Parents as Presenters

WORKSHOP PARTICIPANT GUIDE

Iowa Department of Education
2004

Parents as Presenters

Workshop Participant Guide

Iowa Department of Education

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State of Iowa
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Grimes State Office Building
Des Moines, Iowa 50319-0146

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Purpose...

This workshop was adapted from Enhanced Learning. The Center for Innovation in Special Education, out of Missouri, designed this curriculum to enhance pre-service and inservice training related to early intervention and early care and education by helping to ensure that students and trainees better understand the perspectives of families who have children with disabilities.

It is expected that those who attend family presentations will become aware of:

1. The parent's/family's unique position as the ultimate expert on the child;
2. Each child's individuality, which transcends his/her diagnosis;
3. The family's experiences, positive and negative, with professionals;
4. The rewards and difficulties of having a child with a disability in the family, including the grieving process, stressors (social, psychological, educational, financial), and the effect on all members of the family.

The training is part of the Iowa SCRIPT (Supporting Change and Reform in Interprofessional Preservice Training) Action Plan and was initiated through collaboration with the Parent Training Information Center of Iowa, the Parent Educator Connection, Family Voices of Iowa, Early ACCESS, and Iowa State University.

"Parents as Presenters" Workshop

This two-day workshop provides training for family members who are interested in sharing their experiences with community organizations and college classes for future early intervention professionals. This training will provide information and experience to increase the comfort level of family members who tell their story. A variety of pointers and techniques will be shared, and participants will have guided practice in sharing their story. Additionally, tips in accepting an invitation to speak and preparing a presentation will be addressed.

Speaker Directory

A directory will be published, following the training sessions, to identify families who are available to speak. The directories will be distributed to college faculty and other appropriate organizations.

For more information about this, please contact:

Mary Schertz, Iowa Department of Education
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Part I

Setting the Stage

"Our stories shape us. They give us our songs and our silence. When they are full of joy, they allow us to soar. When they are full of pain, they allow us to journey into the darkness of our souls where we meet ourselves, sometimes for the first time. They destroy us and allow us to rebuild. We must share our stories. They are our gifts."

Zimmermann, S. (1996). *Grief dancers: a journey into the depths of the soul.* Golden, CO: Nemo Press.

Telling Your Story

- Participants will understand the multiple purposes of being able to tell their family story to an audience in a positive way;

- Participants will understand presentation strategies and will formulate creative ideas for their presonal presentation;

- Participants will demonstrate and receive feedback from other participants as they present a sample “Telling Their Story” presentation;

- Participants will develop a network among themselves to support “Telling Your Story” around the state.

Your Role Today

- Clear Your Thoughts;
- Open Your Mind;
- Decide That You Will Learn Something;
- Decide to Contribute;
- Listen to the Thoughts, Perspectives and Experiences of Others;
- Assume the Roles of Teacher and Learner;
- Support the Facilitators;
- Make New Friends to Support You in the Future;
- Have Fun!

Word Power

The Way We Speak About Ourselves and Others

What do you say about yourself?

- When people first meet you, what do you want them to know?
- Your interest? Your age? Your job?
- When you meet others, what do you want to know?

We can advocate by the way we speak

- Direct the focus on the person;
- Use family and person supportive language;
- People are people, not their diagnosis.

HANDOUT — People First Language

Value yourself and others

- Speak of the person first;
- Emphasize abilities not limitations;
- Don't group people under a label (for example, the disabled or the blind);
- Remember, people are not owned (my chair kid);
- Present a positive image for persons with disabilities.

Information adapted from: Community Leadership Solutions, Center for Learning and Leadership, UCEDD, Word Power Training Module.

Examples of People First Language

http://www.diversityisnatural.com/peoplefirstlanguage.htm

SAY:	**INSTEAD OF:**
people with disabilities	the handicapped or disabled
he has a cognitive disability	he's mentally retarded
she has autism	she's autistic
he has Down syndrome	he's Downs
she has a learning disability	she's learning disabled
he has a physical disability	he's a quadriplegic/crippled
she's of short stature	she's a dwarf (or midget)
he has an emotional disability	he's emotionally disturbed
she uses a wheelchair or mobility chair	she's wheelchair bound she's confined to a wheelchair
he receives special ed services	he's in special ed
typical kids/kids without disabilities	normal or healthy kids
congenital disability	birth defect
brain injury	brain damaged
accessible parking	handicapped parking
she needs... or she uses...	she has a problem with...

