Childhood Hearing Loss: Interdisciplinary Collaboration and Family-Centered Care

Beth Walker, PhD, CCC-A/SLP; Meaghan Foody, MS, CCC-SLP
Department of Communication Sciences and Disorders

Acknowledgements

meaghan-foody@uiowa.edu
319-467-4274
University of Iowa
2323 Health Sciences Academic Building (HSAB)
Iowa City, IA 52242
United States

Disclosures

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Outcomes of Children with Hearing Loss Consortium

FASTRAK

What is OCHLCON?

- Started in 2008 by Mary Pat Moeller (Boys Town National Research Hospital) and Bruce Tomblin (University of Iowa)
- Goal: to examine the impact of newborn hearing screening, early intervention, and advances in hearing technology on developmental outcomes of children who are deaf or hard of hearing
- Continuous funding from the National Institutes of Health for the past 18 years

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Agenda for Today's Talk

- Overview on the need for interdisciplinary collaboration
- Principles and Benefits of Family-Centered Care
- Roles and Contributions of Professionals
- Best practices in interdisciplinary case management
- Case study example on interdisciplinary management

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New generation of children who are deaf or hard of hearing

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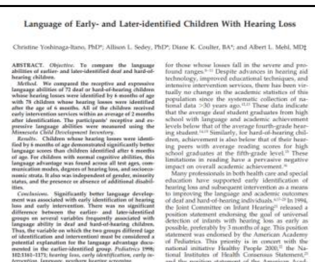
Yoshinaga-Itano (1998): Children IDed < 6 months have better language outcomes than children IDed > 6 months



Language of Early- and Later-identified Children With Hearing Loss

Christine Yoshinaga-Itano, PhD*; Allison L. Sedey, PhD*; Diane K. Coulter, BA*; and Albert L. Mehl, MD‡

ABSTRACT. *Objective.* To compare the language abilities of earlier- and later-identified deaf and hard-of-hearing children.

Method. We compared the receptive and expressive language abilities of 72 deaf or hard-of-hearing children whose hearing losses were identified by 6 months of age with 78 children whose hearing losses were identified after the age of 6 months. All of the children received early intervention services within an average of 2 months after identification. The participants' receptive and expressive language abilities were measured using the *Minnesota Child Development Inventory.*

Results. Children whose hearing losses were identified by 6 months of age demonstrated significantly better language scores than children identified after 6 months of age. For children with normal cognitive abilities, this language advantage was found across all test ages, communication modes, degrees of hearing loss, and socioeconomic strata. It also was independent of gender, minority status, and the presence or absence of additional disabilities.

Conclusions. Significantly better language development was associated with early identification of hearing loss and early intervention. There was no significant difference between the earlier- and later-identified groups on several variables frequently associated with language ability in deaf and hard-of-hearing children. Thus, the variable on which the two groups differed (age of identification and intervention) must be considered a potential explanation for the language advantage documented in the earlier-identified group. *Pediatrics* 1998; 102:1161–1171; *hearing loss, early identification, early intervention, language, newborn hearing screening.*

for those whose losses fall in the severe and profound ranges. Despite advances in hearing aid technology, improved educational techniques, and intensive intervention services, there has been virtually no change in the academic statistics of this population since the systematic collection of national data >30 years ago. These data indicate that the average deaf student graduates from high school with language and academic achievement levels below that of the average fourth-grade hearing student. Similarly, for hard-of-hearing children, achievement is also below that of their hearing peers with average reading scores for high school graduates at the fifth-grade level. These limitations in reading have a pervasive negative impact on overall academic achievement.

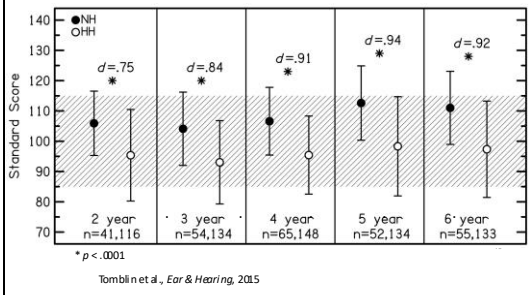
Many professionals in both health care and special education have supported early identification of hearing loss and subsequent intervention as a means to improving the language and academic outcomes of deaf and hard-of-hearing individuals. In 1994, the Joint Committee on Infant Hearing released a position statement endorsing the goal of universal detection of infants with hearing loss as early as possible, preferably by 3 months of age. This position statement was endorsed by the American Academy of Pediatrics. This priority is in concert with the national initiative Healthy People 2000, the National Institutes of Health Consensus Statement, and the position statement of the American Academy of Audiology. All of these position statements

