

Meet the Parents!

Sarah Thomas, MS, CCC-SLP, LSLS Cert. AVT
Hearing School of the Southwest – Coppell, Texas


Becky Clem, MA, CCC-SLP, LSLS Cert. AVT
Cook Children's Medical Center – Fort Worth, Texas



Upcoming Events

- Parents Only! Listening, Learning, and Literacy, Saturday, March 21 8:00 am to 3:30 pm. Cook Children's Medical Center, Fort Worth. FREE.
Becky.clem@cookchildrens.org
- TCU Listening and Spoken Language Institute. June 8-18, 2009, TCU in Ft. Worth, TX. www.tcu.edu (search Dept. of Communication Disorders)
h.morrison@tcu.edu

S. Thomas & B. Clem
EHDl 2009 Dallas

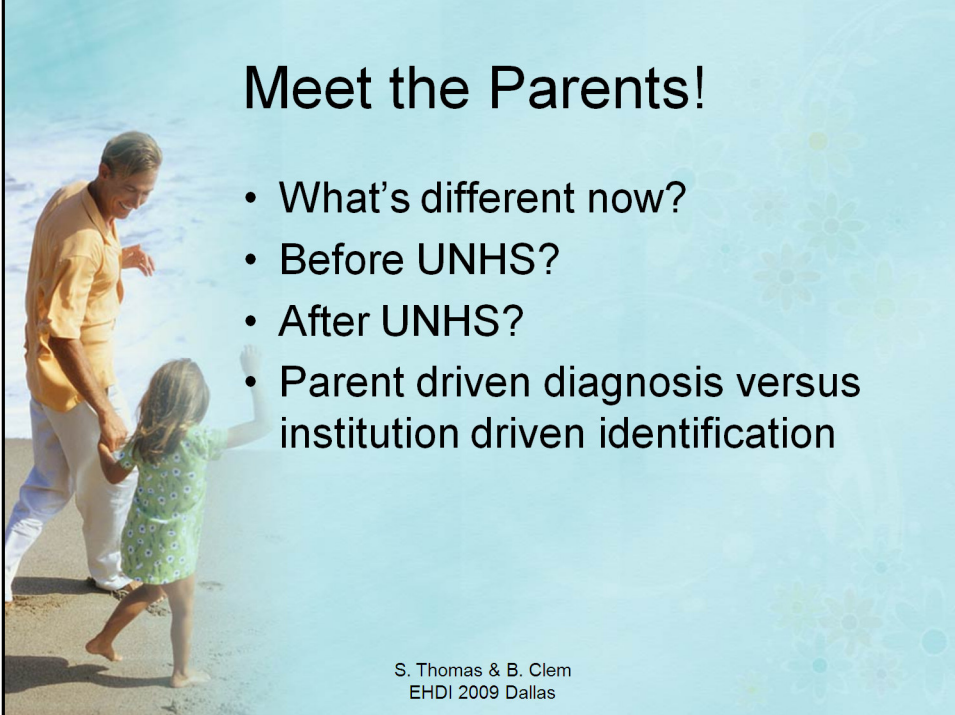


Meet the Parents!

- Grief Aspect
- Parent Participation Model

S. Thomas & B. Clem
EHDl 2009 Dallas

2 aspects of our talk today which is part of a 2-day presentation as part of training in listening and spoken language for AVT or AVEd.



Meet the Parents!

