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- Call 800-753-2160 (M-F, 8 AM-8 PM ET)
- Email customerservice@AudiologyOnline.com
Empowering Parents:
Navigating the Birth to Three Period to Reach Desired Outcomes

Gayla Guignard, M.A., CCC-A/SLP, LSLS Cert. AVT
Julie Swaim, B.A.

Learning Outcomes

After this course, participants will be able to:

- Learning Outcome 1: describe the components of Early Hearing Detection and Intervention (EHDI) and the interface with and impact on parents during the EHDI process.
- Learning Outcome 2: list strategies to use to successfully partner with parents/caregivers by learning how to listen to, interact with, and support families in the identification of their desired long-term outcomes and related benchmarks.
- Learning Outcome 3: identify relevant written resources tools that can be shared with families whom they serve.
As a professional, I have experienced and/or observed:

• Parents are immediately presented with the need to make decisions upon being identified
• Most parents want to prioritize effectively leading their own families and want to know how to do that now that they have a child who is deaf or hard of hearing
• Parent-professional relationships are important in parents and professionals can and often do successfully partner to improve a child’s outcomes
• Children who are deaf or hard of hearing can, Lead a Life Without Limits!

Why this Topic?

As a parent and as an EHDI Parent Consultant, I have experience and/or observed:

• Families overnight introduction into hearing loss
• Empowerment as knowledge is gained
• Engagement with services and systems
• Parents effecting change in systems for other children and families
• Parents make the difference in their own child’s life!
Video Clip: Two Siblings

Getting on the Same Page

- The Lay of the Land
- Terminology
- Myths and Misconceptions
  - We all have them. What are yours?
- Facts: Let's Try to Make Assumptions Based on Evidence:
  - Data is powerful
  - What we know from longitudinal studies
Identification of Hearing Loss in the U.S.

- Hearing Loss in One vs. Both Ears
  - EHDI, 2016 Babies

Identification of Hearing Loss in the U.S.

- Degree of Hearing Loss by Ears
  - EHDI, 2016 Babies


Identification of Hearing Loss in the U.S.

- Degree of Hearing Loss by Person

NHANES II & III Prevalence
Ages 6-19 years

Donahue (2007), Eisenberg et al. (2007); Tomblin & Hebbeler (2007)

Retrieved from 11/15/17 handout, Longitudinal Outcomes of Children with Mild to Severe Hearing Loss: Auditory Experience Matters, Audiology Online, Mary Pat Moeller, Ph.D
“What does research say?” and Other Questions Parents Ask

- https://www.agbell.org/Annotated-Bibliography
- https://learn.hearingfirst.org/mission_probable
- https://www.nidcd.nih.gov/
  - https://www.nidcd.nih.gov/research/extramural
    - https://www.nidcd.nih.gov/research/extramural/hearing-program
  - https://www.nidcd.nih.gov/research/labs

Research Portfolio Online Report Tool (RePORT)

Examples of Large-Scale Studies

- The Child Development after Cochlear Implantation Study (CDaCI)
  - https://www.cdacistudy.org/
- Outcomes of Children with Hearing Loss (OCHL)
- Longitudinal Outcomes of Children with Hearing Impairment (LOCHI)
Early Hearing Detection and Intervention (EHDI)

- EHDI:
  - Process
  - Program
  - System
Parent Matters and Parents Matter

An Australian Parent Study

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<thead>
<tr>
<th>Personal Resources</th>
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<td>Service Resources</td>
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<tr>
<td>Child and Family Characteristics</td>
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Parents take a central role according to five themes that emerged from the study:

- Parents work behind the scenes
- Parents act as case managers
- Parents always have their child's language development in mind
- Parents' role extends to advocacy for all children with hearing loss
- Parents serve a number of roles but, at the end of the day, they are parents

An Australian Parent Study

- Personal Resources
  - Personality traits
  - Beliefs, values, & experiences
  - Expectations
  - Health & mental well-being
  - Education and professional background
  - Socio-economic status
  - Skills

