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AMERICAN COCHLEAR IMPLANT ALLIANCE

Early Hearing Detection and Intervention 101, in partnership with American Cochlear Implant Alliance

Linda A. Hazard EdD CCC-A

Moderator: Donna Sorkin, MA

Negotiating the Early Hearing Detection and Intervention (EHDI) System: What Hearing Healthcare Providers Need to Know to Support Families and their Children who are Deaf or Hard of Hearing: A Two-Part Series

Donna L. Sorkin, MA
American Cochlear Implant Alliance

Why another organization in hearing health?

- Membership organization focused on cochlear implantation and access to care
- This series supports the access to care (for children) aspect of our mission
- Members are audiologists, physicians, speech pathologists, educators and others on CI teams + consumers/parents, advocates, hearing aid specialists
- Website designed for those in and out of CI
- Highly collaborative with other organizations

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American Cochlear Implant Alliance

- Mission: Advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness
- Address factors contributing to underutilization of cochlear implants
- Improve awareness regarding candidacy and outcomes of utilization of appropriate technology

Why this topic is critical

- **Although we now screen ~98% of babies for hearing loss within one month of birth, we fall short on getting children into the hearing care system**
 - Missed opportunities for children served late are huge
 - Many hearing health professionals are unaware of why children fall out of the system and how they can help
- **This series will explore:**
 - How we can do better
 - Barriers to early intervention services for children



Linda Hazard, EdD, MS

Dr. Linda Hazard is the Program Director for the Vermont Early Hearing Detection and Intervention Program (VTEHDI) and an audiologist. She earned her audiology degree from Boston University and a Doctorate in Educational Leadership and Policy from the University of Vermont. Linda is one of the Co-Past President of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA). Additionally, Linda has been appointed by the Vermont Governor to serve on the Vermont Deaf, Hard of Hearing and DeafBlind Advisory Council and the Vermont Interagency Coordinating Council. She has several scientific publications to her credit, including peer reviewed articles and has presented both nationally and internationally. In February of 2017 Linda received the prestigious Antonia Brancia Maxon Award for EHDI Excellence.



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Linda A. Hazard Ed.D CCC-A
Vermont EHDI Program Director

Disclosures

- **Presenter Disclosure: Financial:** Linda Hazard is the Program Director for the Vermont Early Hearing Detection and Intervention Program. She receives grant funds from CDC and HRSA support EHDI Programs. She received an honorarium for this presentation. **Non-financial:** Linda Hazard has no relevant non-financial relationships to disclose.
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Please review these bullets and make any revisions/additions as applicable for your course.

- The applicability and accuracy of the course content may vary by the clinical, geographical, and cultural context; you should evaluate the course accordingly.
- As healthcare is rapidly evolving, new findings may change the validity of the information presented in this course. Providers should always consult the latest research and guidelines from professional associations.
- The interventions discussed in this course may be limited in generalizability, requiring practitioners to consider specific individual and population factors.
- The course may not cover all possible risk factors, diagnostic methods, or treatment options, and complex cases may require additional considerations.
- Healthcare providers should apply cultural competence and sensitivity to ensure effective and respectful care based on their patients' diverse needs.
- Providers should always evaluate the limitations of diagnostic and screening tools, considering their potential for false results as well as any ethical implications.
- It is the responsibility of course participants to critically evaluate the evidence from multiple sources to guide professional practice.

Learning Outcomes

After this course, participants will be able to:

- Describe the complex EHDI system of care.
- Describe emerging initiatives in EHDI programs.
- Explain how to collaborate with your state or territory EHDI Program.

EHDI State and Territory Programs: Who are we?

- State EHDI programs are different state to state:
 - If you know one EHDI program you know one EHDI program
- 50 states and 9 territories
- The EHDI Federal Legislation
 - Birth to 3 years of age
- Grant funding supports EHDI Programs
 - HRSA/MCHB
 - CDC
- Other State Funding may be available to EHDI Programs



Expectations of EHDI Programs; 1-3-6

- Tracking and Surveillance: The National Benchmarks
 - Screen hearing by 1 month of age
 - Collaborate with Hospitals, Midwives and Primary Care Providers
 - Diagnostic evaluation by 3 months of age
 - Collaborate with Audiologists
 - Entrance into Early Intervention by 6 months of age
 - Collaborate with Early Intervention Providers



