provide information and advocacy for families who have children with mental health concerns.

◆ Talk to your Child's School

Most schools have a social worker or school psychologist who can help you find resources and services. You can discuss services available during the school day and whether your child may qualify for special education services. To learn more about special education go to the [DPI website-dpi.wis.gov](http://dpi.wis.gov) and see [Special Education in Plain Language](#). To learn more about best practices in school mental health see [The WI School Mental Health Framework](#).

Mental Health and Behavioral Health Services for My Child

Treatment and Program Options for My Child

What Treatment and Programs Are Available?

There are many programs and treatment options for children and teens who struggle with mental health challenges. Parents and caregivers should not feel embarrassed or afraid to seek help for a child. **Starting early and partnering with your child's primary care doctor to find the right treatment and services can make a life-long difference for a child.**

Treatment Options

There are two primary types of treatment, **psychotherapy and medication.**

- **Psychotherapy**, also known as "talk therapy," is when a person speaks with a trained therapist in a safe and confidential place to explore and understand feelings and behaviors and gain coping skills.* Cognitive Behavioral Therapy is one form of psychotherapy used commonly for children with mental health challenges. To learn more go to the National Institute of Mental Health website at nimh.nih.gov/health/topics/psychotherapies
- **Medications** may be an important part of your child's treatment plan. While school may recommend medication, you and your child's doctor will need to determine if medication is appropriate. The doctor (usually a psychiatrist or primary care doctor) can write a prescription, closely monitor your child and adjust the dose if needed. **Don't be afraid to ask questions or contact the doctor if you are concerned that your child is having side effects.** Go to parentsmedguide.org to learn more about medication as a treatment option.

Program and Treatment Settings

Mental Health programs and services can be provided in a variety of settings for children and teens. A few examples include private practice, community mental health agencies, residential care centers and psychiatric inpatient units. To find programs and agencies in your area contact Well Badger Resource Center at 1-800-642-7837 or wellbadger.org

- **Private Therapy Practices** - Individual, family and group therapy sessions are held in different settings, most commonly **private practice**. A professional in private practice may work out of an office, clinic or his or her home¹⁴. Mental health professionals who provide therapy in private practice may include: psychiatrists (medical doctors), clinical psychologists, marriage and family counselors and clinical social workers. Go to mentalhealthamerica.net/types-mental-health-professionals to learn more.

Mental Health and Behavioral Health Services for My Child

Waiting for Services

In most parts of Wisconsin there are not enough mental health providers to serve every child who could benefit from their services. This means that families may experience some wait time before their child can be evaluated or be seen by a mental health or behavior health provider.

What Can Families Do While Waiting for Services?

While waiting for formal services can be frustrating, parents/family members can be actively involved in finding programs and informal services. **You can also advocate for your child and do what you can to get your child off the wait list.** Below are some ideas for families as they wait:

- If you are waiting for an appointment, ask if you can be put on a cancellation list. You should also call back regularly to see where your child is on the wait list. If you are waiting for private therapy, ask about other options like group therapy or support groups.
- Talk to your child's school social worker or school psychologist about incorporating some supports into the school day. School may be able to access a behavioral consultant who can work with your child and their teacher during the school day.
- Look for supports in your community that can help you and your child while you wait for more formal therapy services. The **Regional Centers for Children and Youth with Special Health Care Needs or Wisconsin Family Ties** (see [contact information](#) on page 2) can help you find local groups and supports.
- Connect with your **County Human Services Department** to learn about county-based supports, including "wraparound" services or contact **Well Badger Resource Center at 1-800-642-7837**.
- Connect with other families either in person or online. Other families can share their experiences and help you learn about resources, providers and programs. Parent to Parent of WI (P2P) is a statewide program that matches families who have a child with similar needs or who live in the same area. See [page 2 for contact information for Parent-to-Parent](#).

If your child is in crisis there are programs to help your child and family that do not have wait lists. Your child's primary care doctor and clinic can help you find crisis mental health programs.

Mental Health and Behavioral Health Services for My Child

Paying for Mental Health Care

If your child or teen needs mental health or behavioral health treatment services one of the first questions you might ask is *how will I pay for it?*

Private Insurance

If your family is covered by private health insurance, your health plan should cover the cost of therapy and prescription medications. Most private insurance plans are now required to cover mental health and substance abuse services at the same level as other medical services, as required by the Affordable Care Act. *Be aware that private self-insured plans don't have to cover these services, so check with your employer benefits department.* Also, while most private insurance plans can't deny paying for mental health or substance abuse services, they can limit which providers are covered (for example, only providers in their network) and the total number of visits per year.