And no more "special needs!" A person's needs aren't special to him — they're normal and ordinary! Keep thinking — there are many descriptors we need to change. Practice new ways of thinking!

Part II

TELLING YOUR STORY

"Our stories are the retelling of our personal journeys, our walks down steep hillsides into green valleys, our climbs over ridges into dry canyons, our ascents to summits and falls from rocky cliffs."

Zimmermann, S. (1996). *Grief dancers: a journey into the depths of the soul.* Golden, CO: Nemo Press.

Your Story is Important!

To promote sensitivity and awareness

- Your story is a way to let current and future service providers know how they can be sensitive to families;
- Most service providers have little or no opportunity to interact with families of children with disabilities before they begin working in the field. Your story will contribute to their education and preparation to work with families and to include children with disabilities with other children.

To educate about family-centered services

- Children with disabilities are a part of a family. As you speak about your family, they will see that you focus on other families members as well as your child;
- Service providers will understand that their own expertise is enhanced when they consider the family as a valuable resource.

To show your audience that KIDS are KIDS

- Children with disabilities are kids first and have the same hopes and dreams as other children;
- Children with disabilities need opportunities to be with other children in natural community settings.

To advocate for quality programs

- Your story and your helpful suggestions will assist service providers to improve their programs, making them more child and family friendly.

It is important that you know that there is no "right" or "wrong" story. It is your family story — how you feel and how you see it now. Tomorrow your story may be different. You are the expert in the care of your child with special needs.

Information adapted from: Telling Your Story, Training for Family Faculty, Jan Moss, UCEDD, and the Parent Leadership Program. The Arc Michigan (Blough, Brown, Dietrick and Fortune).

"Accepting the Invitation"

Objectives of the Presentation

- Who is the audience?
- What is the topic of the presentation?
- What is the focus of my presentation?
- What do I want the audience to know when I am finished with my presentation?
- What does the person who invited me expect the audience to learn from the presentation?

Topic of the Presentation

- Who selected the topic?
- How much time will I have?

Presentation Focus

- What specific area of the topic am I to address?
- Determine a sequence/outline;
- Follow the outline.

What do I want my audience to know?

- Be clear before beginning;
- Be specific;
- Check for understanding.

What is expected of me?

- Meet with the person to discuss any specific learning outcomes she/he may have for the audience;
- Discuss any special format she/he wants you to follow.

Variety of Roles for Family Partnerships

ROLE:	DESCRIPTION:
Panel Presentation	Parents (usually 3 or 4) sharing together their personal experiences usually following similar themes or questions.
Sharing "Telling My Story"	Parents sharing their personal family experiences to help students understand family strengths, issues, and problems.
Family Mentor	Parents providing an opportunity for students to visit their home and meet their family to learn firsthand about family life.
Initial/Limited Presentations of Course Content	Parents providing content to students in areas about which they feel comfortable and knowledgeable, such as: developing IFSPs and IEPs, grief and coping, and communication skills.

Variety of Roles for Family Partnerships (cont.)

ROLE:	DESCRIPTION:
Shared Co-instruction of Course Content	Parents taking an equal role in planning and delivering course content and participating in the role of co-instructor.
Shared Use of Family Scenario Method of Instruction	Parents taking an active role in discussion of family scenarios to help students generate possible solutions to problems and potential family consequences.
Shared Class Organization and Management	Parents taking an active role in organizing the schedule, agenda, readings, and assignments for class and participating in grading.
Evaluation and Development of Curriculum	Parents taking a leading role in helping personnel preparation programs to evaluate their curriculum and recommend changes or revisions.
Training for Faculty on Co-Instruction	Parents taking a leading role in training faculty on how to include parents in a variety of preservice roles.

