
MODULE II

Public Supports Systems Available to Assist You and Your Child

FAMILY VOICES OF WISCONSIN

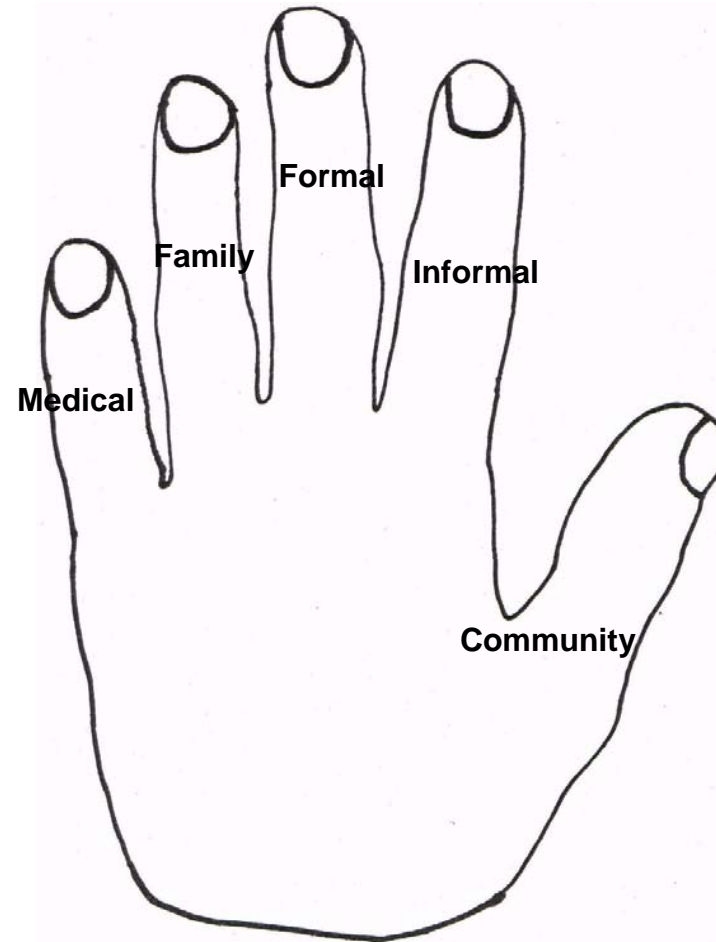
DID YOU KNOW? NOW YOU KNOW!

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

MODULE II:

**Public Support Systems
Available to Assist You and Your Child**

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: Finding Support

Meet Brad & Angelina Fitt

Our Story: Finding Support

Their names might sound familiar, but you really don't know Brad and Angelina Fitt. Still, their story could be anyone's.

Brangelina, as the couple likes to be called, have two daughters - 3-year-old Apple and 3-month-old Kiwi. "Good thing our little fruits don't spoil!" Brad likes to joke.

Our Story: Finding Support - continued

But, all kidding aside, things are becoming overwhelming for the Fitt family. Shortly after birth, Kiwi was diagnosed with cerebral palsy. Even though she's stable and out of the hospital now, she still requires considerable care. Angelina tries her best to make sure Apple doesn't feel left out, but it's getting harder each day. The Fitt's mention this to Beyonce', their somewhat flashy Birth to 3 service coordinator.

Our Story: Finding Support, continued

Beyonce' realized that between her high caseload of families and after work karaoke engagements, she had forgotten to make a referral to the county Family Support Program.

Beyonce' talked to Brad and Angelina about respite care and other services that Kiwi might be eligible to receive. Brangelina were still confused. How do all these services work together? Why do they have to apply for each one? Why is their service coordinator wearing sequins?

Our Story: Finding Support, continued

Beyonce' tried her best to explain how federal state and local systems of support are coordinated. She said a Family Support case manager would likely have them fill out more forms and ask questions about Kiwi.

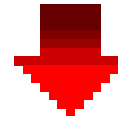
Brangelina, being very private people, couldn't understand why they had to share their story over and over - they were starting to feel like the details of their lives were on the cover a supermarket tabloid!

Questions and Considerations

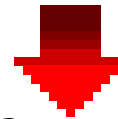
- What are some of the programs and supports that families get involved with on their journey raising a child with a disability?