But…identification is only first step

Also need to think about

- Confirmation of hearing loss
- HA fitting (timing and quality of fitting)
- Early intervention
- CI evaluation (if needed)
- Medical considerations
- Family Support

Continue to see group differences in language outcomes post-UNHS



Tomblin et al., *Ear & Hearing*, 2015

What happens after the newborn hearing screen?

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Research Article

Factors Influencing Follow-Up to Newborn Hearing Screening for Infants Who Are Hard of Hearing

Lenore Holte,[a] Elizabeth Walker,[a] Jacob Oleson,[a] Meredith Spratford,[b] Mary Pat Moeller,[b] Patricia Roush,[c] Hua Ou,[a] and J. Bruce Tomblin[a]

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What factors predict timeliness of service provision following NHS?

- pure-tone average
- sex
- recruitment site (Iowa, Boys Town, UNC)
- maternal educational level

→ Age at service provision (Dx, EI, HA fit)

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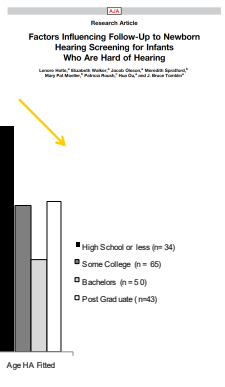
What factors affect follow-up?



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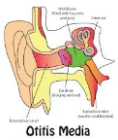
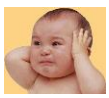
When there were delays in confirmation of HL, what were the reported reasons?





Family or physician did not believe child had a hearing loss due to observable responses to sound

Family told by primary care physician to wait until behavioral testing was possible

Dificulty obtaining appointment for ABR

Multiple rescreenings (up to 10)

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What about service delivery for children who are later-identified?

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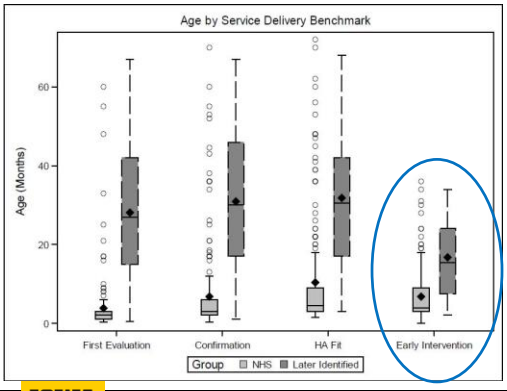
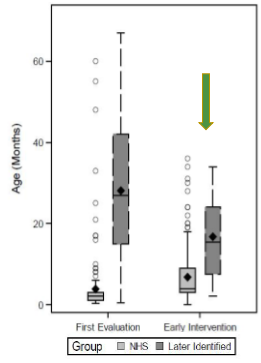
Research Article

Timeliness of Service Delivery for Children With Later-Identified Mild-to-Severe Hearing Loss

Elizabeth A. Walker,[a] Lenore Holte,[a] Meredith Spratford,[b] Jacob Oleson,[a] Anne Welhaven,[a] and Melody Harrison[c]





"On average, these children ***received early intervention for over one year (14.17 months) before receiving a hearing test.***"

Walker et al. 2014

Take-home points

- Since 2000, universal newborn hearing screening has been successfully implemented across most of the U.S., but there are still significant barriers to early diagnosis and intervention
- Socio-economic status is the major predictor of delays in service delivery for children who refer on the newborn hearing screen.
- Children who have passed the newborn hearing screen but show later delays in language acquisition should still have their hearing screened again. It may be the SLP or early interventionist's responsibility to ensure that is done.

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What is the big picture?