Expectations: Language and Developmental Assessments

- State/Territory EHDI programs work to improve programs for screening, diagnostics, referral to early intervention, family support early periodic screening although we generally do not have authority over the entities who provide some of these services.
- Early Intervention
 - Language and Developmental Assessments
 - SKI-HI Language Development Scale (LDS)
 - MacArthur-Bates Communicative Development Inventories (MB-CDI)
 - Developmental Assessment of Young Children (DAYC-2)



State Example: VTEHDI and the Parent Infant Program

- Part C Program in Vermont: All children who are Deaf, Hard of Hearing or DeafBlind qualify for services.
- Data Sharing Agreement: Business Associates Agreement
- Providers: Qualified, specialized and licensed
 - Teachers of the Deaf and Hard of Hearing
 - Speech Language Pathologists
 - Educational Audiologists

Demographics: Vermont and ELO

Demographic Characteristic	UVM	ELO
Hispanic ethnicity	10%	38%
White race	90%	83%
English is the primary language of the home	100%	85%
Passed newborn hearing screening	23%	6%
Acquired loss	21%	4%
Bilateral: Mild/mod hearing levels	76%	62%
Unilateral: Mild/mod hearing levels	71%	42%
Primarily spoken language used with the child	80%	85%
Deaf/hh adult(s) in the home use sign language	0%	28%
Bilateral children not using hearing technology	33%	20%
Number of indiv intervention sessions per month	5.8	4.4
Number of min of indiv intervention per month	340	250

Sex, Race and Ethnicity

Sex	UVM	ĒLO
Boy	49%	54%
Girl	51%	46%

Ethnicity	UVM	ĒLO
Not Hispanic	90%	62%
Hispanic	10%	38%

Race	UVM	ĒLO
White	90%	83%
Native/American Indian	0%	1%
Hawaiian/Pacific Islander	0%	<1%
Black/African American	0%	6%
Asian	0%	3%
Two or more races	10%	6%

Disabilities and Audiology Variables

Additional disabilities thought to interfere with speech/language development	UVM	ĒLO
No additional disabilities	74%	75%
Has additional disabilities	26%	25%

Laterality	UVM	ĒLO
Bilateral	69%	66%
Unilateral	31%	34%

Newborn hearing screening result	UVM	ĒLO
Referred	74%	89%
Passed	23%	6%
Not screened	3%	3%
Result unknown	0%	1%
Onset of hearing difference	UVM	ĒLO
Congenital	69%	92%
Acquired	21%	4%
Unknown	10%	5%

Hearing Levels: Bilateral and Unilateral Hearing Differences

Hearing Level (bilateral)	UVM	ĖLO
Mild	47%	41%
Moderate	29%	22%
Moderate-severe	6%	12%
Severe	0%	8%
Severe or profound	18%	9%
Profound	0%	9%

Hearing Level (unilateral)	UVM	ĖLO
Mild	43%	19%
Moderate	29%	23%
Moderate-severe	14%	24%
Severe	0%	14%
Severe or profound	14%	8%
Profound	0%	11%

Hearing Technology: Children with Bilateral Hearing Differences

Type of Amplification (bilateral)	UVM	ĖLO
Hearing aids	44%	64%
Cochlear implant	11%	16%
Cochlear implant + hearing aid	4%	2%
Bone conduction aid	7%	8%
None	33%	10%

Communication Mode

Communication Mode	UVM	ĒLO
Primarily spoken language	80%	85%
Spoken language only	23%	41%
Spoken language w/ very occasional sign	56%	44%
Sign + spoken language	20%	14%
Sign language only	0%	1%

DAYC-2: Mean Percentiles

- No additional disabilities
- (mean for typically developing hearing children = 50th)

Subscale	UVM Bilateral	ĒLO Bilateral
Cognitive	52	57
Communication	40	43
Receptive	39	40
Expressive	41	45
Social-Emotional	58	61
Physical	33	45
Gross Motor	33	49
Fine Motor	36	40
Adaptive Behavior	49	53

DAYC-2: Percentage in the Average Range

- (no additional disabilities)

Subscale	UVM Bilateral	ĒLO Bilateral
Cognitive	89%	95%
Communication	76%	78%
Receptive	72%	74%
Expressive	79%	81%
Social-Emotional	95%	96%
Physical	84%	96%
Gross Motor	75%	92%
Fine Motor	100%	97%
Adaptive Behavior	95%	92%

MacArthur-Bates CDI: Expressive Vocabulary

- (no additional disabilities)