- What's different now?
- Before UNHS?
- After UNHS?
- Parent driven diagnosis versus institution driven identification

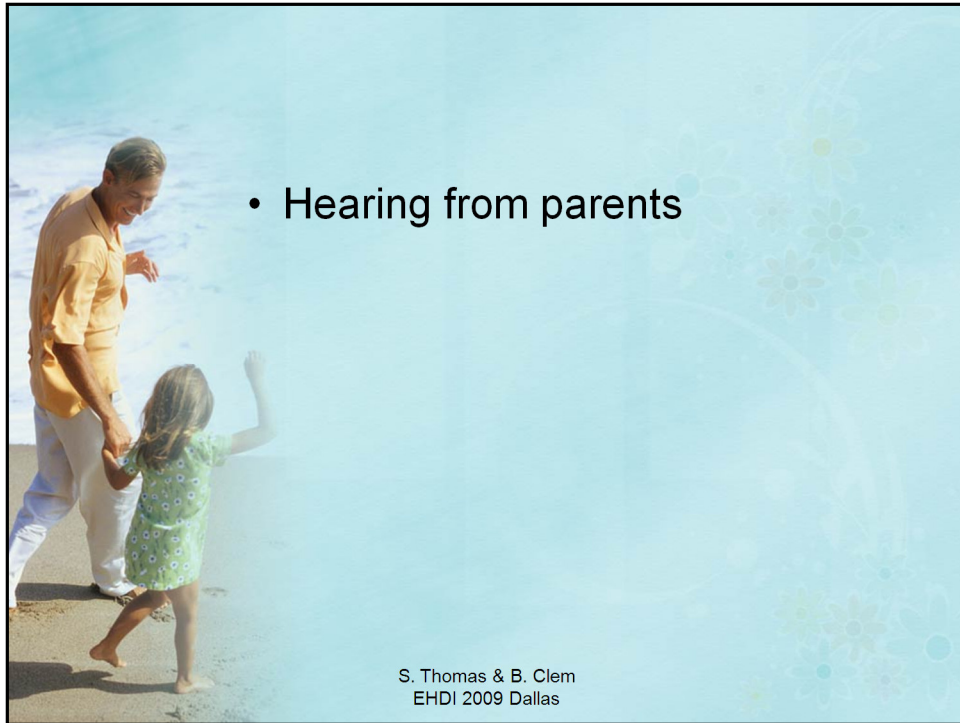
S. Thomas & B. Clem
EHDI 2009 Dallas

What's changed about the grief process? The biggest change has to do with technology and how that has changed everything – not just outcomes but how we do things as professionals, and how parents cope and deal with the diagnosis

Before UNHS – parent driven dx – parent suspected, tried a million different actions to reassure themselves that their child didn't have a HL – had a spouse or friend, or significant other, or other family member to try those things and say no, just slow, stubborn, he's fine. And then finally a hearing test, and underlying suspicions confirmed. Uncommon to have the physician or teacher be the one to bring up the hearing in question – usually family member since they spent the most time with child

UNHS – institution driven diagnosis – babies tested when family not around, tech might be the one who tells the parents, might not be a big deal and down play the 'refer' and not follow up....but in a very joyous moment, learned that child has a hearing loss, deafness, what does that mean.

Best place to hear about it is from the parents.



We made a DVD as part of our Meet the Parents 2-day workshop and the first part was about how parents felt when they were told their child had a hearing loss. Here is a clip from one of our parents.



Meet the Parents!

- Aspects of Diagnosis of Hearing Loss/Deafness
 - Anger
 - Guilt
 - **Identity Crisis**
 - **Overprotection**
 - Confusion
 - Vulnerability and Existential Crisis
 - Isolation
- Coping
 - **Denial**
 - **Resistance**
 - Affirmation
 - **Integration**

S. Thomas & B. Clem
EHDl 2009 Dallas

From David Luterman's book "Children with Hearing Loss a Family Guide". Often the grief process for families whose children who are diagnosed with hearing loss has been illustrated by the stages of death and dying by Elizabeth Kubler Ross. Dr. Luterman's book and some other articles relate the process as just that a process and similar to the literature and stages in chronic grief associated with chronic illness. In death, there is finality and acceptance. With a child with hearing loss – it's a lifetime – there is no end to the process.

MY CHILD HAS A HEARING LOSS

Information from "Children with Hearing Loss: a Family Guide, ed. David Luterman, D.Ed.

no specific order – and can re occur

Meet the Parents!

