

# From Experience to Influence: The Power of a Parent's Story

A parent, sleep-deprived and overwhelmed by the day-to-day demands of parenting a six month old child with complex challenges, was invited to tell her story to a group of early intervention professionals. Like many parents, she began at the beginning and attempted to relate the events in the order in which they had occurred. Panic set in when she realized she had used 10 of her allotted 15 minutes and was still only as far as the birth experience. Although she made a frantic attempt to speed up the story, she never made it to the part her audience was hoping to hear about: her family's experience of learning about and using early intervention services. Fortunately, as a new parent representative on the Interagency Early Intervention Committee, she would have future opportunities to relate the rest of the story. And she would be ready next time.

Never underestimate the power of your story. A well-told story has the potential to touch hearts and change minds. While impersonally delivered facts can easily be forgotten or dismissed, a story lingers and mingles with all the other stories that shape our shared human experience. As a parent leader championing the cause for children with disabilities, your personal experience stories can pave the way for policy change. To maximize the impact of your story, customize it for each opportunity by addressing these essential components:

## **The people**

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The same story can be told in different ways, depending on the particular audience. Ask yourself: Who are my listeners? What experiences do we have in common? What are their concerns and constraints? What are their goals? What is their position on a related policy?

## **The purpose**

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- Inspire, motivate, or encourage listener toward a desired outcome
- Illustrate the impact of the disability in a particular area that may be difficult for the listeners to understand Put a face on the disability to help listeners focus on the individual, not the system
- Provide a reality check for listeners who have limited hands-on experience
- Inform or educate about a topic or issue
- Promote a possible approach or intervention
- Persuade listeners that policy change is needed

## **The (power) point**

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What's the main point you want to make by presenting a particular slice-of-life story? Attach your point to the purpose and design the story to intentionally draw the listener to the desired destination. Depending on how much time you will have, you may wish to have two or three smaller points as well. To strengthen your position, include brief references to research and statistics that support your point. It is important to show how your personal experience has a broader application.

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You will also find that predetermining your main point will help you with your biggest challenge: deciding what not to say. If a particular piece of information won't eventually connect in some way with the purpose and the point, it will be beside the point: leave it out.

## The policy

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When the purpose of your story is to influence decision-making about the way things are done at a system-wide level, match your example of personal experience to a policy objective. Frame your story in terms of the policy impact. You may be able to compare your experience before and after a particular policy went into effect, or how your experience would have been different with or without the policy. Tie your points directly to the policy. As you share your experience, refer repeatedly to the policy objective and impact on your child and family.

## The props

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- A tangible item can help your story leave a lasting impression, and provide helpful story markers for you and your audience to follow at the same time. Depending on your purpose and point, consider using one or more of the following:
- Photos or slides
- Related items: e.g., the child's artwork, communication notebook, baby calendar, birthday card, first lunchbox or backpack
- Audio or videotaped clips of the child and family
- Other family member or team member as co-presenter

## The payoff

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Planning, preparing and presenting a parent story takes time and energy. It may even be emotionally challenging as difficult memories resurface or fears for the future rise to the surface. But for most parents, the potential payoff outweighs the cost. Many report that sharing their story brings meaning to the experience beyond the experience itself. Others find that through relating their stories, connections are made with those who have experiences and goals in common.

As a result of parent stories, professionals may receive the encouragement and motivation they need to continue in their work and to find new, creative ways to make a difference in a child's life. Parent stories help keep the focus on children and families. In a larger sense, the real payoff comes in the form of systems-wide decisions and policies that are family-centered and based on the real needs of all children with disabilities and their families. The power of a parent story is significant: from experience to influence.