You will be responsible for **deductibles** (your up-front cost before the plan starts covering any medical services) and **copays or coinsurance** (a set amount per visit or percent of the bill you are responsible for paying).

How Do I Find Out if a Specific Provider or Service Will be Covered?

Start by calling your health plan's **Members Services Department** to verify that the provider will be covered under your plan. Have your **member identification** available as well as the **name and address of the provider, the type of treatment and the number of visits** recommended.

You can also learn more by reviewing your written benefits summary, called the **Summary of Benefits and Coverage (SBC)**. If you don't have a copy, your health plan can send you another. It may also be available online. If you are starting the process of finding a provider, review your plan's **Network of Providers and preferred clinics**.

Private Pay

Some therapists or other mental health providers do not accept private insurance or Medicaid. Clients are billed directly for services. However, many providers will work with families to ensure that the services are affordable. For example, they may have sliding fee scales (bills are based on your family's income or ability to pay) or bills can be paid over time. Before your child is seen, it may be helpful to discuss payment options with the provider or their billing staff.

Mental Health Fact Sheet Series

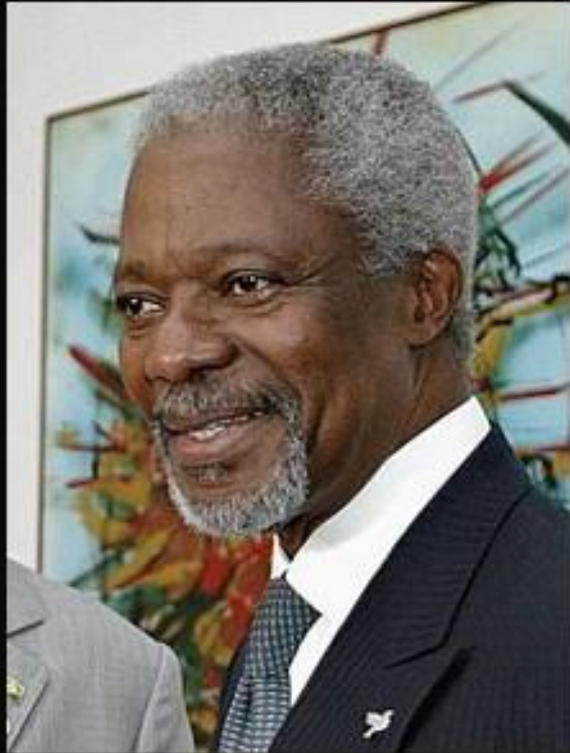


*Family advocacy driving
care coordination for
children in a state where
the concept is in its
infancy*

Spreading the Word

“Hello, I don't want to be the one who is negative but I wanted to mention that I have taken the training which has great information but unfortunately there is nothing in place to support it. My husband and I, at the end of the day, are the coordinators/managers and it's exhausting even when dealing with a rather large hospital as Children's and having social workers to support us. Hoping the providers will get on board some day! —Thank you!”

Advocacy Grows One Family at a Time



Knowledge is power. Information is liberating.
Education is the premise of progress, in every
society, in every family.

(Kofi Annan)

