Partners in Learning: Supporting Parents of Infants & Toddlers who are Deaf or Hard of Hearing

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Clarke Webinar Series
Wednesday, November 5
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Martha deHahn

• Parent of two young adults who are deaf
• Prior experience as Parent Outreach Specialist with UNHS
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Clarke Schools for Hearing and Speech

Our Mission...
Providing children who are deaf and hard of hearing with the listening, learning and spoken language skills they need to succeed

Founded in 1867
Locations
Massachusetts
New York
Pennsylvania
Florida
Introduction

– *Wednesday Webinar Series* is designed for professionals interested in the development of listening and spoken language with children who are deaf and hard of hearing.

– Recorded webinars on the topics of Mainstreaming, Preschool Parent Involvement & Building Professional Networks are available at [www.clarkeschools.org/webinars](http://www.clarkeschools.org/webinars)

– The last of 2014 series is our topic today: *Partnerships with parents of infants and toddlers.*
Learning Objectives for this Webinar

• Cite reasons, supported by evidence, of the importance of parent-professional partnerships.
• Identify roles of the practitioner in developing and sustaining relationships with parents.
• List specific strategies or practices that serve to connect parents and practitioners.
• Recognize the impact of loss on parent behavior.
Why Partner with Parents?

Growing body of research demonstrates significant impact of parent/caregiver interaction on outcomes for children-- with or without hearing loss.
Hart and Risley

*Meaningful Differences, 1995*

- Longitudinal study of parent-child talk in 42 families in Kansas
  - 3 years of language input data (7-36 mos)
  - Follow up at age 9
- Examined the relationship between PARENT language input and CHILD language abilities at age 3 and later
Hart and Risley Key Findings

• IQ and LANGUAGE abilities related to amount of parent child-directed language
  > The more parents talked to children
  > faster the vocabulary growth
  > greater LATER language and IQ scores

• Academic success at age 9-10 linked to amount of talk heard from birth-3
The Widening Gap

- Children from disadvantaged homes hear an average of 616 words/hour
  - 1 encouragement: 2 discouragements (ratio)

- Children from professional homes average of 2153 words/hour
  - 6 encouragements: 1 discouragement (ratio)

- Extrapolating to 14 hour days
  - Estimated 30 million word gap by age 3
  - 144,000 encouragement gap by age 4
Cumulative Impact

Baltimore, MD: Brookes.
LENA Studies

LENA records & analyzes auditory input to children (words, utterances, turns, background noise, etc.)

• 2008 study with 329 participants
• Confirmed most Hart and Risely findings
• Child language gains related to amount of direct parent talk to children
• Great variability within SES groups
• Greatest differences related to “talkative” vs. “taciturn” parents
Kathryn Hirsh-Pasek:
Quality of Language Interaction

Better predictors of language skills at 3:

• Quality of interactions involving words
• Use of shared symbols
• Conversational fluency

White House conference on “bridging the word gap” October 2014

Even Hart & Risley looked at qualitative features of language such as parental tone, responsiveness and use of symbols.
Amount and quality of language addressed to children more predictive of child language skills & IQ than SES or Parent Education
Children with Hearing Loss

Parent engagement and involvement is a major predictor of child outcomes

2 examples....
M.P. Moeller, 2000

• Examined impact of EI factors on language outcomes at age 5
• Degree of HL *not* predictive
• Age of enrollment was a significant predictor
• **Family involvement** explained most of the variance
• Strong interactions between age at entry and family involvement
Quittner et al, 2013

- National study
- 188 children (5 mos - 5 yrs.) with CIs
- Parent behaviors predicted language gains 4 yrs. later
- High parent sensitivity, cognitive & linguistic stimulation ➔ 1.5 year greater language gains
Language is Learned...

