YOUR PLACE AT THE TABLE: The Role of Families as Change Agents

Family Leadership Institute
Session 1
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Greater than Your Own Child

• Focus on working for a meaningful life for children with disabilities and CYSHCN, not just your own child:
  • Having an impact on improving services and supports
  • Making a community more welcoming
  • Building opportunities for children and youth
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
- We are creative and have great ideas to come up with ways to get the job done
- We know what works and what doesn’t work
- Providers better understanding families of children with disabilities and SHCN
Why are Leadership Skills Important?

• Help us to be effective advocates for ourselves and others
• Helps us communicate a perspective critical to the successful development of effective policies and practices.
• Increased the likelihood that we will impact the design, implementation and evaluation of systems of support
• Gives us tools to build and evaluate effective and responsive systems of support
• Increases the likelihood that systems of support and services are helpful, effective, and efficient
What Happens When Families and Professionals Get Involved in Policy?

1935
The Social Security Act included provisions for crippled children and vocational Rehabilitation programs.

1973
Parents and providers advocate for Section 504 of the Rehab Act. Protection from discrimination.

1981-1984
Advocates blocked an attempt by the Reagan administration to take away parts of IDEA and Section 504.

1990
Advocates work to pass the Americans with Disabilities Act (ADA) – full participation and independence for people with disabilities.

2001
The Olmstead Supreme Court Decision interprets ADA to end unnecessary institution of people with developmental disabilities.

2010
Advocates work to pass the Patient Protection and Affordable Care Act – people with disabilities and special needs can no longer be excluded from health care coverage.

2014
ABLE Act creates tax-free savings accounts for individuals with disabilities - without losing public benefits.

1950s
Beginning of parent advocacy movement. Focus on winning civil and legal rights for their children. Parents still encouraged to institutionalize their children.

1963
Developmental Disabilities Act established University Affiliated Facilities (UAFS), charged with expanding the number of professionals to address the needs of persons with developmental disabilities.

1975
Parents and educators help to pass Education for all Handicapped Children Act which becomes IDEA.

1988
Technology Related Assistance for Individuals with Disabilities Act encourage the development and distribution of assistive technology for people with disabilities.

1990
Advocates work to pass the Americans with Disabilities Act (ADA) – full participation and independence for people with disabilities.

2010
Rosa’s Law changes the terms “mental retardation” and “mentally retarded” to “intellectual disabilities” and “intellectually disabled” in federal laws.
Ways You Are Involved in Systems Change

• School and doctor office opportunities
• Presentation to faith community
• Advisory committees – state and local
• Public hearings – state plans, local and state budgets, statute changes
• Letter writing
• Media
• Training other parents
Serving on Boards, Committees and Councils: Some Examples

• **Advisory:** doctor’s office or hospital, school district, Children’s Community Options Program on a local level and the Children’s Long Term Care Council on a statewide level

• **Governance:** school board, non-profit community organization

• **Evaluation:** review of policies and procedures

• **Planning:** input to state plan for DVR, BPDD, UCEDD etc.
Some things you might need to know

Where do you find information that might be useful as an advisor?

• Internet
• Research journals
• Library
• Universities
• Agency reports
• National organizations
• Media
More things you might need to know

Being part of a group

• Understanding your role
• What skills will you need to prepare for a meeting?
• How do you contribute to the agenda for a meeting?
• How do you feel comfortable participating?
• How to learn about group process and the way members work together?
• What skills will you need to follow up from a meeting?
• What skills do you need to deal with different ideas?
• What skills do you need to facilitate a meeting?
Why Tell Stories?

Families have a unique tool.....

• Stories are what people remember

• Deepen their understanding of issues for children and families

• Makes the problem real

• Help them make decisions that lead to more supportive policies

• Help them find touchstones to our experiences in their own lives
Telling Stories that Persuade

1. Explain an issue or problem that concerns you.

I want families who have children with disabilities to have access to supports, for which they are eligible. These supports allow families to learn how best to support their child, find and utilize community supports and services that lead to a full and integrated life for children with disabilities.

2. Share a personal story or experience about how the issue or problem is affecting your life.

We are struggling to meet the needs of our family and keep a job. I haven’t been able to find anyone to reliably take my daughter with disabilities after school every day. I have had to cut back at work am my employer says I could be fired if I cant be at work after 3:00.

3. Explain what you think needs to be done to fix this issue or problem.

There are currently 2500 children and families waiting. Additional funding to these families would make it possible for them to have someone who could help after school while the we are at work.
Let’s Practice!