

Parents to Professionals: What We REALLY Need to Know

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Aloha! Here's my Family



Quick: Background

- ◆ Ikaika is 4 years
- ◆ Has a tracheotomy
- ◆ Has a g-tube
- ◆ Diagnosed: 2 mo.
- ◆ EI services
- ◆ Bi-lateral, mixed
- ◆ Moderate/severe
- ◆ ASL + speech
- ◆ HCDB preschool



But this is not about me...

- ◆ I created a survey of 30 questions
- ◆ Sent to everyone I could think of
- ◆ Open to any family of a child with hearing loss, regardless of child's age
- ◆ Received responses back from all over the country
- ◆ Families of diverse hearing diagnosis, methodology, philosophy, ages

Parameters of the Survey

- ◆ I asked families to comment on their working relationships with:
 - Audiologists
 - Deaf Educators
 - Speech Language Therapists
 - EI Case Managers
 - Primary Care Physicians
 - Other professionals they are working with

Share a Positive Story about any Professional

- ◆ Our therapist loves our child! When she sees him she hugs him. It makes me feel like no matter how he's performing, she likes HIM, regardless of how he is "doing" in therapy.
- ◆ Everyone has been so great, giving recommendations and advise. They have helped us to help our child. The EI system gives hope and inspiration to hopeless parents.

What negative impacts have you experienced?

- ◆ The therapist came over 3 times and declared that we were already doing everything she would do and we didn't need services. It took a long time to get a therapist to come again and help us.
- ◆ When my child was diagnosed as profoundly deaf and the doctor called to give us the results, he said "well, that means he will probably never talk". We were devastated and he was wrong!

Lessons Learned?

- ◆ I've learned to advocate for my child
- ◆ Parents are the decision makers, don't feel bullied by professionals
- ◆ I would have pushed for more opinions right away to get the answers we needed
- ◆ I would have collected more info on modes of communication before making our choice because once you choose, you stop getting information about other options

Do you think a professional ever gave you biased advise?

49% said yes
51% said no

- ◆ Answers reflected professionals across the board: everyone is susceptible to giving personally biased advice
- ◆ Parent Advisors: they wanted us to sign and choose methods we had not chosen: we went thru 3 in a year!
- ◆ For some professionals, its not just a job but a commitment to help families and their advice reflects that.

Would you prefer to know a professional's personal beliefs?

51% yes

49% no

- ◆ Families want to know that professionals will support and assist them in all their decisions, regardless of personal beliefs
- ◆ I would only want them if I asked for them. I am not seeing them for their personal beliefs, just their professional ones.
- ◆ I think it would help to know the personal beliefs of the person who is advising you.

Which professional provides the most support to your family?

- ◆ They ALL do!
- ◆ But SLP's ranked highest in offering support to families (maybe because they spend the most time one-on-one with children and their families)
- ◆ Remember individuals can offer more (or less) support, even those in the same field, and they leave a lasting impressions, for good or ill

Because this is the EHDI...

When was your child diagnosed?

- ◆ 0-3 months: 46%
- ◆ 4-6 months: 12%
- ◆ 7-24 months: 21%
- ◆ 25 months or later: 21%

Looks like Newborn Hearing Screening
is doing a good job! Way to go!

How long did it take for your family to accept your child's hearing loss?

- ◆ Immediately: 69%
- ◆ 1-5 months: 13%
- ◆ 6-12 months: 12%
- ◆ 13 months or longer: 3%
- ◆ Never accepted: 3%

Did the professionals keep pace with your acceptance?

- ◆ Yes, mostly: 76%
- ◆ No, they pushed us: 0%
- ◆ No, they were lagging: 4%
- ◆ Mixed: some good, some not: 12%
- ◆ Other: 8%

Kudo's to you! It looks like most professionals are in tune to their client's emotional needs.

How do you feel about the EI Services your family received?

