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 Family Support 360 and the Southern Regional CYSHCN Center

January 17, 2008
MODULE V

Advocating for Systems Change
Our Story: Becoming An Advocate

Meet Brad & Angelina Fitt, a.k.a. “Brangelina”
Our Story: Becoming an Advocate

Brad and Angelina Fitt found themselves fiercely frustrated. They couldn’t believe how long some families, including theirs, had to wait for help. Their daughter Kiwi, who had cerebral palsy, was now two years old and the family was still waiting for respite care supports.

Brangelina (as the couple liked to be called) had even met parents whose children were 7 and were still on the Family Support wait list! Something had to be done.
Our Story: Becoming an Advocate

They thought about contacting their new Governor - Bond, James Bond, (the latest in a line of action heroes to take office following Governor Exterminator) but they didn’t quite know how to go about it.

Luckily, their flashy Birth to 3 service coordinator, Beyonce’, knew just how to get the governor’s attention. Beyonce’ had heard the Fitt’s talking about this concern and gave them an idea.
On her karaoke nights, Beyonce’ had heard about an effort being organized by a group of parents. These parents were concerned about waiting lists too. They wanted parents of kids with special needs to send them a photo of their family and a short story about their life.

The plan was then to give these stories to legislators and the governor. Then maybe waiting lists could be exterminated once and for all! The Fitt’s were on board and ready to become advocates for systems change!
Questions and Considerations

- What is systems change?
- What is an advocate?
An Advocacy Quiz

Can you imagine yourself doing any of the following?

Going down to City Hall to complain about a “too high” tax bill?

Helping when your neighbor gets a confusing letter from Social Security, by making phone calls and dealing with the bureaucracy?

Making a presentation for your congregation about a community project you care about?

Responding when your child’s school says they want input from parents about proposed changes to a policy about whether pregnant teens can stay in school?

Testifying before a state legislative committee as part of a panel on a subject you know well and care about?

Questions and Considerations

- What do families offer to decision makers?
- Why is it important to be involved in systems change?
Families Offer a Valuable and Unique Perspective

- We are resourceful and have good ideas
- As parents and guardians, we have a lot of knowledge about what works and what doesn't
- We can take our difficult and challenging situations and do things to make them better
- We can make a difference in the lives of our children and in the systems that support them
What Can Families Offer Decision Makers?

- We don’t have to accept that it’s ok if a system works poorly
- We can see inconsistencies that professionals may not recognize
- We have valuable information to bring changes to a system – we live in the system
- Our expertise is critical to improving services and utilizing resources most effectively
What Happens When Families Get Involved in Systems Change?

- **1875**: Large numbers in institutions; Segregation and sterilization.
- **1940s**: Holocaust — 100,000 children and adults with disabilities killed; Considered flawed.
- **1950s**: Parents still encouraged to institutionalize. Beginning of parent advocacy movement. Focus on winning civil and legal rights for their children.
- **1973**: Parents and providers advocate for Section 504 of the Rehab Act. Protection from discrimination.
- **1981-1984**: Disability rights advocates blocked an attempt by the Reagan administration to repeal parts of IDEA and Section 504.
- **1975**: Parents and educators help to pass Education for all Handicapped Children Act which becomes IDEA.
- **1990**: Self-advocates and community members lobby for the Americans with Disabilities Act (ADA) — full participation and independence.
- **2001**: The Olmstead Supreme Court Decision interprets ADA to end unnecessary institution of people with developmental disabilities.
What Happens When Families Get Involved in Systems Change?

*Handout*
In Willowbrook's Wake

V: Parents As Advocates

FAMILY VOICES of Wisconsin
Our Story: Putting Advocacy Into Practice

Working with Decision Makers
It was the big day and Brad and Angelina didn’t know what to expect. Here they were at the capitol, ready to testify before the Joint Finance Committee about the need for more funding for the Family Support Program.

What were they thinking? Being camera shy, neither of them was prepared for the crowd and the cameras at this event. Would they make the evening news? Would anyone listen?
Our Story, continued:
Putting Advocacy Into Practice

But several things gave Brangelina confidence today. First of all, several of their providers, including Dr. Phil and social worker, Oprah Bornfree, had written letters of support for them to present to committee members.

Also, Brangelina had gone to an advocacy training and connected with other parents – including their friend, parenting expert Britney Shears. They felt like they knew not only what was important for them, but for other families as well.
Partnering with Providers

Our Essential Allies
Ways You Can Become Involved in Systems Change

- School and doctor office opportunities
- Advisory committees - state and local
- Public hearings - state plans, local and state budgets, statute changes
- Letter writing
- Increasing Awareness - Media
- Training other parents to become confident advocates
How to be an Effective Systems Change Advocate

- Represent all families fairly - consider not just the interests of your own family.
- Take your commitment seriously - attendance is important.
- Ask for the support you need to be involved - participation by conference call? Respite? Transportation?
How to be an Effective Systems Change Advocate

- Speak up - share your opinions - you ARE knowledgeable!
- Don’t worry about what you don’t know.
- Choose an issue you are passionate about.
- Use your experiences to inform your advocacy.
Telling Your Family Story

- Limit the length of your story to 1-2 minutes.
- Tell only the parts that best illustrate the point you want to make.
- Choose the story with the most impact.
- Be honest. Don’t exaggerate.

Developed by Liz Hecht: Let Your Voice Be Heard!
Let’s Practice!

*HANDOUT*
A Plan for Systems Change Advocacy
Advocacy Strategies

In My School

- My child cannot participate with other children in much of physical education class because there is no adaptive equipment available. This is true for other children in the school who also use wheel chairs.
Advocacy Strategies

With My Child’s Health Care Provider

- The last time I went to the doctor’s office with my child, the interpreter who was supposed to be there was an hour late. By then, we had lost our appointment slot.
Advocacy Strategies

Within My Community

- I am worried that when my son graduates from high school he will just be sitting at home. He loves working and being out in the community, but our county’s waiting lists are so long. I just don’t see how it will change.
Advocacy Opportunities: Local

- County Budget Advocacy
- County Human Needs Committee
- Long-Term Care Committee
- Family Support Advisory Committee
- School Board Committees
- PTO
- Civic Organizations
Advocacy Opportunities: State

- Birth to 3 Interagency Coordinating Council
- Council of Children’s Long Term Support Needs
- Wisconsin Council on Developmental Disabilities
- Maternal and Child Health Advisory Committee
- Special Education Council
- State Legislature
Serving on Other Boards and Committees

- Ad Hoc (formed for a specific purpose) Committees
- Transition Advisory Committees
- Hospital Consumer Advisory Committees
Working With Elected Officials

- He wants to do a good job
- She wants to be re-elected
- He wants to be responsive
- She is not an expert in your business
- He is busy
- She doesn’t know what you want
- He is concerned with dozens of issues
- She may forget your name – re-introduce
- He deserves respect

Adapted from Bobby Silverstein
Important People to Know

- Find your federal representatives: http://waml.legis.state.wi.us/

- Find your state legislators: 1-800-362-9472 or http://waml.legis.state.wi.us/

- Find your county board or city council member: Ask at the county courthouse, city hall or search the website.
Developing Your Strategy

How Can You Put YOUR Message to good use?

More Advocacy Ideas: www.dawninfo.org
Regional CYSHCN Centers & 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

- Remember your supports!
Contact Us!

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