

Partnering with Deaf Adults: Creating Positive Outcomes for Children and Families

Dinah Beams, MA, CED

Lead Colorado Hearing Resource Coordinator

Stephanie Olson, BA

Deaf Adult Consumer Advisor

NHS 2006



“When we first received our son’s diagnosis, I looked at the doctor, he was hearing. I looked at the audiologist, she was hearing. I looked at the nurse, she was hearing; and as we walked out, I looked back at the receptionist and she was hearing. I had no idea what this (raising a deaf or hard of hearing child) was going to look like until you (the deaf adult) walked in the door.”

Shelly Strickfaden, parent of a two-year-old boy who is hard of hearing

Why a Deaf or hard of hearing adult?

- Most parents with newly identified deaf or hard of hearing child are themselves hearing
- Most have few or limited experiences with someone who has a congenital hearing loss
- Deaf and hard of hearing adults provide parents with a positive and hopeful perspective as well as genuine, real life experience
- It is the closest thing we have to a crystal ball!



Parents ask three basic questions:

What's wrong with my child?

What will my child be like later?

What can be done to help my child?

Bagnato, Neisworth, & Munson, 1997

Deaf adults are uniquely qualified to address
these issues



What does this connection provide for families

- Calms anxiety
 - “It’s going to be ok – I can see that”
 - “I imagined a lot of things that could go wrong but I never thought about a hearing loss – I can’t even imagine it”
- Build relationships with the modalities at hand
 - Parents think they have lost a modality forever
- Communication
 - Can not have a relationship without communication
 - Equalize relationship (communication) between parent & child



How to make this connection

- Most parents of newly identified children do not realize how meeting a deaf or hard of hearing adult will help them until after they have had the opportunity
- System must create opportunities for parents to meet deaf and hard of hearing adults
 - Presentations
 - Workshops
 - Home visits
 - Social events



Why involve a deaf adult soon after identification

- Introduce the child and family to this new community
- Helps normalize the world, the experiences, and the feelings
 - What it looks like is not nearly as awful as parents thought it could be
 - Comfortable in his own skin
- Addresses practical concerns that family may not feel comfortable asking hearing professionals or the medical community

- Assists parents in becoming comfortable with the “new normal”
- Articulates what the child can not
- Ability and creditability to speak for the child’s upcoming/future needs
- Baby’s reality is different than that of the hearing parents



- New way of communicating and thinking becomes the new normal for families
 - Driving with light on for visual cues
 - Say goodnight with light on
 - Going upstairs facing the child
 - Watching for opportunities to close the gap (incidental learning)



- Deaf adult assists the parents in building a relationship with the modalities at hand
 - Parents think they have lost a modality forever
- It is not possible to have a relationship without communication
 - Models communication and relationship building strategies between family members



- The deaf or hard of hearing child lives in a hearing world (family, church, neighbors). Meeting the deaf adult soon after diagnosis may be the family's only opportunity to ask some of their questions and see these communication strategies modeled.



Roles of Deaf and Hard of hearing Adults in the EDHI system in Colorado

- Interventionist
- Role model
- Sign Instructor
- Consumer advisor
- Coordinator
- Members of committees and task forces



Involvement of Adults who are Deaf and hard-of-hearing

- System level
 - Administration
 - Quality assurance
 - creditability
 - Program development
 - Decision-making
 - Representation on key committees and task forces
 - Policy setting



More system issues

- Need a variety of deaf and hard of hearing adults
 - Opportunity to meet more than one individual
 - Ability to match adult to parent's concern/questions
- Job description is important



System involvement

- Hospitals and diagnostic centers can have a deaf adult on the team to meet with the parents
 - Ex. Parent Mentor position at The Children's Hospital of Denver
- Early Intervention programs can introduce parents to deaf adults as providers, role models, leaders.



Barriers

- Family barriers
 - Potential negative experiences with deaf/hh individuals when growing up
 - “I’m living Mr. Holland’s Opus”
- System barriers
 - Funding to pay for involvement of qualified deaf or hard of hearing adults
 - Expectations/ job description/training
 - Time constraints
 - Takes time to build a relationship w/ professionals



For more information contact:

Dinah Beams

dbeams@comcast.net

Stephanie Olson

steph_olson@msn.com