- Identity Crisis

- With life changing events/milestones such as *going to camp for extended time, full time school, high school, college, marriage*



If I'm not Nathan's teacher/therapists/mommy of a child with a hearing loss, who am I? Super involved parent with nothing left over for her marriage or other siblings, or life in general. Everything has revolved around the child with a hearing loss – therapies, audiological appointments, etc.



My Child Has a Hearing Loss

- Overprotection
 - Hard to let a child fail
 - Child doesn't learn to take responsibility for actions
 - Child thinks they aren't capable
 - Grow up blaming others
 - Feelings of inadequacy = Super parent to make up for it
 - Professionals become the parents' 'savior'

S. Thomas & B. Clem
EHDI 2009 Dallas

By rescuing the child within the safe environment of the family unit, preschool and grade school years, the future results in a child who doesn't develop responsibility for their own actions. Parents are already feeling overwhelmed that this bad thing happened to their child (deafness/hearing loss). Children start thinking that they can do anything b/c they have a hearing loss. Having a hearing loss is NOT an excuse for bad behavior. Not an excuse for thinking that one is entitled to special privileges. Child must learn to own their hearing loss. As early as possible to change the batteries, tell parent it's not working, move to where they can see the interpreter, tell the teacher that they don't understand.



My Child Has a Hearing Loss

- Confusion
 - 90-95% of parents with children with hearing loss – DO NOT have any experience with hearing loss
 - Professionals they meet are often passionate and biased , and present varying options with equally compassionate feeling
 - Unsolicited advice from strangers
 - Information provided parents aren't ready to hear

S. Thomas & B. Clem
EHDI 2009 Dallas

Parents are looking for answers. They need time to process the information. Yes, they have to get going on developing communication skills however, perhaps we do them a disservice by pushing them to choose an option quickly. We definitely do them a disservice by not presenting ALL options – and if we are not content experts about one option – our services only offer one or two, and we convey to parents that here are these options but we have this to offer, or only this option is available where you live/child will go to school, AND NOT refer them to professionals in other options, revisit how we are practicing.

Loss of privacy



My Child Has a Hearing Loss

- Confusion
 - Loss of privacy
 - Bombarded with a lot of information from many different sources, much information is conflicting
 - PCP, ENT, Audiologist, SLP, Teacher of the Deaf, Regular Teacher, Cert. AVT, CI Audiologist, Grandparents, Friends, Colleagues

RESULTS? Overwhelmed, confused, inadequate

S. Thomas & B. Clem
EHDI 2009 Dallas

Get information from many different professionals and despite the changes in technology from UNHS to Cochlear Implants, the internet, ASSR and ABR, testing of the device intra-operatively, bilateral, there are still very strong emotions from professionals about habilitation and education, communication of children with hearing loss and deafness.

My Child Has a Hearing Loss

- Where parents do too much for their children, the children will not do much for themselves.” *Elbert Hubbard*
- “Good parents give their children Roots and Wings. Roots to know where home is and wings to fly away and exercise what’s been taught them.” *Jonas Salk*

S. Thomas & B. Clem
EHDI 2009 Dallas


My Child Has a Hearing Loss

Coping

- Denial
- Resistance
- Affirmation
- Integration/Acceptance



S. Thomas & B. Clem
EHDl 2009 Dallas



My Child Has a Hearing Loss – Coping

- Denial
 - Acts as if child doesn't have a hearing loss; Doesn't keep hearing aids on
 - Thinks tests results are wrong; looks for indications child can hear after all
 - Case of acquired loss – thinks it will return; diagnosis can't possibly be correct
 - Audiologist/Doctor is wrong

S. Thomas & B. Clem
EHDI 2009 Dallas

Real denial can't see the problem. Maybe this is a temporary loss; my child will be the one that is different and it will get better, not need hearing aids. Doesn't see need for hearing aids now; thinks that a test while baby is asleep doesn't really tell if she can hear. If the diagnosis is wrong, then parent can continue with the initial dreams had for the child...On the other hand, one parent may think the worst not knowing much if anything about hearing loss and current technology and intervention. Parents who have high levels of academic accomplish may think that they are going to be raising a child with brain damage and then feel guilty that they are being intellectual snobs about their child – who in actuality may only be a few days old.



