Twists and Turns: 
The Social and Emotional Impact of Hearing Loss

A Parent’s Perspective on Navigating the Journey

Sherilyn M. Adler, Ph.D.

Department of Otolaryngology
University of Miami
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Navigating Your Child’s Emotional Journey
A Parent’s Perspective

Parent of child born with profound bilateral sensorineural hearing loss

Aunt to two nephews (now adults) with profound bilateral hearing loss

Developmental Psychologist

Volunteer/Mentor/Consultant
Navigating Your Child’s Emotional Journey
A Parent’s Perspective

Our Family’s Story*

Diagnosis
Appropriate amplification
Early Intervention
Education
Branching Out

*Our Family’s Story
Navigating Your Child’s Emotional Journey
A Parent’s Perspective

Supporting the Emotional Development of Your Child
First, Take Care of Yourself
Know your child: Understand the Needs of Your Child
Make Yourself and Your Expectations Known - At Home
Making Needs Known - In School and Community
Development of Peer Social Interaction
Giving Back - Advocating for Others
Promoting Healthy Emotional Development

Acknowledge, identify, express and manage your own feelings!

Learn and teach vocabulary of feelings

Encourage awareness and identification of feelings

Respect child’s right to their feelings

Teach appropriate expression of feelings

Check in regularly on child’s feelings
Birth to Five

Unexpected News - Newborn Screening or Later ID

Family Support - Or not

Hearing Professionals Everywhere
  MDs. Audis, Therapists, Educators

Learning the new language/lingo of hearing loss

Find a Parent and/or Professional Mentor

Establishing Your Child’s Team - Who’s the Leader?

UJHealth
UNIVERSITY OF MIAMI
MILLER SCHOOL of MEDICINE
Where to Start

Resources

Family, Professional, Community, Social Media

Initial information provided should be: unbiased, factual and inclusive of all potential treatment options, language choices, modalities and choices

Comprehensive and neutral regarding family choices and modality

Neutral: e.g. Early Steps and/or Hands and Voices
Dedicated: e.g. A.G. Bell and N.A.D.
How We Chose a Language and Modality

Mom’s and Dad’s Previous Experience with hearing loss

Reaching out to Family, Friends and Colleagues

Finding Information and Professionals

Word of Mouth
Social Media: Blessing or Curse?

Advantages

Disadvantages
How Did We Promote Language Development?

Maximize Use of HA’s and CI’s

Stay close and talk, sing, converse

Seek out and work with professionals on same page

Focus on listening and spoken language

Read, Read and Read Some More
The Importance of Reading

When to start
What to read
How to make it interactive
Library Card
Foster a Love of Reading
Holding Tight and Letting Go

Childhood
Protection
Dependence

Adulthood
Freedom
Independence
Be Prepared to Change Course
Embrace Mistakes

- Expect to make mistakes
- Reframe as learning experiences
- Discuss the process
- Anticipate/Avoid future mistakes

“Boy, I spent the whole day learning from my mistakes.”
Unhelpful Messages from Professionals

There is only “one right way.”

My way is the only way.

Your child will fail unless you do ...

Don’t worry... (fill in the blank...)

There are many paths to success for kids with hearing loss

Some ways work better than others for achieving certain outcomes

Own your truth:

“At our facility, we take ABC approach and encourage XYZ intervention because we believe…”
What is Unhelpful to Parents*

Making assumptions
Focus only on what our child isn’t doing (yet)
Refuse to listen to our questions, concerns and feelings
Insist that everything is related directly to our child’s hearing loss
Try to convince us we are wrong or ‘incapable’
Are rigid and/or inflexible or narrow-minded
Accept (or insist) that ‘average’ is okay for ‘our kids’
Believe that they knew better for our child/family what is right for our child
Tell us what we need to do in a way we can’t (yet) understand – Audi/TX/MD/Ed
Refuse to provide regular & written assessments of progress and goals
Refusal to communicate regularly with us or with other members of our child’s team

*same for children
What is Helpful to Parents*

Listen to us
Create a safe place for us
Believe we’re the expert on our child
Provide us with fact-based information
Assess our children regularly and refer when warranted
Use tests based on developmentally approp. milestones and language models
When provided with all options, trust us to make the right choice for our family
Show respect for our time
Be open-minded and flexible
Accept our decisions - provide support and help us follow through
If not accepting or unable to provide intervention, …
provide support and refer, as appropriate for our family’s needs

*same for children
Choosing a Learning Environment

- Play-based
- School as team member
- Good teacher-student ratio
- Peer language models
Feeling Inadequate or Overwhelmed?

The Three Little Bears

“Too much, too little and just right!”

