



The Impact of Emerging Technologies on Families: Considerations in Real Life

Current Developments and New Directions in Pediatric Audiology
5th European Pediatric Conference

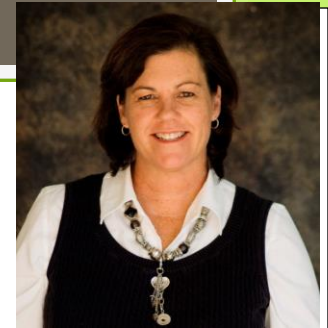
Berlin June 16-18, 2016

Janet DesGeorges

A brief history of our family

- Sara was born in 1991 – prior to universal newborn hearing screening
- Late I.D. at age two – with 2 year language delays
- Successful, young deaf adult – bi/modal communicator; recent college graduate
- Technology – hearing aids, (4 pairs); FM systems (school owned, privately owned); down to one. What she wishes she owned...
- Transitions to adulthood – my ‘other’ presentation: “Confessions of a Controlling Mother”





My Professional Background

- **Credentials: M.O.M. (*"Mom, you wouldn't have a job if it wasn't for me"*); our family story**
- **Systemic involvement for over 15 years (medical, educational, community)**
- **Executive Director and Co-Founder, Hands & Voices (over 50 chapters in the U.S. and abroad)**

Presentation today

- “Miracle” and “Real Life”
- Considerations that contribute to the impact of technology in the real world.
- Strategies that enhance partnerships with families in technology decision making and use.

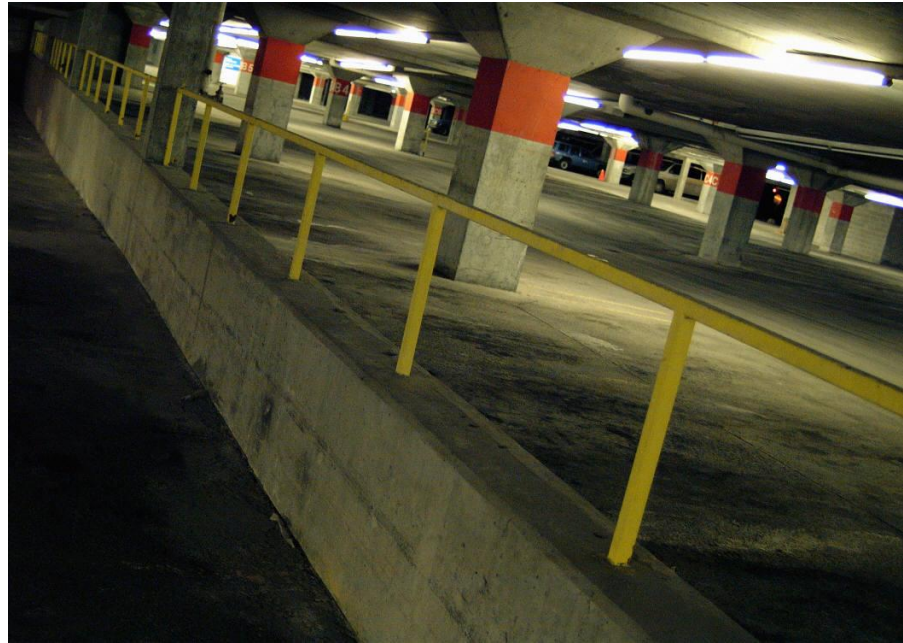
The “Miracle” and “Real Life”

We are the sacred holders of two ideas for families. The miracle of technology and the limitations of technology.

**CALL ME AS
SOON
AS POSSIBLE!!!**



**“Can I take it
out now?”**



The little miracles

“What’s that sound?”

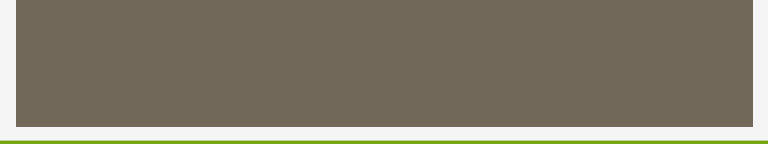


“The Universe is experiencing a paradigm shift”



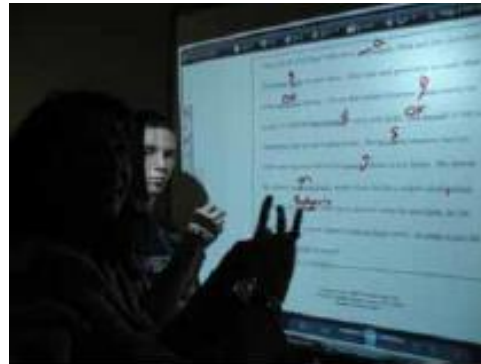
Considerations in Real Life





**Not just hearing technology
itself but how the world has
changed...**

At School...



In motion...



“Hey, slow down!”



Audiologist to parent –
“Keep the hearing aid in during ALL waking hours... after all, hearing people have their ‘ears’ on all the time.”

At Home...