My Child Has a Hearing Loss – Coping

- Resistance
 - Resistance to own the hearing loss
 - Rules/experiences of others don't apply to them
 - Don't want anyone else to know
 - Hides the hearing aids/cochlear implant
 - Example – pictures of child w/o hearing aids

S. Thomas & B. Clem
EHDI 2009 Dallas

In the closet hearing loss; group outings child doesn't have device; grandparents – they think it hurts him/doesn't like it so they don't make him wear it. Embarrassed about the hearing aid or cochlear implant. Doesn't take child's pictures with HA/CI on. Embarrassment more reflection of parents who feel that they have a child that is less than perfect – and as the child gets older and parent continues at this stage, then child's self esteem suffers...though as we all know, low self esteem is on exclusive for hearing loss. VERY generational (C. Flexer) BB no one to know, failure on their part, scared of technology; Gen X and Millennial very accepting of technology...

40s – take it off, don't want them to be broken or see them

20-30s – tech savvy, ipods, text messaging; blue tooth,

Paradigm shift – used to be that parents were embarassed, ashamed to have others ask about it – newer parents

Professionals may be in a different generation in the and comfort zone than the parents w/ the child w/ HL – so we need to step up to where the parents are.

First thing Gen X and Mill are going look up everything on the internet – seek knowledge and info; Baby Boomer- are stuck in their generational comfort zone – professional will come in and tell you what to do.

My Child Has a Hearing Loss Coping

- Integration
 - **Hearing loss isn't the most important part of life**



S. Thomas & B. Clem
EHDI 2009 Dallas

Triggers for denial and resistance may be poor success in the regular classroom, progressive loss – such that child is no longer benefiting from hearing aids and needs a cochlear implant; device failure; realizing that parents emotions are not dependent on what type of day the child is having; Luterman states that when families have achieved acceptance; parents who can connect with other parents have support and opportunity to share the day to day issues with other families of dealing with hearing loss. Some grieve longer than others and then ultimately most make the most of the situation and grow with their family.

Meet The Parents

**Following the
Parent Participation Model**



*"A child's life is like a piece of
paper on which every
passerby leaves a mark."
Chinese Proverb*



S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents

- Teach the Parents
- Support the Parents
- Guide the Parents
- Encourage the Parents
- Laugh/Cry with the Parents
- Learn with the Parents

S. Thomas & B. Clem
EHDI 2009 Dallas





**THE
PARENT
EDUCATOR**

Meet the Parents!

Building a Partnership

S. Thomas & B. Clem
EHDl 2009 Dallas



What do I need to know?

- Auditory development
- Speech and Language norms
- Child development
- Audiology

- _____
- _____
- _____

S. Thomas & B. Clem
EADI 2009 Dallas



Goals

- Based on developmental norms
- Compared to typical hearing peers
- Long-term / Short-term
- 6-month intervals
- Parent-centered (especially in the beginning)

S. Thomas & B. Clem
EHDI 2009 Dallas

Outcome-Based Goals

Parent says, "I want him to _____."

PE says, "Here's what it takes."

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!

- Listening
- Language
- Speech
- Parent Education
- Developmental
- Family

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!

- Alex will wear his hearing aids during all waking hours.
- Ben will participate in singing to develop breath control and suprasegmentals of speech.
- Carly will detect and identify the Ling 6 sounds.
- David's parents will understand and explain his aided and unaided audiogram.

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!



- Ellie's grandmother will learn to check her batteries and insert her hearing aids.
- Fanny will increase vocal turn-taking during face-to-face play.
- Graham will use "power-words" to request.