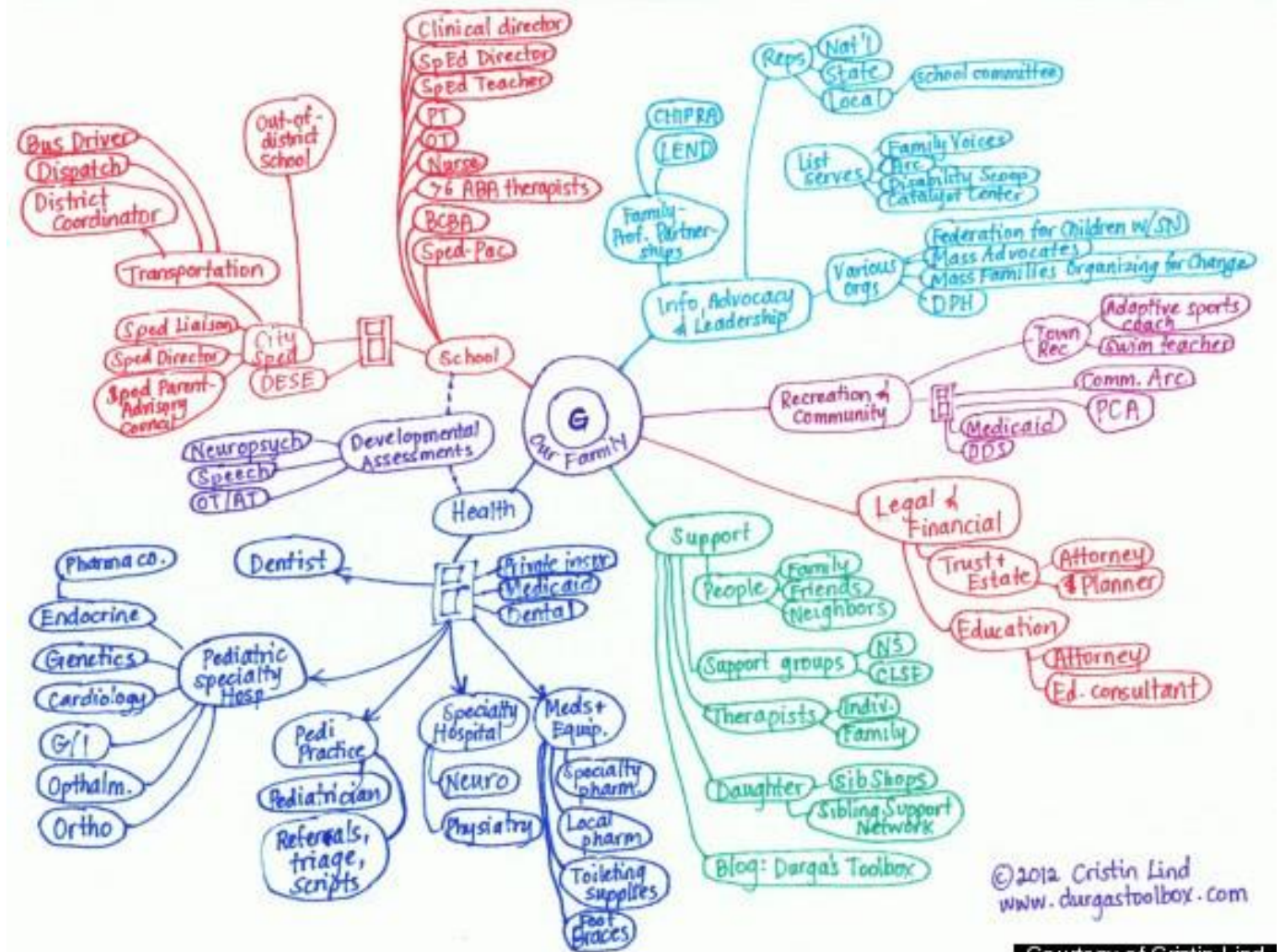
Educate and Empower



**Introducing the Amazingly
Convenient Medical Home.
Now Available with Care
Coordination!**

- ✓ **It organizes your entire family!**
- ✓ **It's a time saver!**
- ✓ **It's a memory booster!**
- ✓ **It lets you see the whole picture!**
- ✓ **It helps you predict the future!**






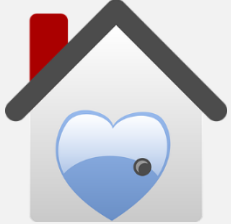



See the Whole Picture!



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www.durgastoolbox.com

Courtesy of Cristin Lind

Solve a Problem

<p>Important Family Members</p> <p>Immediate family Extended family Friends like family</p> 	<p>Recreation/Community/Social</p> <p>Special Olympics After School Program/Clubs Adaptive Classes Summer Camps Hippo Therapy</p> 	<p>Legal/Financial</p> <p>Trust/Estate Attorney Economic Services Social Security Employment</p> 
<p>Health</p> <p>Doctors Insurance/Medicaid Dentist Hospital Pharmacy/Medications Specialists OT/PT/Speech Equipment</p> 	<p>Education</p> <p>School Transportation Special Education Regular Education School District Nurse Case Manager Lunch / Recess</p> 	<p>Home Care</p> <p>Respite Private Duty Nurse Personal Care Worker Home Health Services Guide Dog Child Care Vacation</p> 
<p>Social Services</p> <p>Case Manager Programs WIC Birth to Three Early Intervention Waiver Programs</p> 	<p>Advocacy and Information</p> <p>Children & Youth with Special Health Care Needs ABC for Health Family Voices of WI Representatives – local, state, national</p> 	<p>Support</p> <p>Spiritual Community Parent to Parent Parent Support Groups SIBShops Blogs</p> 

