
DID YOU KNOW? NOW YOU KNOW!

**An Introduction to Health Care Coverage and
Community Supports for Children and Youth with
Disabilities and/or Special Health Care Needs**

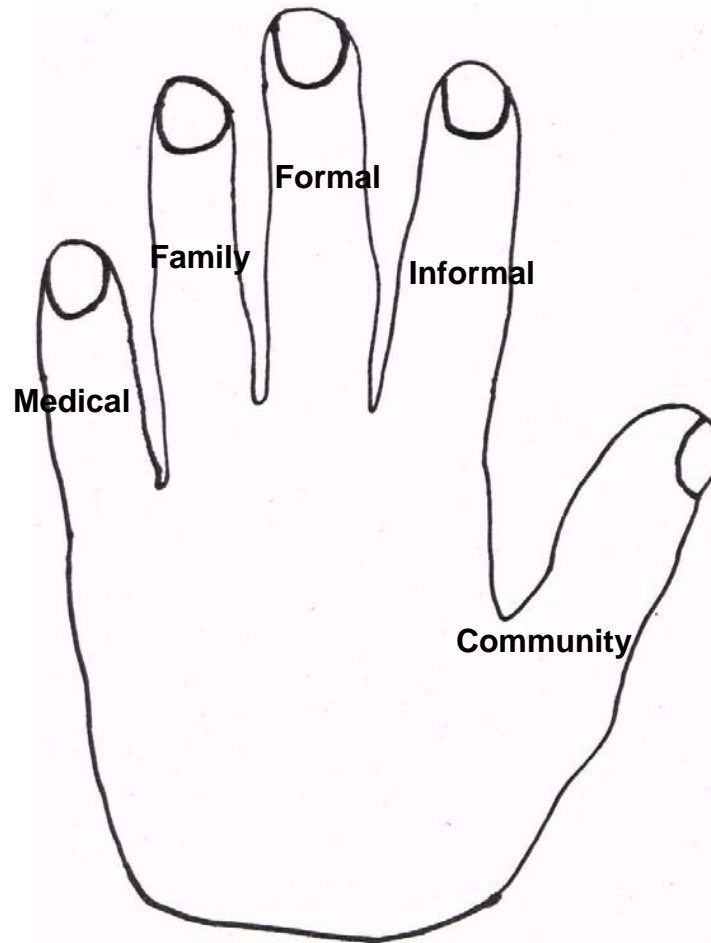
A Family Voices of Wisconsin training sponsored by
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Southern Regional CYSHCN Center

September 20, 2007

MODULE I:

Parents & Partners on a Journey

What Do I Have At My Fingertips?



Rosin P., Green M., Hecht L., Tuchman L., & Robbins, S. (1996). Pathways: A training and resource guide for enhancing skills in early intervention service coordination. Madison: University of Wisconsin-Madison, Waisman Center.

Our Story: A Parent's Journey

Meet Brad, Angelina and Family

Our Story: A Parent's Journey

Consider Brad and Angelina Fitt and their two children, Apple, age 3, and her newborn sister Kiwi. It seemed as if the family's life changed the day Kiwi was born. Kiwi had a difficult birth and lost oxygen to her brain during delivery.

Shortly after Kiwi was born, she was rushed to the local children's hospital and spent five weeks in its Neonatal Intensive Care Unit or what the nurses called "the nick-you" (NICU). "Brangelina", as these parents preferred to be called, were glad some places had short nicknames too.

Our Story – A Parent's Journey, continued

A renowned specialist, Dr. Phil, told Brangelina that Kiwi likely had cerebral palsy and that she would have developmental delays as she grows. This was difficult news.

While the Fitt's were in the NICU, the hospital's fabulous social worker, Oprah Bornfee, got to know the family and shared with them many resources that she felt could be helpful to them. (She had learned much of this from her years as a T.V. talk show host before fulfilling her dream of becoming a social worker.)

Our Story - A Parent's Journey, continued

Brangelina knew nothing about disabilities. They simply couldn't take in all the information that was given to them by Oprah, Dr. Phil and many other well meaning individuals.