• With someone who adores you
• In the course of play, caregiving routines, and daily life
• During all waking hours, if conditions are optimal
• When the language is adapted to your needs and interests
Preschool Child’s Week

- Asleep: 70 hrs
- Awake (not at school): 71 hrs
- School: 20 hrs
- Bus: 7.5 hrs
Infant/Toddler’s Week

- **ASLEEP**: 91 hours
- **AWAKE**: 77 hours

**EARLY INTERVENTION**—2 hrs.
Implications for Children with Hearing Loss

• “Language Intervention” should be happening during all waking hours
• Caregivers are key!
• EI must focus on maximizing parent knowledge, skills, engagement
What are the Challenges You Face?
(Based a Survey of E.I. Providers)

• Effective communication with parents
• Counseling parents through assessment/diagnostic process
• Getting parents to follow through on recommendations for intervention
• Encouraging parent involvement/carryover into the home
More Challenges...

• Involving parents in intervention, school program, treatment
• Encouraging buy-in, follow-through
• Supporting parents who are dealing with numerous challenges
• Working effectively with families from diverse cultures/language backgrounds
• Developing a personal, but professional relationship
Wisdom of Three Pioneers

• Louise Tracy, 1943—Parent, founded a program based on parent education and emotional support
• Ken Moses—Psychologist and parent, developed framework for supporting parents through grief
• David Luterman—Audiologist, emphasizes psychological support for and trust in parents
How Do We Address these Issues?

There is no magic bullet, but there are 3 evidence-based approaches

• Providing emotional support and education
• Re-framing parent-professional roles
• Addressing family values, culture, diversity
David Luterman’s Tenet #1

“If you take good care of the parents, the children will turn out fine.”

- Emotional support—beginning with initial diagnosis/contact
- Understanding and supporting the grief process
- Facilitating parent to parent support
Shattered Dreams
(Ken Moses)

• Most hearing parents grieve the loss of the child they anticipated.
• Hearing loss shatters their dreams
• Loss is akin to the death of a loved one
• Mourning process allows separation from lost dreams and generation of new ones—i.e. HOPE
Grieving Emotions

• Grieving feelings do not occur in stages
• Grieving process is “messy,” uncomfortable, often unpredictable
• Healthy grieving leads to growth
• Central to the well-being of the child
• Professionals cannot “fix it” or rush process
Grieving States & their Functions

- **Denial**—time to gather internal & external support
- **Anxiety**—gathering and focusing energy
- **Fear**—attach to and love child intensely
- **Depression**—time to rest, reevaluate capabilities
- **Guilt**—what is the meaning of my child’s hearing loss?
- **Anger**—examine rules/principles of fairness and justice; motivation to act
When a caregiver is experiencing grief, which of the following grieving states is the hardest for you, as a practitioner?

• Denial?
• Anxiety?
• Depression?
• Guilt?
• Anger?
Grieving States & their Functions

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Early Versus Late Experiences

• Feelings of parents of newly diagnosed children:
  – intense
  – obvious

• Feelings of parents of school-aged children:
  – present
  – not always apparent
  – intense feelings re-emerge, often in disguise
Re-emergence of Grieving

• Life with deaf child becomes normal
• Adjustment is challenged by, e.g.
  – School milestones, transitions
  – Family gatherings/holidays
  – Need for support services (FM, interpreter)
  – New assessments and evaluations
  – Social or academic difficulties of child
  – Frustration about lack of appropriate services
Loss: 2\textsuperscript{nd} Time Around

- More confident about their parenting abilities
- Can be more emotionally devastating than 1\textsuperscript{st} time
- Know the extent to which their life will be challenging and complicated
- Coping strategies may be well established but unresolved grief from their first parenting experience may resurface.
- Professionals and extended family members may be less available for understanding and support
- Parent Group: \textit{One More Time with Feeling}
Supporting Grieving Parents

- Take the time to listen

  - Practice ENUF by offering support that is
    - Empathetic
    - Non-judgmental
    - Unconditional
    - Feeling focused
Professional Role

• Need not be a professional therapist or psychologist to be supportive

• You can help by
  – listening to and respecting parents
  – acknowledging painful feelings and struggles
  – remaining nonjudgmental
  – supporting, but NOT rescuing!
What Helps? Parents Say...

- Professionals who listen
- Support groups
- Online parent forums
- Meeting more experienced parents
- Meeting adults with hearing loss
- Seeing older well-adjusted children
- Becoming knowledgeable
What Works?