Family Partnerships Invitation Worksheet

ROLE:	Things I need to know in order to do this. Make a list of questions to ask or issues to address in order to take on this role.
Panel Presentation	
Sharing "Telling My Story"	
Family Mentor	
Initial/Limited Presentations of Course Content	

Part III

HOMEWORK

"Every Triumph that we have is the result of a struggle because of the special need."

Zimmermann, S. (1996). *Grief dancers: a journey into the depths of the soul.* Golden, CO: Nemo Press.

Homework Activity

1. Prepare to "tell your story" of the impact and influences your child with a disability has had on your life (positives and negatives).

2. Prepare to describe your experience and thoughts in two of the following areas:

   - Development and implementation of IEPs/IFSPs;
   - Coping strategies and supports you have used;
   - How professionals, family, and friends have, and have not, been supportive;
   - Most important message you want new professionals to hear;
   - Most positive contributions of your child.

Telling Your Story Worksheet

What is the purpose for my presentation?
What outcome would I like from my audience?
What powerful examples do I have that I am willing to share?
How should I organize my points with my examples?
What visual aid, creative wording/reading, or "audience hook" will I use?
What solutions or suggestions will I give my audience?
How will I close?
What will I do if I get nervous and don't know what to say next?

Part IV

Polishing Your Presentation

"This has given me a sense of what's important. I can't empathize anymore with my friend whose day is ruined because the cleaning lady didn't show up."

Simons, R. (1997). *After the Tears: Parents Talk About Raising a Child with a Disability.* San Diego: Harcourt Brace Jovanovich.

Making Presentations

by Deborah Manning

The average person speaks over 34,000 words each day, which adds up to the equivalent of several books per week! And yet, when polled, the number one fear of American people is that of public speaking. The fear of speaking to a group ranked above fear of dogs, fear of flying, and even fear of death!

> ***"Courage is resistance to fear, mastery of fear — not absence of fear."***
>
> ***—Mark Twain***

What is it that causes this discomfort in some of us and downright terror in others? What can we do to minimize these feelings?

The most important tool is preparation. Prepare yourself; prepare your material; and prepare for the actual presentation.

Preparing yourself. It is difficult to feel comfortable if you don't feel adequately prepared. Make sure you have done your homework. Once you are certain that you know the subject matter, you can begin to concentrate on your delivery.

Preparing the presentation. What are the key points you will be making? What can you do to reinforce them? Are there supporting materials that can help to drive the point home? Perhaps a video, handouts, or an easel and markers? Add variety and materials to reinforce your presentation when possible.

What's in a Message?

The message that people get comes from more than just the words they hear. According to communication studies, how the message is delivered has more impact on what we hear than the actual words themselves.

So, what's in a message? First, there are *the words*. A speaker needs to make sure that (s)he has chosen words that the audience can understand and relate to.

Next there is *how the words are said.* No matter how good your material is, no one will want to listen if the message is delivered in a monotone or with such low volume that it cannot be heard beyond the third row. Your voice should express interest in what you are saying.

Then there is *body language*, or the "nonverbal" part of communication. Body language includes your gestures, posture, and facial expressions. These have a major impact on how your message is received.

As you prepare your talk, think of all the factors that make up the message. Try rehearsing so that you feel comfortable incorporating them into your presentation.

QUICK TIP: Remember to Breathe

When we get nervous we tend to begin rapid, shallow breathing. And when you begin to breathe this way, it is difficult to project your voice and speak clearly. So, before that very first sentence, get a good lungful of air!

Check-up

Before you make a presentation, it is wise to analyze the group you will be speaking to. Here are some questions that can help you do that.

- What does the audience already know about the subject you will talk about?
- What more do they need to know?
- How much can they absorb in one sitting?
- What's your audience's attitude toward your subject?
- What different jobs or positions are included in your audience?
- What is the best way to present the material so that it will be understood by all?
- How many people will be in your audience?

By answering these questions, you can begin to determine the material that should be covered and how best to present it.

Action Plan

The following pointers can help you to prepare for your presentation.

1. Be prepared. Know your topic and your audience.
2. Practice (to yourself, with a friend or colleague, or perhaps on tape).
3. If possible, check out the room beforehand so that you'll know where to stand and where to set things up; then arrive early to finish your preparations.
4. When possible, use visuals to reinforce your remarks; charts and graphs, slides, and posters help; so does the use of color.