Manageable Chunks

“Just Right Challenge!”

Modeling vs Teaching
Social FOMO (Fear of Missing Out!)

**Parent Version**

**Child Version**

Not sure if I want to go out and wish I was home

Or stay in and wish I was out
The Development of Trust

How we feel safe and learn to trust others

Be honest
Ask questions
Be Kind
Be Expansive
Focus on Process
Be Consistent
Tailor Information
Accept Mistakes
Observe Others
Listen
The Development of Self-Esteem

How we feel about ourselves and our value

Security  Belonging  Purpose  Competence
Pride  Responsibility  Empowerment  Self-Control
Acceptance of Mistakes  How we’re treated by others
The Myth of Laziness

My baseline belief:
All children want to be successful and to please you!

If they don’t, there’s a reason.

Hearing Equipment  Sensory Regulation  Listening Fatigue is real!

To increase a child’s likelihood of being successful, figure out what’s interfering and set them up for success.
Levels of Understanding - Challenges

Hear the Words

Hear the Meaning

Hear the Implication

Nancy Rowe, Au.D. NeuroNet www.neuronetlearning.online
Levels of Understanding - Challenges

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What to Do About Poor Behavior

Do I correct?
Do I confront?
Do I concede?
Do I teach?
Other Puzzle Pieces

Hearing Loss isn’t always the (only) reason for what’s going on!

Understand the child’s “pace”/regulation
Respect the child’s individual differences
Pay attention to sensory-processing differences

Sensory Regulatory Challenges for Kids with Hearing Loss

Trust your Gut - Check it out - No down side!!
If no problem, reassurance. If problem, better to intervene early
School Age

Establishing Child’s Educational Team
Who is the Leader?

School Placement Choices

ABC’s, IEP’s and Other Important Stuff

Family Relationships

Peer Relationships

Self- Advocacy
Walking the Parental Tightrope

Please remember to treat my child like a typical child.

Please remember that my child is not typical.
Adolescence and Young Adulthood

Growing Independence

Power Struggles

Finding Your Tribe

Fitting In

Planning for the Future

After High School, then what?
“How was my day? How was my day? Must you micromanage my life?”
Driving, Dating, Diplomas and Losing Your Grip

Licensed Driver  Senior Year  Dating  Graduation
Doing Less as they Do More

THAT MARGE WINKLE STOLE MY IDEA FOR HER "CLASS-MOM" PROJECT! I'M SO MAD, I DON'T EVEN KNOW WHAT TO DO!

WELL, YOU COULD: TALK TO HER ABOUT IT; PICK ANOTHER TOPIC; TALK TO THE TEACHER; LET IT GO; CONSIDER IT A COMPLIMENT...

THIS IS ONE OF THOSE TIMES WHEN I'M JUST SUPPOSED TO LISTEN, ISN'T IT?

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Finding Your Own Tribe
How Our Family Gives Back

Using Our Voices! Leading by Example!
Advocate for Newborn Screening
Encourage Development of Early Access to Services
Support Equal Access/Opportunity
Raise awareness about NIHL and its prevention

Volunteer with organizations that support kids/ families with hearing loss
AG Bell, Barton G Kids Hear Now Family Resource Center, Cochlear Corporation, UM Ear Institute, FCCDHH, Ear Peace Foundation, Facebook, and other Online Support Groups
How Our Son Gives Back

Involve your children in giving back
mentor a younger/newer family, public speaking
Don’t Let Anyone Underestimate Your Kid!

“Your son’s audiogram won’t be accurate; he’s too young for play audiometry

“Why are you so impossible to satisfy? You should be thrilled he’s doing ‘average’

He’s age-appropriate for language with a HA, why would you pursue a CI?

Play a musical instrument? He’s deaf… maybe drums?

Learn a foreign language? He’s deaf. Maybe ASL?

Competitive Policy Debate? He’s deaf!

College? Where?
Don’t Let Anyone Underestimate Your Kid!

Played the flute

Studied Hebrew & Latin

MCH ‘I Make a Difference Award’

Junior Orange Bowl Award

Silver Knight Honor in Social Sciences

Tufts University Jumbo!

Fluent in Spanish!

Fluent in Spanish!
Then What?... The World Beckons!

- College Applications - where/what?
- College Visits and Interviews
- Office of Student Support Services
- Academics and Accommodations
- Social Life and Relationships
- Travel Abroad - Madrid
- European Travels with Friends
- First College Job
- Another Graduation!!
- Applying for Jobs in the Real World
THANK

Contact Information:

Sherilyn M. Adler, Ph.D.
sherilynmara@bellsouth.net or Sherilyn@EarPeaceFoundation.org
305-439-5444