People Learn Differently

Learning Styles

Visual (special): Learn best by seeing

Auditory (aural): Learn best by hearing

Reading/Writing: Learn best by reading and writing

Kinesthetic (physical): Learn best by moving and doing





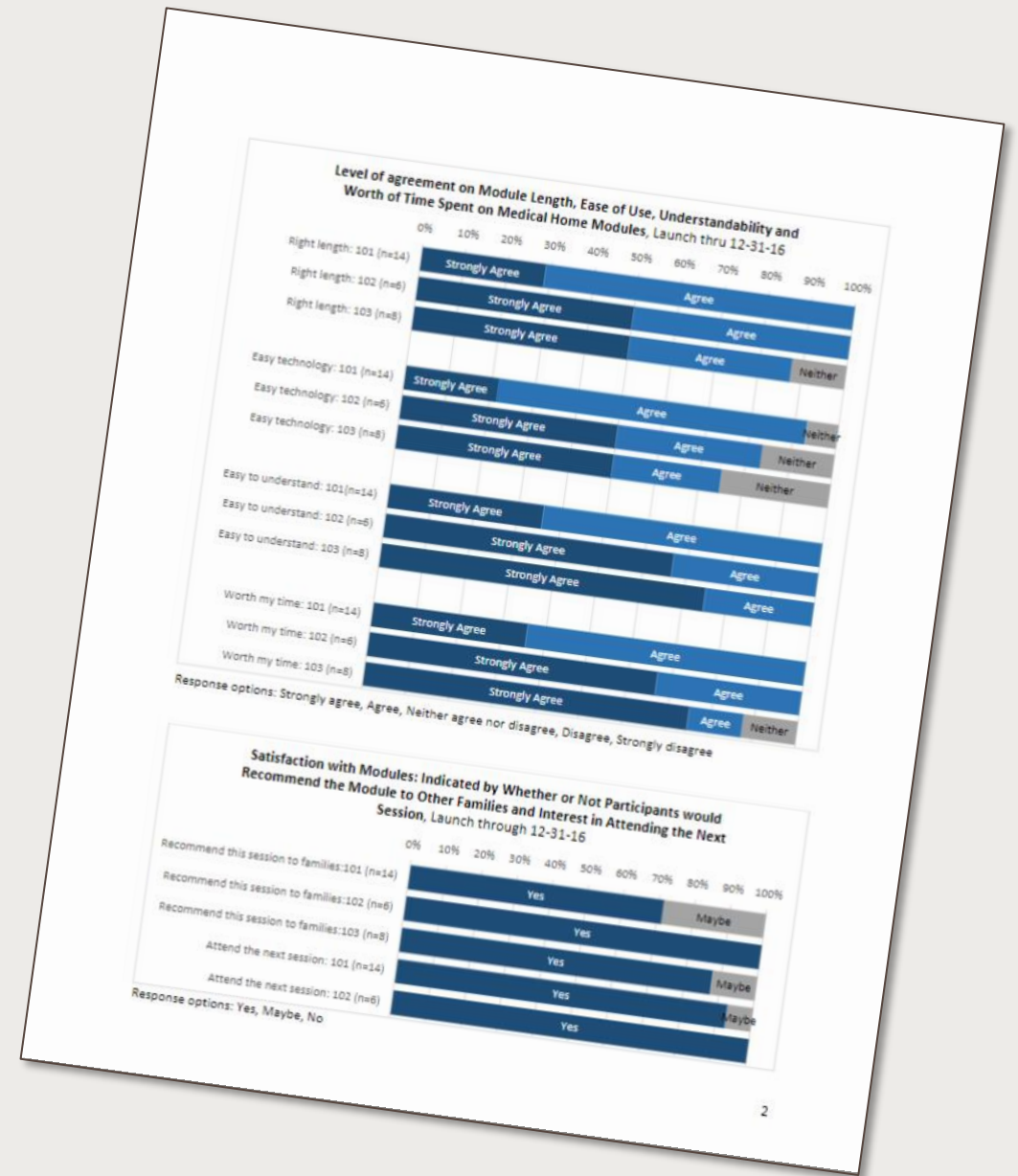
It's a Time Saver!