5. Have a comfortable beginning, middle, and end to your presentation.
6. Involve your audience by keeping eye contact, showing enthusiasm, asking questions, and encouraging input.
7. If you are using humor, be careful; it can backfire.
8. Don't be afraid to say, "I don't know the answer to that... but I'll find out and get back to you."
9. Relax! Your audience is there to get information from you, not to judge you. They want you to succeed.
10. Learn from what worked well and what did not, and use that information for your next presentation. Practice makes perfect.

QUICK TIP: *KISS*

People are inundated with information. The best way to get their attention, and then to keep their attention is to:

Keep It Simple, Speaker
(KISS)

Quality Presentations

Use this list to help you both present and provide constructive feedback to your presenter.

Posture

1. Stand up straight but not stiff.
2. Keep your weight evenly distributed on both feet so you don't sway and shift.

Movement

1. Take a few steps to the side and toward the audience.
2. If you are using a lectern or a table, step to the side or front occasionally to make contact with your audience.
3. Stay close to your audience to keep them engaged.

Gestures

1. Use gestures as you do in a normal conversation with your friends.

Orientation

1. Be sure to keep your shoulders square with your audience and to speak only when you are facing the audience.

Eye Contact

1. Eye contact is crucial to establish and build rapport with your audience.
2. Focus on one person and maintain eye contact 1-3 seconds before moving on to another person.
3. Smile more and frown less.

Voice

1. Articulate clearly.
2. Speak loudly and don't trail off at the end of your sentences.
3. To deliver a talk with natural animation that is not monotone, relax by gesturing and breathing normally.
4. Keep talk free of repetitive sounds such as "um," "uh," and "OK?"

Overall Presence

1. Look relaxed.
2. Keep focused and to the topic.
3. Use visual aids and props effectively.
4. Story is appropriate length.
5. Story keeps attention of audience.

Part V

Dress Rehearsal

"Turning the anger that could go inward and become depression, turning it outward to make change, can be energizing."

Woodbine House. (1995). *From the heart: On being the mother of a child with special needs.* Bethesda, MD: Woodbine House.

Sample Peer Feedback Form

For _____

Strengths of Your Presentation...

- You stayed on the topic and presented your story clearly.
- You did a nice job of using your pictures to engage the audience.
- Your voice was loud enough.
- You controlled your emotions well.
- Your story held my attention.

Suggestions for Next Time...

- You have a lovely smile — Use it!
- Use more hand gestures to make your points.
- Strengthen your conclusion.

Other Comments...

- Great first attempt!

Peer Feedback Form

For _____

Strengths of Your Presentation...

Suggestions for Next Time...

Other Comments...

Peer Feedback Form

For _____

I Like the Way You...

Other comments...

Next time you might...

Next Time I Tell My Story, I will...

Part VI

RESOURCES

"We are our stories. Our stories give meaning to our lives. Through them, we discover ourselves. By sharing them, they give us strength and make us part of something larger that embraces all the mysteries of life's joys and sorrows."

Zimmermann, S. (1996). *Grief dancers: a journey into the depths of the soul.* Golden, CO: Nemo Press.

"Parents as Presenters" Network

I belong to a network of Iowa parents of children with disabilities willing to share our family stories and build stronger bridges between families and professionals. We have received training in presentation skills and are ready to share experiences with your group. We feel we can build understanding among current and future professionals concerning:

1. Families' unique positions as the ultimate experts on their children;
2. Each child's individuality;
3. Families' experiences, positive and negative, with professionals; and
4. Rewards and difficulties of having a child with a disability.

If interested, please contact me!

Name: _____ Phone: _____

Sponsored by Iowa SCRIPT (Supporting Change and Reform in Interprofessional Preservice Training), Early ACCESS, The Parent Training and Information Center of Iowa, the Parent Educator Connection, Family Voices of Iowa, and Iowa State University.

The Benefits of Parents Speaking to Classes: The Family Perspective

"She [the instructor] made us feel we were important, and our information was valued."

"He's a little boy not a problem. He's my son, my husband's son, my Kyle's brother, a grandson, a nephew, a neighborhood child... life goes on and you learn to enjoy and **treasure** your children **just the way they are!** Keep sending parents into classrooms!!"