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There is no simple or straightforward case of childhood hearing loss

- Medical, socio-economic, cultural-linguistic factors all play a role

Need for collaboration among professionals and families

- Awareness of possibility of post-natal onset of hearing loss
- Effect of mild or conductive hearing loss or unaided hearing on language outcomes

Need for support for families, especially those experiencing barriers or challenges

- Ensure access to hearing healthcare and communication services for all children and their families

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Family-centered practice: key principles

1. Family, not the professional, is the constant in the child's life
2. Family is in the best position to determine needs and well-being of the child
3. By helping and supporting the family, you (as the professional) are helping the child
4. Families and professionals can work collaboratively by forming partnerships

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Family-centered counseling and support

Informational counseling	Provide unbiased, clear information about diagnosis, prognosis, and options
Adjustment counseling	Help families cope emotionally and psychologically with diagnosis
Cultural sensitivity	Respect family values, language preferences, and beliefs about hearing and communication

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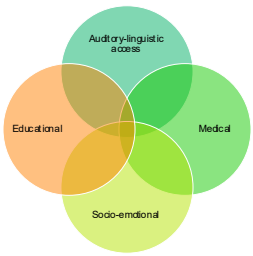
Why is a collaborative, interprofessional approach essential for optimal outcomes in children who are D/HH?



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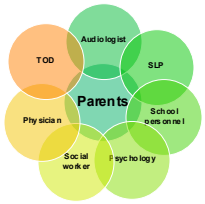
The Interprofessional Team: Diagnostics

- Audiologist: Conduct diagnostic testing, select and fit hearing devices, and monitor auditory development
- Speech-language pathologist: Support language development and communication strategies
- Teacher of the Deaf: Ensure equitable access to curriculum, communication, and instruction
- Mental health, community support, or social workers: Connect families with support and resources
- Pediatricians: Coordinate care, monitor developmental milestones, and refer to specialists
- Otolaryngologists: Evaluate anatomical and medical causes of hearing loss



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Collaborative Strategies for Professionals to Support Families

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Audiologist to SLP

- Datalogging & consistency ratings tracked and shared between providers.
- Speech perception monitoring & progress sharing.
- Regular contact re: current caseload with all providers
- Encourage visits in the audiologist's office.
- Progress reports, IFSP sent to all providers.
  - HA use goals; listening check goals?
- Hands-on training for increasing self-efficacy and confidence with hearing device technology.
  - Watch, do, teach for parents and providers

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Audiologist to Educator(s)

- Visual supports for classroom/daycare device monitoring and basic troubleshooting.
- Support in how to manage device retention.
- Education related to self-advocacy skill development.
- Assistive technology support.
- Sharing information related to datalogging.
- Classroom based questionnaires for educators.

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SLP to Audiologist

- Monthly summaries of progress.
  - Ling 6 sound checks and auditory response monitoring.
- Sharing of updated testing.
- Tracking developmental milestones and sharing progress.
- Important information shared by family members.
- Everyday observations of device use.
  - Does the child come to therapy with devices on and working?
- Progress reports, IFSP sent to all providers.
  - Do our receptive language/auditory goals match up?

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SLP to Educator(s)

- Sharing goals as well as progress with educational team.
- Attending IEP/IFSP meetings when possible.
- Education/support related to self-advocacy goal support and development.
- Communication modality support.
- Communication questionnaires for educators.

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SLPs and Audiologists to Parents

- Open environment that supports honest communication.
- Reviewing concepts that your fellow professional has discussed as appropriate.
- Visual supports to help support long term acquisition of skills.
- Modeling strategies.
- Individualizing recommendations.
- Checking in on parents as well as their child.
- Navigation and interpretation of confusing documentation.

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Parents to Audiologists and SLPs

- Everyday environments and challenges with device use.
- Retention issues.
- Concerns.
- Communication across natural environments.
  - Not just expressive.
- What doesn't make sense right now?
- As the expert on your child, what do we need to know?

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Complex Case Study

- 4-year-old child.
- Bilateral progressive hearing loss.
- CMV.
- Colic.
- Born during the COVID-19 pandemic.
- 1 older sibling.
- Mom is a full-time caregiver to her children. Undergraduate degree.
- Dad is in his residency, planning to specialize in family medicine.

IOWA View>>Header and Footer>>Add Unit Name

Background Audiology Information

- Referred in the left ear 2x NHS.
- Fluid in left middle ear when she initially presented at the Hearing Loss Clinic at 7 days of age.
- CMV testing was positive.
  - No other stigmata of CMV.
- No family history of hearing loss.
- Older sibling initially referred bilaterally on NHS but passed subsequent tests.