The Relationship Between Federal, State and Local Programs

Federal Government provides Funding and
Requirements to



State Governments who provide Funding and
Requirements to



Local Systems of Services, including
Counties

Federal Programs

- **Some federal programs that affect CYSHCN include:**
 - Centers for Medicaid and Medicare Services (CMS)
 - Medicaid services
 - Home and Community-Based Waiver Services
 - Medicare services
 - Maternal and Child Health Bureau (MCHB)
 - Provides funding for Wisconsin's Title V program and its Regional CYSHCN Centers
 - Provides funding for Family to Family Health Information Centers
 - Office of Special Education Programs (OSEP) from the US Department of Education
 - Birth to Three Programs
 - School based special education
 - Social Security Administration (SSA)
 - Supplemental Security Income (SSI)
 - Supplemental Security Disability Insurance (SSDI)
 - Vocational Rehabilitation

Statewide Programs

- These programs include:
 - Birth to 3 Program
 - Family Support Program
 - Medicaid
 - Forward Card Services (Badgercare, Katie Beckett, SSI, Title 19)
 - Home and Community-Based Waivers (e.g. Children's Waiver, CIP, COP, Wraparound)
 - Regional CYSHCN Centers
 - Early Childhood (ages 3-5) through the public schools with IEP
 - K-12 special education through the public schools with IEP
 - Transition planning begins at age 14
 - Transition services are provided through age 21
 - DVR (Department of Vocational Rehabilitation)
 - Social Security Programs (including Supplementary Security Income (SSI))

County Based Programs

- Family Support Program (FSP)
- Medicaid waiver programs, including CIP, COP, Children's Home and Community Based Waivers
- County services, e.g. Respite Program
- Community Support Program (wraparound)
- Respite Program
- Day Care Assistance
- Recreation

County Delivery of Services

- In Wisconsin, county governments have a lot to do with how, and to what extent, services are delivered to both children and adults with disabilities
- There is great variability in the delivery, availability (waiting lists) and quality of services among all 72 of Wisconsin's counties
- Important to continually keep county supervisors aware of issues that affect your child and your family

When Help Isn't Available

**What to Do When You're
Waiting or Not Eligible
for Services?**

Our Story: Waiting for Help

One more case manager and program had now entered the Fitt's lives. Paris Milton from the county Family Support Program told Angelina that there was a two year waiting list for services. And, not only that, but she didn't even know for sure if Kiwi would qualify. Paris said there were "eligibility requirements".

At least a place on a wait list would provide Brangelina with some respite services. Hopefully they could get a break soon. But why did people who needed help have to wait?

Waiting Lists

- They are an unfortunate reality
- They exist throughout the state, even though they vary from county to county
- They affect amount of services and quality of services received
- There is not enough money for people with disabilities to have the help they need to live in the community
- Families need money to keep their children with disabilities safe and healthy in their homes

For What Kinds of Services Might My Child Need to Wait?

- Respite care
- Family support
- Home and Community-Based waivers
- Limited access to some Medicaid providers, including dentists and mental health professionals

- Your child CANNOT be placed on a waiting list for:
 - Birth to Three services
 - Medicaid card services
 - Waiting lists are not allowed for these services, but there are often "lag" periods while eligibility for these programs is determined

What's Important to Know about Eligibility for Programs?

- Sometimes a child won't meet eligibility criteria
- Eligibility criteria can change
- There are different ways in which eligibility is determined and interpreted

What Other Help is Out There?

- Be creative - not everything needs a formal solution
- Look at possible funding for one-time support needs, such as Dane County's Families Can't Wait program
- Look at alternative sources of supports, such as using personal care as supported by the Medicaid card to help care for your child while you are waiting for respite services (remember that this is not the same service)
- Call your Regional Center for ideas

What Other Help is Out There?...continued

- Investigate your Independent Living Center (help with peer support, independent living skills, information, referral and more)
- Find out what WisTech may offer (assistive technology, loans, library of equipment)
- Ask agencies about used equipment or look through rehabilitation catalogs for ways to modify

What Other Help is Out There?...continued

- Connect with other families (conferences, list-servs, support groups)
- Subscribe to Family Voices of Wisconsin list-serv and newsletter
- Check out national resources - disability websites; non-profit organizations
- Think about community organizations (Rotary, Lions Club, faith communities, service clubs)
- Consider advocacy

More Information

HANDOUT

- **Ending Waiting Lists - Families and Programs Working Together**

Don't Leave Without Knowing About...