"The program is essential for parents/professional communication to continue to progress. I really enjoyed participating."

"As a father, it was a true pleasure to participate in the program. Often I do not take nor have the time to devote to the 'communication' process — really felt it was a good experience for class to hear from a 'father'."

"I thoroughly enjoyed myself!"

"Sometimes, seeing is believing and personal appearances help increase interest in the subject."

"What a great thing to do — to have parents talk to future teachers. I could tell from the looks on the students' faces that they were gaining insight into things that perhaps they hadn't considered. Thanks for the opportunity to help."

"I believe speaking to university students is an excellent experience for parents and a necessity for students!"

The Benefits of Parents Speaking to Classes: The Student Perspective

"Listening to a 'real' person talk made it more real. It [the situation of the person] became less of a statistic."

"I think I developed empathy toward these parents and learned of how they overcame their difficulties and how they cope on a daily basis."

"The true, actual stories are much more interesting and we can remember and even learn more from them."

"I gleaned some information about children with Down syndrome, but most important I loved Lori's statement about letting the parent be in the driver's seat. I want to remember that."

The Benefits of Parents Speaking to Classes: The Faculty Perspective

"It really helped make concepts 'real'. Vicky did an excellent job. I could see by student expressions and questions that the course material was now being applied to 'real' situations."

"Created empathy and understanding."

"The students appreciated the opportunity to hear first-hand the concerns of families with children facing developmental challenges."

"Bringing reality to all aspects of my instruction."

"It was a good experience to have students apply the concepts we've been learning in class, i.e., grieving, resources, etc., to a real-life situation."

Whitehead, A. (1996). International Parent to Parent Conference. New Mexico.

Examples of What Parents can Teach Professionals

- How and when sensitive information (e.g., diagnosis) should be delivered;
- Showing feelings is okay;
- Share information openly — "I don't know" is okay;
- Parents may have selective hearing or may not understand the words you use;
- **Definitions** of diagnosis are important, not just labels;
- Parents need to hear that it is not their fault;
- Parents need to hear that it is okay to use respite;
- Parents need to know that any questions is okay;
- Parents need to hear positives.

Adapted from: Poyadue, F.S. (1988) Parents as teachers of health care professionals. In *Children's Health care* (pp. 43-45) Washington, D.C.. The Association for the Care of Children's Health.
Whitehead, A. (1996). International Parent-to-Parent conference, New Mexico.

Family Experiences:*
Ways to Lead Change Through Telling Your Story

by Glenn Gabbard

NECTAS at the Federation for Children with Special Needs, Boston, Massachusetts

I recently attended a conference about model programs serving children with disabilities and their families. After one parent gave a particularly moving account of her family's struggles, the audience took a break. During the break, I overheard a remark from another audience participant. "I don't know if I can listen to any more tear jerking stories," the person complained. "What's the point?"

"Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children."

I was initially startled by the remark, then insulted. How could someone be so callous as to question the experience of a parent? As a parent of two children who receive special education services, I took this comment personally — as if the person were talking about my story — and telling me that it wasn't worth listening to. As I thought more about this situation, however, I realized the problem was not one of insensitivity, but that somehow the story had no impact on some listeners. It did not move them to think and consider using the themes and information as a prompt to change their personal and professional lives.

Whether it be to pediatricians, neighbors, legislators, therapists, conference audiences, teachers, administrators, or peers, parent of children with disabilities are frequently asked to tell all or part of their family's life story.

Parents reveal their stories as a way to understand the past in relation to an imagined future for themselves and their children.

Stories help us connect. Stories also reveal the details, the impact of the system on the daily lives of families and children. They are a powerful way to develop relationships among parents and professionals. These stories are what connect us to our work and to each other in meaningful ways. They deepen our understanding of individuals and shared experiences. Stories often spur change in systems that seem impossible to understand. They can also help clarify disagreements.

Storytelling can also be a huge risk. By sharing a story, you can easily make a point; however, you can also be vulnerable to criticism or misinterpretation. Often, the powerful lessons that these stories reveal are not fully appreciated; often parents grow fatigued with revealing private experiences that are frequently painful to recall.