Their good friend, parenting expert Britney Shears, was one of the only friends who actually stopped by and congratulated them. She said, "Special children are only given to special people."

Our Story – A Parent's Journey, continued

Brangelina didn't know what to think. They didn't feel special. They mostly felt overwhelmed.

Oprah left the family with some brochures for some local programs and her business card which were now stuffed in a folder by Kiwi's crib.

Questions and Considerations

- What is different about having a child with a disability or a special health care need?
- What has been most helpful to you as you learn about health care and community resources?
- What has been most difficult part in learning about these resources?

The Learning Journey

Remember:

- Raising a child with a disability is hard – it presents additional challenges.
- Well-meaning professionals will attempt to provide information to parents whether they are ready or not.
- Parents should ask for information in a format they are comfortable with.

The Learning Journey, continued

- Friends and professionals will say/do the “wrong” thing. We choose how to react.
- This is a lifelong journey - parents cannot know everything there is to know.
- Parents know their child best and must always bring that expert perspective to any conversation.

More Information

HANDOUT

Useful Web Sites for Parents of Children with Special Health Care Needs



More Information

HANDOUT

Advice to Professionals Who Must “Conference Cases”

By Janice Fialka

www.danceofpartnership.com

Partners on the Journey

**What do Parents Bring to the Table
When Working in Partnership
With Others?**

Our Story, Partners on the Journey

One of the most useful connections that Oprah Bornfree made for the Fitt family was to the Birth to Three program in their county. Oprah made sure that the new, flashy B-3 Coordinator, Beyonce', met the family in the hospital before Kiwi was discharged.

Beyonce' then set a date to visit with the family at home the following week. Beyonce' explained that her title was something called a service coordinator and she would help the family figure out what they needed to support Kiwi.

Our Story – Partners on the Journey, continued

Brad and Angelina were more excited than two movie stars on Oscar night! How wonderful, they thought, that there was someone who could help them with all of Kiwi's needs.

Then Beyonce' asked Brangelina what type of support they'd like for Kiwi in the next few months.

"Why is she asking us?" they thought. She's obviously the expert.

Questions and Considerations

- Who helps you in support of your child?
- Do you have more than one support person?
- If so, do they partner with each other?
- What do you see as your role in discussions with these partners?

Parents Know Things No One Else Knows

- A parent is a child's first and best advocate.
- A parent is the most important person in a child's life. Parents have expertise about their child no one else has.
- Parents of children with special needs may need to develop relationships with people they had not expected.
- Parents might have to communicate and voice their opinions more often than they are comfortable with.

Effective Communication

**I am the parent
of a child with special needs.**

What is Effective Communication?

Effective Communication means:

- ❑ Expressing your needs clearly and directly
- ❑ Expressing your ideas without feeling guilty or embarrassed
- ❑ Sticking up for what you think your child needs - even though the "experts" might not agree
- ❑ It may also mean not having to agree with the said experts or providers

Effective Communication Does **NOT** Mean:

- Being angry, aggressive or offensive
- Being indirect
- Feeling too guilty or afraid to express your needs
- Agreeing with professionals no matter how you feel because you think professionals know best

What is an Advocate?

1. One that argues for a cause; a supporter or defender.
2. One that pleads in another's behalf.

*To advocate is to speak,
plead, or argue in favor of.*

How to be an Effective Advocate

- You can disagree without being disagreeable
- be well informed, calm, prepared and persistent
- Remember your goals - take one issue at a time
- Set reasonable goals - set one goal and try to be clear and focused

How to be an Effective Advocate, continued

- Think about where you might be willing to compromise. Agreeing on part of an issue is often a start in the right direction.
- Express your feelings without blaming messages - "I" messages rather than "You" messages
- Stay informed - read newsletters, check out websites, attend workshops, talk with other parents, participate on advisory committees.

How to be an Effective Advocate, continued

- Parents should continually bring up concerns and ideas about their child to partners
- Remember that partners often have high caseloads; it is helpful when families communicate regularly

What Do You Do When Communication Gets Challenging?