Lessons Learned

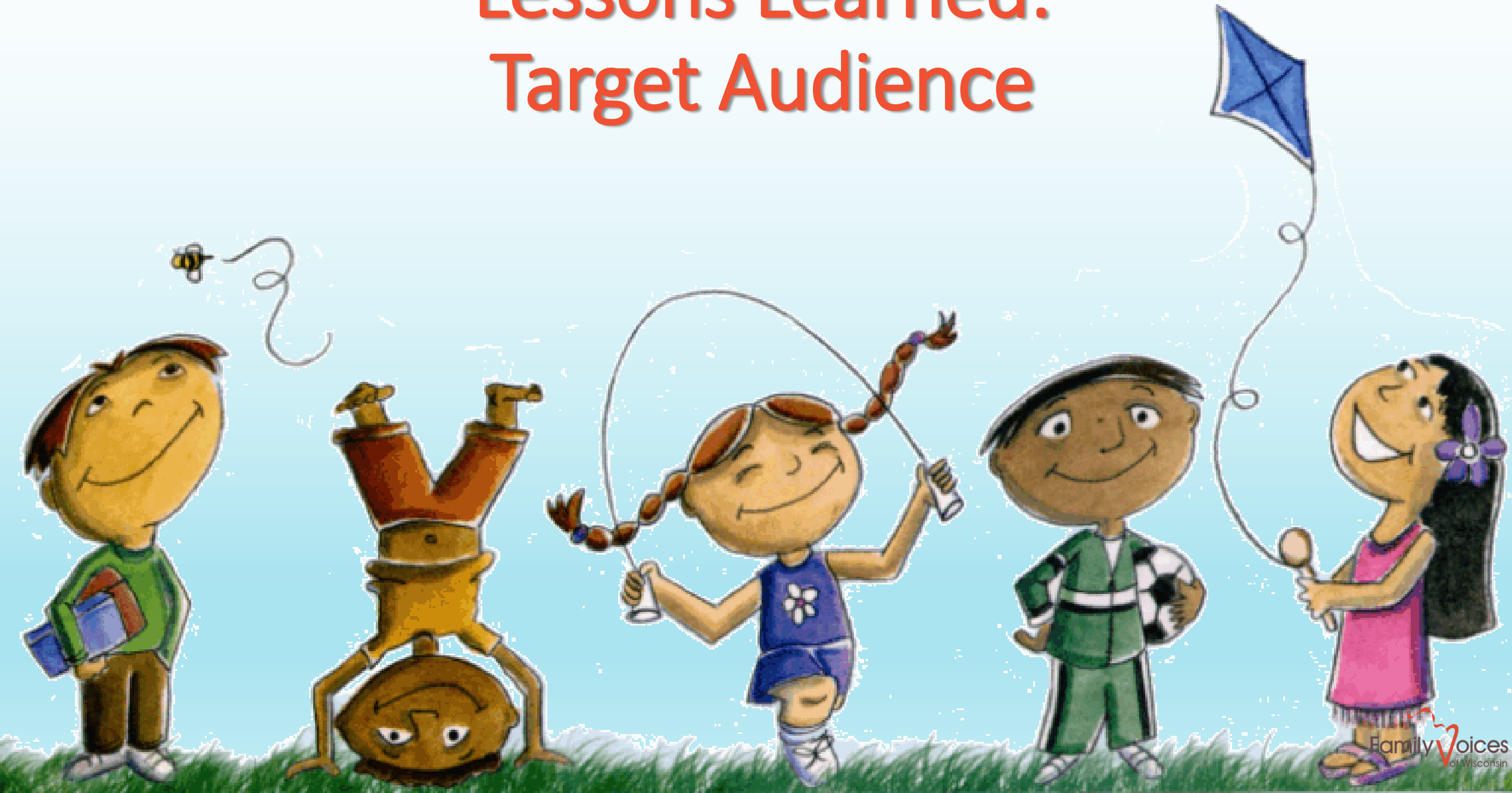




The Importance of Constant Feedback



Lessons Learned: Target Audience



Lessons Learned: Outreach



COMING
Soon

Engaging Families in Care Coordination

- Be aware of different reading levels
- Think about issues with technology
- Try to be flexible in partnering with families



Questions

Contact Information

Family Voices of Wisconsin
familyvoiceswi.org

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