This edition of the *Early Childhood Bulletin* will focus on ways parents can shape

their stories so that key themes are emphasized and improvements are made within a program or system. We'll cover some of the key issues to consider in preparing and presenting a story. We've also included some additional resources to consider if you wish to pursue this topic.

Family or parent involvement has become a hallmark of many programs and services for young children with disabilities and their families. Though being "involved" may translate into many different kinds of activities and interactions, one of the ways that parents can make a difference is by telling their story.

Outlined in the next pages are some important guidelines to consider when a story is to be told. The guidelines are designed around three phases of storytelling:

1. ***Preparing what you have to say***
2. ***Presenting the story***
3. ***Following up the story and assessing the impact of your story***

It's a good idea to spend at least some time on each of these phases — even if the story that you tell is one you've told before, even if the audience to which you tell it is a familiar one.

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1. Preparing the Story

What's the Purpose?

Parents tell their stories in many situations, sometimes when they are invited, others when they discover the opportunity informally. Parents speak in formal settings, including parent training, professional development, keynote speeches or panels for conferences, legislative hearings, school presentations to teachers and students. A group of parents gathered at a recent Part C conference in the Midwest discussed some of the key purposes for speaking out. They mentioned the importance of using one's own experience to bring change and broaden their experience to apply to others.

- Turning grief and anger into constructive energy by talking publicly;
- Helping service providers by sharing stories for effective networks to programs;
- Reinforcing values to guide a family's commitment to themselves and their children;
- Influencing public opinion by illustrating how policies affect families;
- Helping yourself and others to feel less alone in efforts to make change;
- marketing key strengths of early intervention to legislators and other policy makers;
- Entertaining others
- Sharing information that cannot be easily presented by charts or graphs with others who do not directly experience the problem;
- Raising awareness and promoting sensitivity to the experience and knowledge that grows from these experiences.

Where Do Family Stories Get Told?

"As part of our Parent-to-Parent program, I often meet families who have newly diagnosed children. I find that the telling the story of my own children's births helps create an almost immediate bond."

—Parent Support Staff Member

"Managed care had made life for kids with special/health care needs a real nightmare in our area. I told my story to my HMO's board of directors to help them understand how unique my family and others like mine are."

—Parent Representative, State Interagency Coordinating Council Member

1. Preparing the Story cont.

Who's the Audience

It is important to think a bit in advance about who will hear your story. A little ground work can help to make the story effective and help you be comfortable in telling it. Who is in the audience can help you to decide which parts to emphasize and, more importantly, why you are telling it. Aspects can change depending on the audience: a story about a wonderful preschool program can emphasize the need for funding with a group of legislators considering the next year's budget; to a group of preschool teachers, it can emphasize the importance of parent/teacher communication and collaboration.

How to Organize a Story

Although most stories have a beginning, middle, and an end, they can also vary in length — some are 30 seconds long; others can last over an hour. Engaging stories rely on a beginning that "hooks" the listener who then listens for the details in the middle of the story, and awaits the punch line at the end. The ***beginning*** sets the stage, identifies the key characters and location, and gets the listener interested. The ***middle*** — where the plot thickens — adds details, examples, and interesting information to understand the key ideas and people. The ***end*** usually ties things together and often gives an idea of what can be learned from it — what was the theme or lesson? Sometimes this theme can be stated directly; at other times it is best to let the listeners draw their own conclusions.

Some Questions to Consider:

- Who is your audience?
- What is their purpose?
- What is their education level?
- How many people are you speaking to?
- Age?
- Where are you presenting?
- Numbers of men and women?
- Did the audience pay to hear you?
- Numbers of parents and professionals?

The Organization of a Story

Beginning

- Where does the story occur?
- Who are the important people?
- When did the story take place?

Middle

- What happened first, second, third, etc.?
- What was the major conflict?
- What were some of the key feelings elicited?

End

- What happened to conclude the story?
- How was the problem resolved?
- What was the key theme you learned?
- What is the key theme you want the audience to understand?