Key Resources in Wisconsin

Our Story: Resources

When we last left them, Brad and Angelina were waiting for their name to come up on the respite waiting list. They were still looking for help in many areas.

Fortunately they got a tip one day from their friend, parenting expert Britney Shears, while dropping their daughter Apple off at daycare. It turns out Britney's child also has special needs. (Apparently there had been an unfortunate accident related to a carseat malfunction.)

Our Story: Resources, continued

Britney now knows a lot about community resources. She mentioned how she got information about adaptive car seats and personal care from the Regional Center for Children and Youth with Special Health Care Needs - a “totally hot” one-stop-shopping for resources Britney had called it.

Our Story: Resources, continued

Brangelina knew what an expert Britney was on Rodeo Drive shopping so they took this shopping advice and called right away!

The Information and Referral staff person at the Center told them about parent support groups as well as sibling support resources for Apple.

Our Story: Resources, continued

Brangelina were also surprised to find out that, just like Britney, they likely qualified for personal care under their Buddy Hackett Medical Assistance card. They would still wait for respite, but personal care could be a great help.

Their next step would be to ask someone they trusted, maybe their friendly neighbors, Rosie O'Blowhard and Donald Frump, to be their care providers!

Resources in Wisconsin

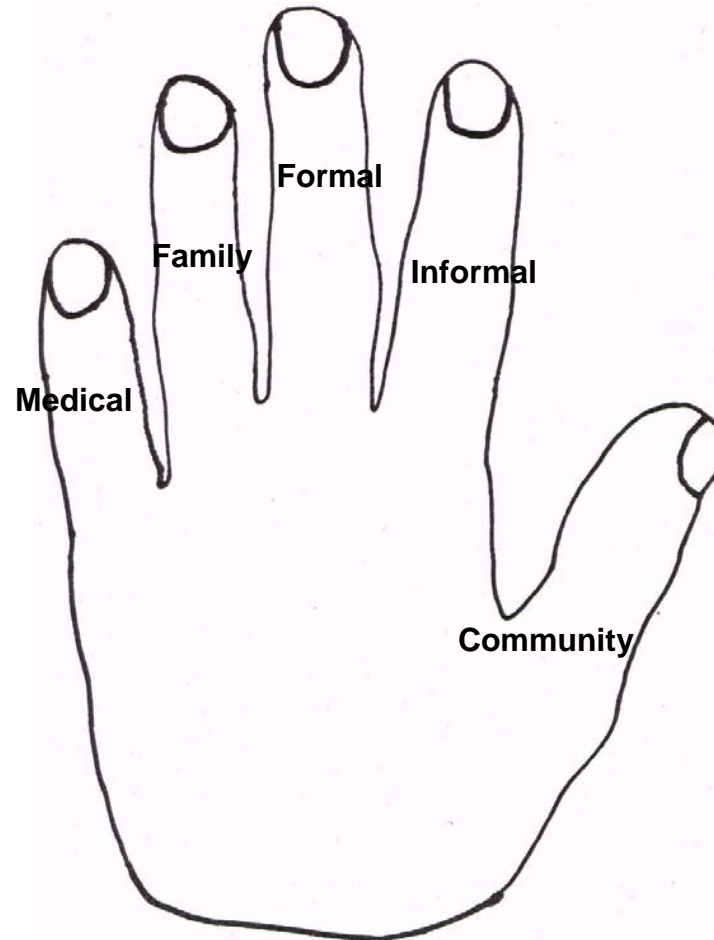
HANDOUTS

- Regional CYSHCN Centers - Five locations throughout Wisconsin
- First Step 1-800-642-7837
- Disability specific and need specific resources
- Does your county have a roadmap?

Resources in Wisconsin, continued

- **Information, Assistance and Advocacy Resources**
- **Family Voices Of Wisconsin Brochure**

Now What Do I Have At My Fingertips?



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Contact Us!

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