- Listen
- Reassure
- Identify what’s Positive
- Connect & Reconnect
Parent Challenges

• Having people see your child with hearing aids
• Explaining diagnosis and child’s needs to family and friends
• Decision making when professionals disagree
• Scheduling nightmares
• Worry about the future
• Unknowns
# Reframing Parent-Professional Roles

**Professionals**

- Content experts on hearing loss, children with hearing loss, technology, facilitating language development
- Parent coach, mentor, educator

**Parents**

- Experts on their child
- Take an active role as facilitators of child’s development
TENET #2

• You cannot go any faster than the parent is ready to go

and...

• You can’t save children from their parents.
What is the Role of the Professional?

- Supporter
- Coach
- Educator
- Model
- Convener
- Mentor
- Facilitator
Setting E.I. Visit Expectations

• Parent active learner
• Primary focus on parent-child interaction
• Parent observations highly valued
• Emphasis on natural, everyday activities
Coaching

• Parents take the lead ➔ carryover
• Professional may demonstrate, but quickly returns responsibility to parent
• Observe
• Encourage
• Suggest (judiciously)
• Observe again
Addressing Diversity

• 15% U.S. Population speaks language other than English at home
• In many major cities > 40%
• Spanish is language of > ½ of non-English speakers
• > 80 languages spoken in many urban school districts
• > 50% “minority groups” in many cities and some states
Bridging the Language Barrier: Expert Recommendations

• Bilingual/bicultural professional staff
• Professional interpreters
• Language skills training for staff
• Establish “language bank” on staff
• Volunteer interpreters (family/friend)
• Phone-based interpreting
• Written translation
Bridging the Culture Barrier

• Language is not enough
  – e.g. “The Spirit Catches You and You Fall Down”
• Diverse beliefs, attributions, customs, values, expectations, roles, education, social interactions
• Challenges for E.I. service providers
  – Family and child-rearing practices
  – Expectations of parent-professional roles
  – Interpretation of disability
  – Attitudes toward/impact of hearing loss
Lessons Learned: #1

• Parent support can transcend culture
  – If you create the right conditions, parents will find a way to support and nurture each other despite significant linguistic and cultural differences
Lesson # 2

• Make your best effort to bridge the linguistic/cultural gap
  – Effort is appreciated
  – One size doesn’t fit all!!
  – Affect is more important than content
  – Provide back-up written materials, resources,
  – Make TLC contact after appointments, assessments
  – You don’t need to “cover everything”
Grieving States & their Functions

• Develop a Language Plan
  – Language Goals
  – Strategies
    • Language models
    • Settings
      – Who?
      – What languages?
      – When?
      – Where?
      – How?
Lesson #4

• Grieving and culture interact in complex ways
  – Cultural interpreters are enormously helpful to professionals and parents
  – Cultural beliefs can provide both solace and distress
  – Culture practices can become distorted in times of grief
Lesson #5

• Avoid stereotypes at all costs—each family is unique
  – Families experience multiple cultures
  – Each family brings unique history, personalities, life circumstances

• Seek the family’s advice about how best to connect and support them
Connecting with 21st Century Families

• Face to face
• Text, email
• Chat groups
• Phone calls
• Videoconferencing

• But maintain boundaries: avoid “ friending”
tVISIT Project: Expanding Access

What is a tVISIT?
• Virtual home visit
• Uses videoconferencing technology
  – High speed internet connection
  – Personal computers, web-cameras, microphones
  – Skype or similar web-based telecommunication software (VoIP)
Improving Practice

- Reaching, educating, nurturing families
- Promotes reflective teaching
- Increases use of family-centered coaching practices
- Allows for direct supervision and training of specialty providers
What can be Accomplished in a tVISIT?

Some Surprises

• Establish and nurture a relationship with the parents
• Discuss sensitive issues and decision making
• Parent education (basic knowledge, advocacy, CI surgery prep, troubleshooting...)
• Provide interpreting services
• Assessment of child and parent progress
Final Words of Wisdom

“There are no intervention techniques more powerful than those that serve to build parental self-esteem.”
David Luterman
Questions?

Send your questions to: webinars@clarkeschools.org
Resources in Print


Resources in Print


