



Your Voice Counts! Advocacy and Storytelling

Spring 2021



Each family has a voice
Together, our voices will be heard



Connect with Us!

familyvoiceswi.org



Family Voices helps families navigate health care and community supports and services by providing training, in-person and online, information and education.

As a family-run organization, we support families in their own leadership and advocacy journey, and we promote family-centered care and family/professional partnerships.

Visit our website to view our fact sheets, newsletters and online trainings.

About This Presentation

- Families and advocacy
- Why are family stories important?
- How and why do I tell my family story to make an impact?
- What can I do with my family story as an advocate?

Why is this important?



My Journey as Ben's Mom

- At the NICU
- Birth to Three – first press conference
- Advocating at therapy and medical appointments
- Itinerant services at preschool
- Transition years in high school
- Transition to vocational career path
- Service on school and community boards and statewide councils
- Presentations and testimonials
- Change in career path

What is an Advocate?

- An advocate is someone who speaks up on behalf of another person
- When family members advocate, they may do so:
 - on behalf of their own child,
 - on behalf of another child, or
 - on behalf of many children

Families are Natural Advocates for Their Children

- IEP and school teams
- Doctor's offices
- Community therapists
- Health insurance providers
- Service coordinators and case managers

**Your Advocacy
Can Make
Systems Work
Better**

“Systems change” happens when there is a change to a policy or a rule which affects many people.

Systems change is long-lasting. The changes must affect many children and families, not just one, to be considered systems change.

What Happens When Families Get Involved in Systems Change?

1935

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

1965

Medicare and **Medicaid** established to provide federally subsidized health care to disabled and elderly Americans covered by the Social Security program.

1984

Voting Accessibility for the Elderly and Handicapped Act mandated "handicapped and elderly" access to polling places

1990 (R)

Americans with Disabilities Act (ADA) – full participation and independence for people with disabilities.

2001 (R)

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

2010 (D)

Patient Protection and Affordable Care Act (ACA) people with disabilities and special needs can no longer be excluded from health care coverage.

2014 (D)

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.

1973 (R)

Rehabilitation Act with Section 504 of the Act states handicapped individual shall, solely by reason of his handicap, be subjected to discrimination under any program or activity receiving federal financial assistance."

1963 (D)

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 (R)

Education for all Handicapped Children Act later known as IDEA

1988 (R)

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

2008

Mental Health Parity and Addiction Equity Act required group health plans mental health/substance abuse benefits be no more restrictive than all medical/surgical benefits

2010 (D)

Rosa's Law changes the terms "mental retardation" and "mentally retarded" to "intellectual disabilities" and "intellectually disabled" in federal laws

Ways to Advocate for Systems Change

- Serving on advisory committees in schools, hospitals and doctors' offices
- Speaking at public hearings for rule changes or budget decisions
- Training or supporting other family members to become confident advocates
- Sharing your family story with the media, including social media
- Formation of relationships/partnerships – expectation that we are equal partners with professionals

Why is it Important to be Part of Systems Change?

- Our children and family have to live with the changes that are being made.
- If we don't give our view, then do we have the right to complain about how it all turns out?
- If we aren't giving our input to the decisions that affect our children, who is?
- No one cares more about our child's future than their family members.

Families Offer a Unique and Valuable Perspective

- We are creative and resourceful and have good ideas
- We live the system – we know what works and what doesn't work
- We can see inconsistencies that professionals may not see
- Our expertise is critical to improving services and utilizing resources most effectively

How to be an Effective 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 and family story to inform your advocacy
- Represent families fairly – consider not just the interests of your own family
- Ask for the support you need to be involved – participation by conference call? Respite? Transportation?
- Show up and participate!

Advocacy Opportunities: Local

- County Budget Advocacy
- County Human Needs Committee
- Children's Community Options Program Advisory Committee
- School Board Committees
- PTO/PTA
- Civic Organizations/Neighborhood Associations
- Transition Advisory Committees
- Hospital Consumer Advisory Committees
- Disability Specific Organizations

Advocacy Opportunities: State

- Birth to 3 Interagency Coordinating Council
- Council for Children with Long-Term Support Needs
- Wisconsin Board for People with Developmental Disabilities
- Superintendent's Council on Special Education
- Maternal and Child Health Advisory Committee
- Office of Children's Mental Health
- Disability specific organizations
- State Legislature!!!!

Telling Your Family Story – Why?

- Stories are what people remember
- Stories make problems real
- Stories deepen listeners' understanding of issues for children and families
- Stories help policy makers make decisions that lead to more supportive and responsive policies
 - Helps them find touchstones in their own lives
- Importantly, you can use your family story as a way to illustrate a point you want to make

Telling Your Family Story – How?

- Be clear and brief about what you want to say
- Choose one or two “slices” of your family story with the most impact
- The goal is to make a point and be listened to

“Because we could not afford to put a ramp on our house, my daughter has to leave her wheelchair at school and can’t go out to the park or anyplace in our community.”

Telling Stories that Persuade – the set up

**Say who you are and where you live.
Explain an issue or problem that concerns you:**

“My name is Barbara Katz and I live in Madison. I want families to get the services and supports they need to care for their children with disabilities. These services allow families to best support their children so they can lead full and integrated lives in their communities.”

Telling Stories that Persuade – your story

Share a personal story or experience about how the issue or problem affects your life:

“We are struggling to meet the needs of our family and keep a job. I don’t have a way to pay for someone to reliably care for my daughter with disabilities after school every day. I have had to cut my hours at work and my boss says I might be fired if I can’t stay after 3 pm.”

**Telling Stories
that Persuade
– your solution**

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

“There are currently 1,500 children and families waiting for the Children’s Long Term Support Waiver program. Additional funding for this program will allow families to have help after school so parents are able to work.”

**Telling Stories
that Persuade
– your “ask”**

Have an “ask” – what you want the person to do with your proposed solution:

“Senator Risser, I ask that you support the Governor’s budget that puts more money into the Medicaid program to eliminate the waiting list for the Children’s Long Term Support Waiver. Will you do this?”

Let's Practice! Advocacy in School

“My child cannot participate with other children in many of the physical education classes because there is no adaptive equipment available. This is true for other children in the school who also used wheelchairs.”

- What are some solutions to deal with this problem?
- What is the best way to advocate for those solutions?

Let's Practice! Advocacy in a Doctor's Office

“The last time I went to the doctor’s office with my child, the interpreter was an hour late. By then, we lost our appointment slot.”

- What should this family do to advocate for their needs?

What You Can Do Next

- Sign up for the **Family Action Network**: fan@list.wisc.edu
- **Testify** at a Joint Finance Hearing
- Check out **budget and policy resources** from these organizations:
 - Family Voices of Wisconsin: familyvoiceswi.org/about-us/policy-topics
 - The Arc Wisconsin: arcwi.org/public-policy/take-action-issues
 - Board for People with Developmental Disabilities: wi-bpdd.org
 - Disability Rights Wisconsin: disabilityrightswi.org/act/take-action-advocate-for-policy-reform-or-legislation
 - The Survival Coalition: survivalcoalitionwi.org/index.php/budget-priorities
- Consider **joining a board or a committee** in your community

**Now It's
Your Turn!**

How are **you** going to use your knowledge and skills to advocate on behalf of your child or other children?

How will **you** tell your family story?

Thank You!

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