2. Presenting the Story

Finding and Using Your Voice

The way a story is told is often as important as the story itself. To be an effective storyteller you must have something to tell, someone to tell it to, and the ability to make yourself heard. Some suggestions on presenting:

Relax — Before you begin to speak, take a few deep breaths and slowly scan the audience for familiar faces.

Project — With large audiences, use a microphone. In smaller groups, project your voice with confidence.

Pace — The most frequent problem with nerves is they make us speed up our presentations. Remember to speak calmly and slowly — just a bit slower than normal conversational style. Good listeners require some processing time.

Eye Contact — It's always helpful to establish clear and frequent eye contact with your audience. Even in small groups, you will find listeners who appear to be attentive; some folks may nod or smile.

It's often useful to consistently look at familiar or sympathetic faces in different parts of the audience. Look around frequently at these groups so that all of the audience feels included.

Humor— If appropriate, it may be helpful to use a bit of humor. Test any humorous comments with friends or colleagues to see if it works for them. Avoid making any one group (professional or parent) the butt of humorous comments. Teasing and sarcasm are not a good idea — one person's idea of a sarcastic remark might be another's insult.

Give the Audience Time to Ask Questions

- Allow time at the end of your presentation for audience members to ask questions;
- If someone asks a personal questions that hits a raw nerve simply say, "I find that question difficult for me and I would really rather not answer it;"

- Be comfortable saying, "I don't know, but I can find out for you" if you can't answer a question immediately.

Where Do Family Stories Get Told?

"You know, as a preschool director, the connection and empathy I feel with others — parents and professionals alike — is so powerful when I hear stories that connect somehow with my own. I get tired sometimes of hearing broad statements about how important collaboration is in thinking about family centered services and programs. What really makes a difference for me is when I hear stories about what happened today at the center... what kind of difference we made in the lives of the families we serve."

—Community Preschool Director

2. Presenting the Story cont.

Working with Props or Audio-Visuals

- The use of AV materials such as overhead transparencies, slides, videotape selections, photographs, and computer-enhanced presentations can be helpful tools;
- Know how to work equipment yourself. You cannot depend on someone being there who knows what you need.
- Be sure the equipment is working.
- Be sure that you aids are an enhancement of what you are saying and not a distraction.

What if I Cry?

For even the most experienced speakers, telling a story reveals a personal or emotional time can be difficult. Crying is, of course, perfectly acceptable; however, you need to be aware of the audience and their need to understand your emotions and your message. Also, the last audience response you want from telling your story is pity or confusion. Some tips from parent storytellers:

- If you start to cry, pause long enough to take three or four deep breaths, and then go on. The audience will appreciate your taking the time and being able to hear the rest of your presentation;
- Sometimes it is useful to explain to the audience that you need to collect yourself and that you really want them as much to understand what you have to tell them as well as how emotionally difficult it is for you;
- Mentally focus on something that makes you laugh inside; this sometimes evens out the fear and sadness enough to let you go on;
- Take a small squeezable rubber toy or some other object that will fit in the palm of your hand. If you start to cry, squeeze the toy to relieve some of the tension;
- Avoid someone "rescuing" you by interrupting and interpreting what you mean. If you still have a message to convey, take the time to collect yourself and then go on.

Where Do Family Stories Get Told?

"There is so much misinformation in our state about inclusion and natural environments. Recently, I testified at our local school committee meeting and told them how my son was part of his local little league team, even though he uses a wheelchair. A few of the committee people came up later to thank me for showing them some real examples of what we mean by including everyone."

— Parent Advocate

"For the first time in our state, we have to request additional funds for our Part C programs from our legislators. We've set up training in marketing and public awareness for parents and professionals whom we are asking to visit legislators and tell their stories."

— Part C Coordinator

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3. Following Up

How Can I Get Feedback?

Understanding how listeners heard your story is as important as preparing and telling it. If possible, ask trusted colleagues or friends to listen to your presentation and to let you know what they thought of it. Prepare focused questions and listen carefully to their responses. This will help you develop the story and emphasize effective features.

Some questions to ask when getting feedback:

- What key phrases and words caught your ear?
- What was the most successful part of the presentation?
- What was the most difficult to understand?
- If you knew the story was going to be told again, in what ways could it be different?
- What were the major themes?
- How did the audience respond?
- What about volume? Pace?
- Did I use humor effectively?
- Did the story make logical sense?