S. Thomas & B. Clem
EHDI 2009 Dallas

The Parent Participation Model





*"Tell me and I will forget
Show me and I may remember
Involve me and I will understand."
- Unknown*

S. Thomas & B. Clem
EHDl 2009 Dallas

Outline of a session

- Typically 1 hour/once a week
- PE (slp, avt, tod, eci, aud) + child + caregiver
- **AMPLIFICATION!**
- Quiet environment

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!

- Parent report of previous week
- Amplification check/Ling 6
- Review session objectives, get updates from parent

S. Thomas & B. Clem
EADI 2009 Dallas

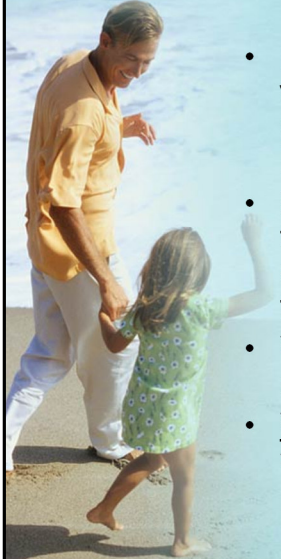
Following the Model

For each objective/goal/activity...

- State the Goal
- Introduce activity
- Demonstrate your strategies
- Hand it over to the parent
- Give feedback
- Home carry-over

S. Thomas & B. Clem
EHDI 2009 Dallas

Meet the Parents!



- Next we are going to work on using the power word “open.” Power words are....
- So, let start with these containers that each have a toy in them. We’ll.....
- We’ll model it with each other first...
- Wait and see if he vocalizes...
- I like how excited you acted when you saw the toy. See how that motivates him to participate?
- Try waiting a little longer for a response. Raise your eyebrows, give him an expectant look.
- How else do you think you could work on open?

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!



- Okay, let's try some singing. It is so important to sing with her everyday, because she is able to hear the nice changes in the pitch of your voice. Singing is important for building breath support for connected speech and a great way to work on development of speech sounds. Also, most kids love music! It's a great way to teach vocabulary. Think about how many times we say our body parts when we sing "If your happy and you know it." Plus its in a fun, interactive and meaningful context."

S. Thomas & B. Clem
EHDl 2009 Dallas

Meet the Parents!




- Let's try the handcue to let him know what we want him to say. You and I can model it first.
- He's saying "go" really nicely, let's highlight a little differently to try to get both words.
- So, you've been keeping a running list of vocabulary, he's at about 50 words expressively. Now its time to really push him to say 2 word combinations. He uses "go " so let's get his cars out and model "go car" in a turn-taking game.

S. Thomas & B. Clem
EHDl 2009 Dallas

Strategies to teach parents

- OWLS – observe
wait listen
- Acoustic
highlighting
- Modeling
- Turn-taking
- Expectant look
- Handcue
- “Listen”
- “I hear it”
- Low-lighting
- Parentese
– (aka “drama
mama/drama dad”)
- Close and quiet
- Whisper
- Sabotage
- Role reversal

S. Thomas & B. Clem
EHDI 2009 Dallas



- See how he's moving his arms and legs and seeking eye contact with us, what do you think he is trying to communicate?
- Try changing the pitch of your voice when you say it, so maybe it will make it easier for him to hear the pattern and repeat it.
- So, he definitely understands when you say do you want some juice. Do you think he understands "thirsty?"
- Looking at his testing and current goals, let's decide where we want to go next.

S. Thomas & B. Clem
EHDI 2009 Dallas

Parent Ed Topics



- Your child's audiogram
- Communication options
- Setting goals
- How to talk to my baby
- Normal language development
- Developing vocabulary
- Speech development
- Is he a CI candidate?
- Choosing the right education setting
- How to read to my toddler
- Behavior management
- Developing question/answer skills
- Incorporating siblings in to therapy time
- Organizations to join, helpful websites
- _____
- _____
- _____

S. Thomas & B. Clem
EHDI 2009 Dallas