Bilateral Hearing Difference: Percentiles

Words produced	UVM Bilateral	ĒLO Bilateral
Mean	22 nd	26 th
% in average range ($\geq 10^{\text{th}}$ %ile)	67%	65%

Unilateral Hearing Difference: Percentiles

Words produced	UVM Unilateral	ĒLO Unilateral
Mean	33 rd	34 th
% in average range ($\geq 10^{\text{th}}$ %ile)	80%	81%

MacArthur Words and Sentences (CA = 19 to 30 months)

- no additional disabilities

Percentiles: Irregular Nouns and Verbs

Irregular Nouns & Verbs	UVM Bilateral	ĒLO Bilateral
Mean	25 th	28 th
% in average range ($\geq 10^{\text{th}}$ %ile)	79%	85%

Percentiles: Mean of the 3 Longest Utterances (M3L)

Mean of 3 longest Utterances	UVM Bilateral	ĒLO Bilateral
Mean	25 th	26 th
% in average range ($\geq 10^{\text{th}}$ %ile)	69%	61%

SKI-HI Language Development Scale

- no additional disabilities

SKI-HI Language Development Scale: Median Language Quotient

	Bilateral			Unilateral	
Subscale	UVM	ĒLO		UVM	ĒLO
Receptive language	94	95		100	103
Expressive language	88	88		100	100

Percentage of children with a language quotient at or above 80

	Bilateral			Unilateral	
Subscale	UVM	ĒLO		UVM	ĒLO
Receptive language	69%	73%		95%	78%
Expressive language	62%	64%		91%	76%

Language Assessments Continued:

1. Analyze the language acquisition and developmental milestone data for example by region, race/ethnicity, gender, family structure, socio-economic status, family structure, parent education.
2. Identify services to enhance and improve language acquisition: Results shared with families.
3. Identify EHDI-IS database enhancements.

Expectations Continued

- Family Engagement : Family Based Organizations
 - Hands & Voices
 - Family Voices
 - Family to Family Support
- Monitoring Newborns with High Risk Factors for developing changes in hearing
- Deaf and Hard of Hearing Mentor Programs

Expectations Continued

- EHDI Website Development and changes
- Family Retreats, Parent and Professional Trainings
- EHDI Advisory Councils
 - State/Territory
 - Family Committees



Emerging Initiatives

- EHDI programs often play a role in supporting emerging initiatives such as
 - Congenital Cytomegalovirus (cCMV) screening
 - Early Periodic Screening for children birth to 3 years of age



cCMV Emerging Initiative



Learn how to protect your unborn baby from CMV (cytomegalovirus), the leading viral cause of birth defects and developmental disabilities, including hearing loss, vision loss, and cerebral palsy.