If there is an evaluation form for the activity in which you were speaking, ask to review the results. If you are speaking in an informal setting, ask someone to observe how the audience responds. This can be useful in meetings, training sessions, or even small groups in which stories are told. In some school or hospital settings, families ask a friend to act as an informal "critic;" this individual can give you feedback about the interaction if it seems appropriate.

A Final Note to Consider

As children grow older and more independent, it's important to consult them about the story details and, sometimes, whether or not the story should be told at all. It's important to remember that as children mature, some will be asked to tell their stories and should understand the importance as well as their right to keep details that they deem private to themselves.

Where Do Family Stories Get Told?

"When I need to make any big changes in my child's Individualized Education Program (IEP), I know that there may be some resistance. I usually introduce the need for a change with a story about my child that illustrates how the change could really help. It helps the group to become more child centered rather than focusing on possible conflict between me and them."

— Parent Representative
Local Interagency Coordinating Council (LICC)

Resources...

On Telling Your Stories

University of Wisconsin-Madison, Waisman Center, Early Intervention Program Parent Projects (Producer), & Geier, D. and Thompson, C. (Directors). (1994). Telling your family story... Parents as presenters [Video recording]. Madison WI: University of Wisconsin-Madison, Waisman Center. 1 Video Cassette plus accompanying video guide. 28 min.

"Telling Your Family Story... Parents as Presenters." Video Cassette. Waisman Center, Early Intervention Parent Projects, University of Wisconsin, Madison, (1994). 28 min. Waisman Center.

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"Using Stories as Catalysts for Change." *Parent Leadership Program Training Manual* (March 1996). Lansing MI: Michigan Department of Education, 608 west Allegan Street, Lansing, MI 48933. Phone 517-373-6335. A useful set of activities designed to foster skill and knowledge building for parent leaders involved in policy making capabilities.

On Public Speaking

Hoff, Ron and Barrie Maguire (1992). I Can See You Naked. New York: Andrews & McMeel.

Stories That Have Been Told

Simons, Robin (1987). *After the Tears: Parents Talk About Raising a Child With a Disability.* New York: Harcourt Brace. A collection of interviews and stories from parents who share their experience of becoming parents.

Featherstone, Helen (1981). *A Difference in the Family: Living With a Disabled Child.* New York: Viking Press. A classic account of one mother's experiences as a parent and advocate.

Coles, Robert (1990). *The Call of Stories: Teaching and the Moral Imagination.* New York: Houghton Mifflin. The nationally renowned psychiatrist and humanist reflects on the importance of learning from the stories we tell and hear.

Mairs, Nancy (1998). *Waist-High in the World: A Life Among the Nondisabled.* New York: Beacon Press. A recent collection of eloquent essays reflecting on the experience of disability and change.

Thank You

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An Important Electronic Resource for Parents Serving on ICCs

NECTAS is pleased to sponsor the ICC Parent Leadership listserv.

Parents serving on ICCs play a unique role. They are often perceived as representatives of large groups of parents within communities and their own personal experiences are considered, many times, to be representative of others. The purpose of this listserv is to facilitate networking and discussions related to the unique leadership challenges and opportunities, etc.

The ICC Parent Leadership listserv is a closed list, which means the request to subscribe are made to a list moderator. Glenn Gabbard, NECTAS Technical Assistance Specialist at the Federation for Children with Special Needs in Boston, MA will moderate. E-mail Glenn with your subscription request at:

ggabbard@fcsn.org

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Innovative Practices

Parents as Co-Instructors in Preservice Training: A Pathway to Family-Centered Practice

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The joint participation of family members and faculty in training activities has been an effective strategy for assisting both faculty and students in gaining knowledge and skills for implementation of family-centered practice. This article describes faculty-parent co-instruction in preservice settings. Goals for co-instruction and implementation issues such as recruitment and selection of parent, preparation for co-instruction roles, student evaluation in co-instruction settings, supports for parents and faculty in co-instruction roles and diversity issues are addressed. The experiences of several co-instruction teams are described as well as the benefits and challenges of this approach for teaching about family-centered practice.