Cochlear Implants FM System IEP Manual Communication Hearing Aids Sign Language
Mainstreaming IFSP Learning Disabilities Residential School American Sign Language
Parental Involvement Auditory Verbal Manually Coded English Sign Systems Interpreters
Speech Therapy Least Restrictive Environment Genetic Disorders Amplification Educational
Placement Communication Options Multiple Disabilities Cued Speech Social/Emotional
Development Auditory Neuropathy Family Dynamics Cochlear Implants Amplification
IFSP Parental Involvement Learning Disabilities Cochlear Implants FM System IEP Manual
Communication Hearing Aids Sign Language Mainstreaming IFSP Learning Disabilities
Residential School American Sign Language Parental Involvement Auditory Verbal Manually
Coded English Sign Systems Interpreters Speech Therapy Least Restrictive Environment
Genetic Disorders Amplification Educational Placement Communication Options Multiple
Disabilities Cued Speech Social/Emotional Development Auditory Neuropathy Family
Dynamics Cochlear Implants Amplification IFSP Parental Involvement Learning Disabilities
Cochlear Implants FM System IEP Manual Communication Hearing Aids Sign Language
Mainstreaming IFSP Learning Disabilities Residential School American Sign Language Parental
Involvement Auditory Verbal Manually Coded English Sign Systems Interpreters Speech
Therapy Least Restrictive Environment Genetic Disorders Amplification Educational Placement
Communication Options Multiple Disabilities Cued Speech Social/Emotional Development
Auditory Neuropathy Family Dynamics Cochlear Implants Amplification IFSP Parental

It's not just about technology...

“New and Improved”

- **Parent Acceptance**

- Emotional Expectations and unrealistic hope
- Not perceiving need at all or ‘this will fix it’

- **Cost**

- -deciding when/what to buy/waiting on newer technology.

- **Understanding and using Technology**

- **Other Health Problems**

- **Appropriate Age range of products**

- **Short term use when waiting on next technologies**



The Ages and Stages

1. Parent Driven/Child Reactive
2. Parent Driven/Child Input
3. Parent Driven/Child Driven
4. Child Driven/Parent Input
5. Child Driven/Parent Reactive

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Strategies to Support Families

The Family Across from you...

- **Individualize to their needs**

- What's their capacity?
- What is their day to day life like?

- **Don't make assumptions**

- Parents can be trained!
- Parents can move up the 'involvement' scale.

Balanced Partnerships with Parents

- Parents want professionals to perceive them as equals in making decisions about their child

What Parents Have Told Us, Harrison and Roush, 1990-2000

- “Listen to us, respect us, be knowledgeable, be honest, tell us everything.”

Connecting with Families: Making Early Intervention Work, Marilyn Sass-Lehrer, Ph.D. Gallaudet University, Washington, DC

- “Don’t just do something – stand there and pay attention” (Dean, 1991)

The Secret Ingredient

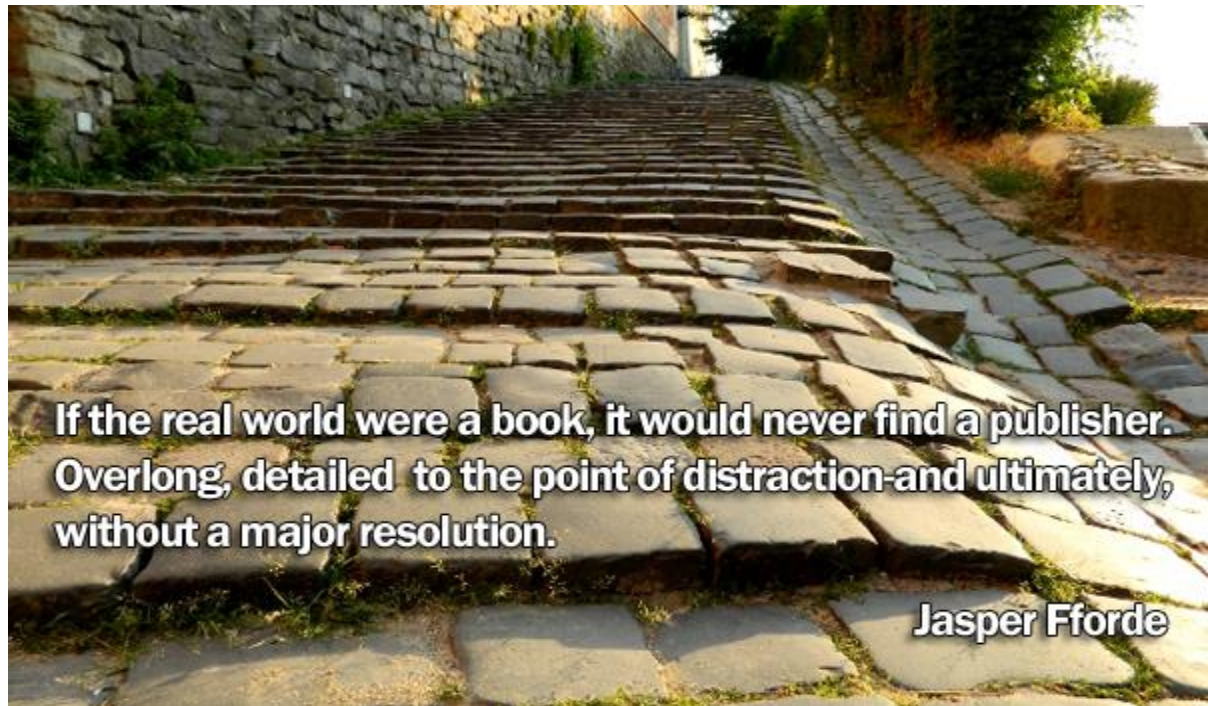
- Relationship building

- Parents will get the most from you when they trust you.
- Why do parents overestimate hearing aid use in studies?
- Transparency in the learning curve for professionals. (competence builds confidence)




“If we knew what it was we were doing, it would not be called research, would it?”

-Albert Einstein



**If the real world were a book, it would never find a publisher.
Overlong, detailed to the point of distraction and ultimately,
without a major resolution.**

Jasper Fforde



**“There are only two ways to live your life.
One is as though nothing is a miracle. The
other is as though everything is a miracle.”**

-Albert Einstein



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VOICES

Janet DesGeorges, Executive Director
Hands & Voices Headquarters

PO Box 3093
Boulder, CO 80307
303-492-6283
janet@handsandvoices.org