



Sharing Your Parent Story

September, 2002

Tips for Impact and Effectiveness

All parents have a story to tell. The circumstances and experiences that accompany a child's disability can have value, both to other parents and providers within the service system. Sharing your parent story with other parents will provide them with useful information and resources, as well as helpful tips learned from your experience. It will also provide them with an awareness that they are not alone in the challenges they face.

Professionals who hear parent stories gain a greater awareness of the reality of what life is like and the impact of the disability for your family and your child. That greater awareness can have far reaching effect. Your story can influence policy and decisions that affect children and families. Sharing your story can present an opportunity to ask the challenging or thought provoking questions of the service system. It can also be an opportunity to build coalitions around issues.

Parents are often called on by other parents and professionals to share their stories. How can these personal journeys be shared with others to enlighten and impact an audience?

CONSIDER THESE TIPS

1. Get some background.

- Why is a parent story being requested?
- What topic, idea, or concept are you being asked to address? (Is it a historical perspective-what it used to be like? How I received the diagnosis? How I became connected to resources and services? How life for us has changed?)
- Who will be in the audience listening? How much background do they have and what is their area of responsibility or circle of influence.
- How long should you speak? (Be time limited. Ask what amount of time they would like you to speak. If no time is specified, limit the time yourself to be respectful to the audience.)

2. Prepare your message

- Write your thoughts on paper.
- Give personal background, current status, and next steps. Give enough specific information to make it real for the listener.
- Identify what key points you want to make.
- Be truthful without being blaming or sounding disrespectful.
- Be concise. Use your words effectively.
- Practice saying it out loud.
- Time yourself. Stay within the requested time.
- Frame your topic clearly, early in your story. Bring a message that is pertinent to the audience.

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- Have an awareness of when you might become emotional about your story. It's okay to feel and show emotion, but be able to pull yourself together and continue.

3. Making the most of your presentation.

- See people in your audience as potential allies. This is an opportunity to build coalitions.
- Respect and foster the concept of parents and professionals working together as partners.
- Make your message flexible to fit various time slots. As you gain experience, identify the key points of your message and learn ways to share them in two minutes, in ten minutes, in twenty minutes, depending on the circumstances.
- It's important to say the challenging things. If you're there just to nod, compliment, and rubber stamp, it may not be very useful. If your role is just to say thank you, recognize that is very different than influencing change, people attitudes and the decisions they make.
- Be aware of when you might become emotional about your story. It is okay to feel and show emotion, but be able to pull yourself together and continue.
- If you have input into selecting a parent to make a presentation, strategically select who will have the most impact on the audience. Don't let your ego get in the way.
- Get to people's heart before you get to their head.
- Get to people's head after you get to their heart.
- Who or what does your message impact?
- Request a specific action from the audience, if appropriate.
- Write a "thank you" note for the opportunity to share your story.

Learning to recognize the value of your story as the parent of a child with disabilities is an important step. Although sharing those experiences and feelings can be very difficult, it can also be an extremely effective informational tool that can make an important difference in the lives of many other children and families. We hope that you find the experience of developing your parent story and sharing it effectively to be a positive step of growth and learning.