- Sometimes communication gets hard
- Know when you need to take a break
- Take a look at yourself. How can you make the situation better?
- Ask a trusted friend how you might be perceived
- Vent!

Who Are Possible Partners?

Partners are people whose paid job it is to help you and your child

You may find partners here:

- ❑ Birth to Three Program
- ❑ Medical Office - Doctors and Nurses
- ❑ Schools
- ❑ Family Support Programs
- ❑ County Programs
- ❑ Child Care Programs

What is the Role of a Partner?

A Partner May Provide:

- ❑ Direct service to children and families
- ❑ Professional expertise
- ❑ Ideas about resources
- ❑ A written plan
- ❑ Access to funding
- ❑ Service coordination

What Plans Might You Develop with a Partner?

- Individual Family Service Plan (IFSP, used in Birth to 3)
- Individualized Education Program (IEP, used in public schools, ages 3 - 21)
- County Individualized Service Plan (ISP, birth to death)
- Medical Care Plan (for medically involved individuals) or Emergency Care Plan
- Others

What Plans Might You Develop with a Partner?, Continued

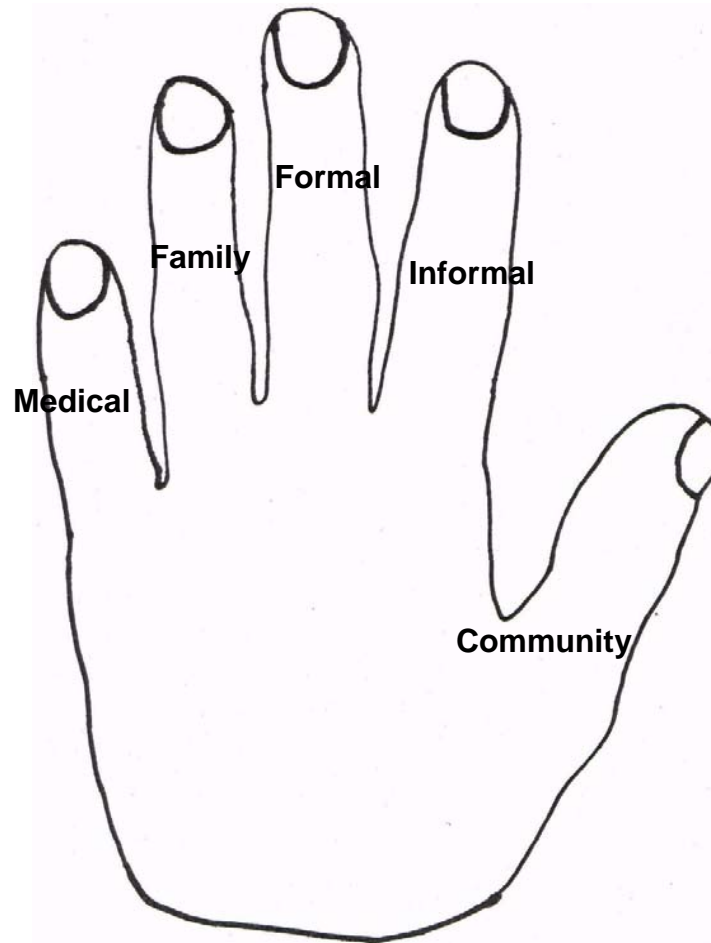
- Some service plans are legal agreements and some are less formal.
- A service plan should support communication about your family's priorities and define services for your child.
- A service plan should be clear and to the point; word choice matters.

More About Our Partners

HANDOUT

- **What can a Partner do for me?**
- **What can I ask a Partner?**

Now What Do I Have At My Fingertips?



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Family Support 360, Southern Regional CYSHCN Center & Wisconsin First Step

- **Family Support 360: 261-9139**
- **Southern Regional CYSHCN Center:**
 - 263-5890
 - 1-800-532-3321
- **Wisconsin First Step - 1-800-642-7837**

Contact Us!

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