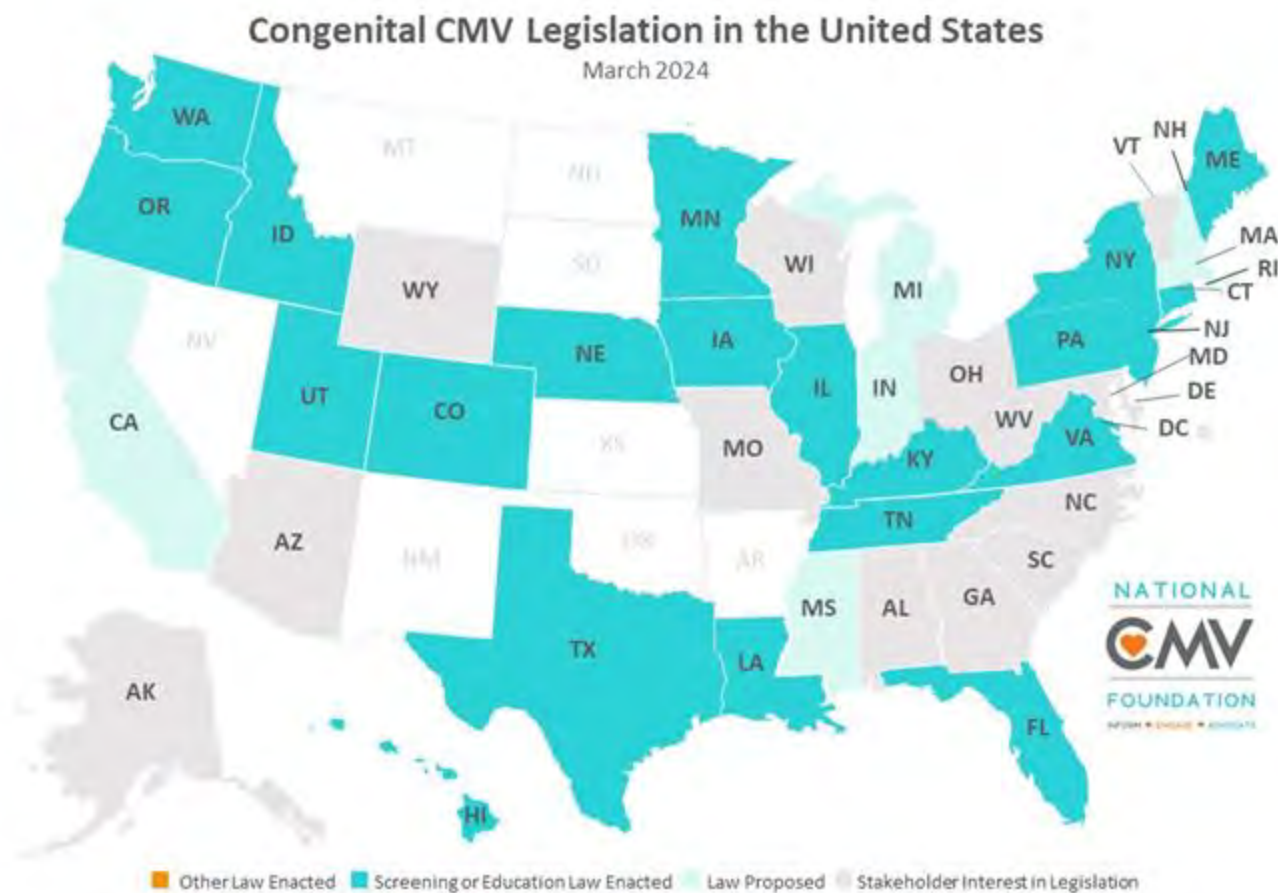
CMV is an often symptomless virus that is spread through saliva, mucus, and urine. Healthy babies, toddlers, and young children can get CMV from their peers and pass it to their pregnant mother.

Tips to protect yourself and your unborn baby from CMV:

- When you kiss a young child, try to avoid contact with saliva.
- For example, you might kiss on the forehead or cheek rather than the lips.
- Do not put things in your mouth that have just been in a child's mouth, including food, cups, forks or spoons, and pacifiers.
- Wash your hands after wiping a child's nose or mouth and changing diapers.

Learn more at: www.NationalCMV.org

CMV Legislation



Early Periodic Screening for children birth to 3 years of age

- HRSA Emerging Goal
- Why is this important?
- Progressive and acquired hearing differences
 - Statistics 6 months to kindergarten

Early Childhood Hearing Outreach (ECHO)

- NCHAM and National Early Head Start Collaboration
- Early Childhood Hearing Outreach (ECHO) Initiative
 - Supported all Early Head Start (EHS) programs to implement OAE screenings (training, equipment, case management, tracking)
 - EHS= birth-3 years of age; additional training and support for Head Start age group screenings (3-5) with established partnership
 - Equipment, supplies and annual calibrations covered by grants or programs
 - On-going collaboration with EHS/HS
 - Entry of screening results into the EHDI-IS state database

Current State of EHDI Nationally: 2025 Plenary EHDI National Meeting

- “The best teacher in the world is the one who loves what he or she does, and just loves it in front of you.”
- Fred Rogers

Current State Continued: Supporting EHDI Programs

- Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA):
 - Representatives serve on several National Committees including Joint Commission on Infant Hearing (JCIH)
- National Center for Hearing Assessment and Measurement (NCHAM)
- Federal Partners: HRSA and CDC
 - National EHDI Network:
 - The Implementation and Change Center: (ICC) Beacon Center
 - The Family Leadership in Language and Learning Center (FL3)
 - The Provider Education Center (PEC)

Current State of EHDI Continued

- Challenges:
 - Future of EHDI: Funding
 - Expansion of Requirements
 - EHDI Reauthorization: Current- 2022 through 2026

How to partner with your state/territory EHDI program....

- Reach out to your State EHDI Coordinator
- Attend your State Stakeholder's meetings
- Understand the issues for your state
- Participate in state level Advisory Councils
- Participate in Learning Communities
- Share your opinions



Questions



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