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Early Days of Diagnosis

- 2 months of age.
  - DPOAEs- noisy one frequency; refer the other three.
  - Recommended to return to clinic in 2 months to assess ears and to consider tubes + ABR.
- 4 months of age.
  - DPOAEs referred on the left side.
- 5 months of age.
  - ABR completed, mild hearing loss at 500 Hz rising to borderline WNL at 2000-4000 Hz on the right. Left severe mixed hearing loss with BC suggesting a mild sloping to mild/moderate SNHL.
  - PE tubes, bilaterally.
  - Fit with BTE hearing aid of the left side.
- Cancelled subsequent appointment 10 days later.
- 7 months of age.
  - Follow up ABR indicating a profound loss on the left with mild-moderate loss on the right.
  - Hearing aid was moved to the right ear.

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Early Days of Diagnosis Continued

- 8 months of age.
  - Right ear-poor normal at 500 Hz, rising to normal, sloping to mild conductive hearing loss.
  - Left ear severe to profound hearing loss.
  - Recommended sedated ABR.
- 9 months of age.
  - Hearing in the right ear is within normal limits; improved at 4000 Hz but otherwise stable.
  - Left ear results consistent with at least a severe SNHL; worse at 1000 and 2000 Hz.
  - Recommended repeat ABR and continued hearing aid use.
- 11 months of age.
  - Repeat ABR, right hearing worse showing mild low frequency sloping to severe high frequency SNHL.
  - Left ear still showing a severe to profound hearing loss.
- 12 months of age.
  - Scheduled for cochlear implant evaluation.
  - Evaluated and determined to be CI candidate on left side.
- 13 months of age.
  - Cochlear implant surgery and activation.

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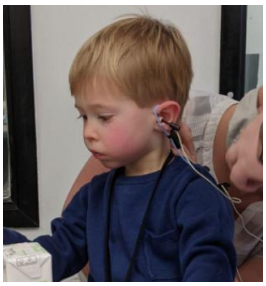
Device Use

- 13 months of age.
  - 2.8 hours CI
  - 2.2 hours HA
- 15 months of age.
  - 5.5 hours CI.
  - 2.2 hours HA.
- 16 months of age.
  - 2.7 hours CI.
  - 1.7 hours HA.
- 18 months of age
  - 2.1 hours CI.
  - 2.2 hours HA.
- 24 months of age
  - 3.5 hours CI.
  - 2 hours HA



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Initiation of outpatient SLP

- Weekly therapy.
- Delayed communication, auditory, cognitive, and adaptive behavior skills

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Collaborative Care

- SLP, CI AuD, HA AuD met to discuss the case.
- Device use was of primary concern.
- Providers discussed experiences and communication with family members.
- Realistic goals for device use were established by the providers and then discussed with the family.
- Email communication was consistent with phone calls as needed.
- Parent consented to team-based communication.

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Difference Makers

- Weekly check-ins related to average wear time incorporated into speech therapy sessions.
- Retention options were trialed and parent feedback was taken seriously and was responded to.
- Counseling related to device use was available to the family on a weekly basis.
- All providers led with the same primary goal.
- The family's grief process was accounted for.

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Third Birthday Check-in

- Improved significantly across developmental milestones.
- Average wear time for the HA and CI reached 8 hours per day.
- Standard scores improved by an average of 17 points after 1 year of collaborative intervention.
- Early childhood team understood how to replace devices appropriately.
- Progress of the child led to increased motivation from the family.

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Today

- Articulation goals, primarily final consonant deletion.
- Following three step directions in the absence of visual support.
- Independently placing her retention headband and devices.
- Answering a variety of –wh story comprehension questions.
- Grammar and sentence structure complexity.
- 11.1 average CI wear time.
- 10.9 average HA wear time.

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Take Aways From This Case

- The diagnostic process can be challenging and emotional for families.
- Open communication and being met without judgement is essential for caregiver buy-in.
- Parent education level only tells one very small piece of the story.
- There is no one size fits all approach for intervention services
- Collaboration not only with professionals, but with families, is essential for success.

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Conclusions

- Since 2000, universal newborn hearing screening has been successfully implemented across most of the U.S., but there are still barriers to achieving optimal outcomes
- Interprofessional care is essential for children who are deaf or hard of hearing because their needs span multiple areas: medical, educational, communicative, social-emotional, and developmental
- Team members work together to ensure that children receive appropriate accommodations, services, and legal protections under IDEA and ADA

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