- ◆ Extremely pleased: 52%
- ◆ Happy: 15%
- ◆ OK, but could be better: 28%
- ◆ Not happy: 5%

Remember: you cant please everyone, and not everyone is pleasant... but it looks like EI is doing an overall great job!

Were you overwhelmed with the new jargon & terminology?

- ◆ Yes: 60%
- ◆ No: 40%

We are all individuals and need to be treated as such. But as we've seen, it looks like professionals are helping us to cope at our own pace.

Did you receive support material? From whom?

- ◆ Yes: 78%
- ◆ No: 22%

- ◆ Speech Language therapist
- ◆ Audiologist
- ◆ Deaf Educator
- ◆ Rehabilitation dept.

Amanda's Dream:
For all families to receive a compilation of information about all their different options and choices, from one office, and make sure everyone gets it

What do you really want to know from your... Audiologist?

- ◆ What does my child hear? What does it sound like?
- ◆ Why are hearing aids so expensive?
- ◆ Is my child really able to use the hearing he has?
- ◆ Where do I go for parent support?
- ◆ What exactly the speech banana means
- ◆ Test results and options explained, not opinions
- ◆ How the technical results affect speech and language

What do you really want to know from your...SLP?

- ◆ Most popular answer: I want you to teach me how to help my child outside of therapy
- ◆ Realistic ways to do their idealistic suggestions
- ◆ What is my child's speech level?
- ◆ Can you give me more than one hour a week?
- ◆ Where my child is, what's concerning and what's not

What do you really want to know from your...EI Case Manager?

- ◆ ALL the resources available in the community
- ◆ How to prepare for mainstreaming
- ◆ How the system truly works
- ◆ What are my options?
- ◆ What equipment and services are available for my child?
- ◆ That they know what our expectations are for our child

What do you really want to know from your...Deaf Educator?

- ◆ Other ways of learning ASL
- ◆ That it's ok NOT to learn ASL
- ◆ How to incorporate their work at home
- ◆ I want to know that they know a lot about language
- ◆ The most used signs and which ones to use if books show different ones

What do you really want to know from your...Primary Care Physician?

- ◆ That they understand the options open to us
- ◆ How to protect his residual hearing
- ◆ How will his hearing loss affect his future?
- ◆ Referral to a competent pediatric audiologist
- ◆ That they will learn more about hearing loss

A few constructive thoughts:

- ◆ We are doing the best we can and would appreciate a pat on the back for doing what we can manage without being made to feel bad for the things we cannot
- ◆ I am the expert on my child
- ◆ The child is a child and not a subject
- ◆ Don't sigh when I ask you the same questions
- ◆ Home is very different from your office
- ◆ Admit it if you don't now, then help us find someone who does

What would you say to your...

Audiologist:

- ◆ Thanks for explaining the ABR as it happened
- ◆ Be careful how you tell us loss has progressed
- ◆ You need to be on me to make more appointments
- ◆ It's not just a science

Speech Language:

- ◆ Every time you come, my child makes progress
- ◆ Can we have therapy every day?
- ◆ Remind me of what I'm doing well
- ◆ You have modeled the best strategies for us to use

What would you say to your...

EI Case Manager:

- ◆ Are there any parents I could meet?
- ◆ Don't tell me you can meet all my child's needs
- ◆ Do you have an integrated calendar of community events?

Deaf Educator:

- ◆ Can you facilitate meetings with Deaf people?
- ◆ Can you provide an informational flyer for parents
- ◆ Your not allowed to retire until my child graduates college

What would you say to your...

Primary Care Doctor:

- ◆ Please learn about auditory neuropathy
- ◆ Can you attend just one IFSP?
- ◆ Balance, speech and hearing go hand in hand
- ◆ Educate yourself
- ◆ Thanks for caring
- ◆ You're not getting it yet, please listen to me

Over all, families would like to say:

THANK YOU!!!!

And so would I!
Mahalo and Aloha!