- Social Resources
  - Support from professionals
  - Support from partner
  - Support from family & friends
  - Support from other parents of children with hearing loss or a disability

- Service Resources
  - Access to early intervention framework
  - Access to family-centered practices
  - Access due to geographical issues
  - Access to varied modes of service delivery
  - Access to an interpreter

- Child & Family Characteristics
  - Child characteristics
    - Personality traits
    - Age & level of independence
    - Additional disabilities
    - Cooperation in intervention
    - Outcomes
  - Family characteristics
    - Size of family unit
    - Siblings behavior & participation in intervention
Desired Outcomes: The Impact of Decisions

A Critical Question: What are the family’s desired outcomes?

- What is/are your long-term goals for your child?
- How do you want to communicate with your child?
- What language(s) do you know?
- Where do you want your child to be at age 3, 5, 14, 20? What does it take to get there?
- 95% of children with hearing loss are born to hearing and speaking families and so, if you are a “hearing” parent, lots of other families are “in the same boat” with you.
- Many families use one language at home while another language is used at school, so they are interested in having their child be bilingual or multilingual.

Desired Outcomes: A Discussion Framework

Play-Pause-Stop-Play

Things We Should Tell Parents from the Beginning
1. Support for the Journey---(e.g. family counseling)
2. There are critical periods of development
3. Being intentional matters
4. Begin with the end in mind: Pacing, Progress and Parents
5. Using evidence (data) along the way
6. Initial and periodic assessments
7. Goal determination and Goal monitoring
Desired Outcomes: Discuss Roles of the Parent, Professional and Others

1. Defining What Needs to be Done and Who Does What?
2. Establishing authority (e.g. during behavioral audiology testing)
3. Decision making (Set in stone? Changeable? How/when to change)
4. Counseling and support

The Family Journey

Making Travel Plans:
1. Know your options
2. Choose your destination
3. Determine your route
4. Choose your travel partners
5. Be aware of travel costs and other related details and plan for them
Who is on the Journey?
If a Listening and Spoken Language Outcome is Desired:

- Pediatric Audiologist
- Primary Care Provider and other Medical Specialists
- Listening and Spoken Language Specialist Cert. AVT or Cert. AVEd and other Intervention Specialists
- Parent (Primary Caregiver(s))
- The Child
- Other Children
- A Supportive Community

Resources

- Decision Guide to Communication Choices
- Making a Plan for Your Child
- Questions You May Want to Ask Your Child’s Audiologist
- Questions You May Want to Ask Your Child’s Early Interventionists
- Questions You May Want to Ask Your Child’s Physician

https://www.cdc.gov/ncbddd/hearingloss/freematerials.html
Some Resources

Government Entities:
- Centers for Disease Control & Prevention (CDC) EHDI
- Health Resources & Services Administration (HRSA)
- National Institutes of Health (NIH)
- U.S. Department of Education Office of Special Education Programs (OSEP)

Government Grant-funded National Technical Assistance Centers
- National Center for Hearing Assessment & Management (NCHAM)
- Family Leadership in Language and Learning (FL3)-Hands & Voices
- Early Childhood Technical Assistance Center (ECTAC)-Frank Porter Graham Center

Non-Government Organizations with a Listening and Spoken Language Focus:
- AG Bell/AG Bell Academy
- Hearing First
- Option Schools
- University Training programs
- Specialized Centers of Excellence (e.g. hospital)
Listen-Learn-Link
New Parent Hotline

Hotline Available
Monday-Friday
newparenthotline@agbell.org
In the U.S.
1-833-LSL-LINK
(1-833-575-5465)
International - Zoom video conference calls can be scheduled by request.
Sponsored by:
Cochlear Americas
GN Resound

Question and Answer Period

- Gayla Guignard gguignard@agbell.org
- Julie Swaim jswaim@agbell.org

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