



Advocating for Systems Change

Care in the Community Conference

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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 for Today's Presentation

- What do families offer to decision makers?
- Why is it important to be involved in systems change and what opportunities are there?
- Suggestions for developing your message



A Question You Might Ask...

- What is “systems change?”
 - One definition is: “Systems change is the permanent change to policies, practices, decisions and environments in the public and/or private sector that control resources necessary to enhance integration, inclusion and independence of people with disabilities as a group and/or their families.” (NY Center for Independent Living definition)



What Does Systems Change Mean to Families?

- o Families working to make lasting changes that affect people with special needs: where they live, what services they receive, how decisions are made that affect them. The changes should help include them, give them access to places and services, and encourage their independence. ***The changes must make things different for all families, not just one, in order to be considered “systems change.”***



Another Question You Might Ask...What is an Advocate?

- o “to plead the case of another” (Nancy Amidei)
- o This means: Someone who argues for another person so that they can have the same rights as others have.
- o Policy advocacy takes the “plea” into the political arena. It is a practical way to translate basic values like respect for human dignity into policy and laws, and is a core part of our democracy. (Nancy Amidei, *So You Want to Make a Difference*)



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 live in the system
- We can take our difficult and challenging situations and do things to make them better
- Our expertise is critical to improving services and utilizing resources most effectively



What Happens When Families Get Involved in System Change?

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.

1975:

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



What Happens When Families Get Involved in System Change?

1981-1984:

Disability rights advocates blocked an attempt by the Reagan administration to repeal parts of IDEA and Section 504.

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.



Parents are Natural Advocates for their Kids

- IEP and school teams
- Doctors' offices
- Community providers
- Advisory Committees
- Health insurance
- Policy Makers



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



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



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 Board for People with Developmental Disabilities
- Maternal and Child Health Advisory Committee
- Superintendent's Council on Special Education



Serving on Other Boards and Committees

- Ad Hoc (formed for a specific purpose) Committees
- Transition Advisory Committees
- Hospital Consumer Advisory Committees



How to be an Effective Systems Change Advocate, continued

- 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?



Telling Your Family Story -- Why Tell It?

- Stories are what people remember
- Deepens listeners' understanding of issues for children and families
- Makes the problem real
- Helps policy makers make decisions that lead to more supportive policies
- Helps them find touchstones to our experiences in their own lives



The Power of Family Stories

“These parents told emotionally powerful stories and made a compelling argument that this program was vitally necessary to help children live healthier, happier and more productive lives. These are good kids with loving families who at a young age have encountered a lifetime of barriers. They certainly didn't deserve to have their government turn it's back and fail to provide the funding to help these programs achieve their promise.” (Senator Bob Jauch)



Your Message

- Who you are
- Explain the issue or problem
- Share a personal story about how the issue is affecting your or your child's life
- What you think needs to be done and what you want the policy maker to do
- What will happen if the problem is fixed
- Ask for a commitment of action
- Leave written information, including your contact information



Telling Your Family Story -- How To Tell It

- Be informed, brief and clear about what you want
- Choose the story with the most impact and best illustrates the point you want to make (e.g. "Because we could not afford to put a ramp on our house, my daughter has to leave her wheelchair at school and crawls around at home. She is 13.")
- The goal is not to be liked, but to be respected and listened to. Be honest, don't exaggerate, and don't tell "hearsay" stories
- Deliver your basic message in about 2 – 3 minutes. Share additional information if time.



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.



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
- **THE ONLY WAY YOUR LEGISLATOR WILL KNOW WHAT IS IMPORTANT IS IF YOU TELL THEM!**



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
- Find your school board members. They are often listed on the school's website



Developing Your Strategy

- How Can You Put YOUR Message to good use?
- To stay current with statewide advocacy initiatives, visit:
www.dawninfo.org



Contact Us!

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