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Barriers to Enrolling Children with Hearing Loss in Early Intervention, in partnership with American Cochlear Implant Alliance

Donna L. 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

Welcome your involvement!

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AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

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

Disclosures

- **Presenter Disclosure**: Financial: Donna Sorkin is employed by the American Cochlear Implant Alliance. She received an honorarium for this course. Non-financial: Donna Sorkin wears a cochlear implant. She has served on federal, corporate, and university boards, including the U.S. Access Board, the National Institute on Deafness, NIH, and Gallaudet University.
- **Content Disclosure**: This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure**: This course is presented by AudiologyOnline in partnership with the American Cochlear Implant Alliance.

Limitations/Risks

- 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:

1. List three factors related to service delivery or child specifics that impact on access to EHDI services.
2. Discuss how to assess barriers to EHDI related to specific state and local programs such as Medicaid.
3. Suggest approaches to utilize in overcoming state and local challenges to EHDI to achieve more uniform access to hearing care for children.

What is Early Intervention (EHDI)?

- Established in the US in 2000 with aim of identifying hearing loss in infants and children
- Incentives to states to begin ***universal*** screening
- Prior to Federal legislation, most children born with hearing loss were not identified until age 2+
- Initially opposed by a number of groups (including pediatricians)
- Goal: Maximize language and literacy and enable children to reach milestones of typical hearing children

It all begins with the hearing screen

Photo Courtesy: NCHAM

Poll: How has early hearing loss detection changed over time?

- Most babies born with hearing loss are identified within the first week of life
- It has improved but about a quarter of children are still not identified until they are one year of age or older
- Identification of newborns with hearing loss has changed little since Federal hearing detection programs were initiated

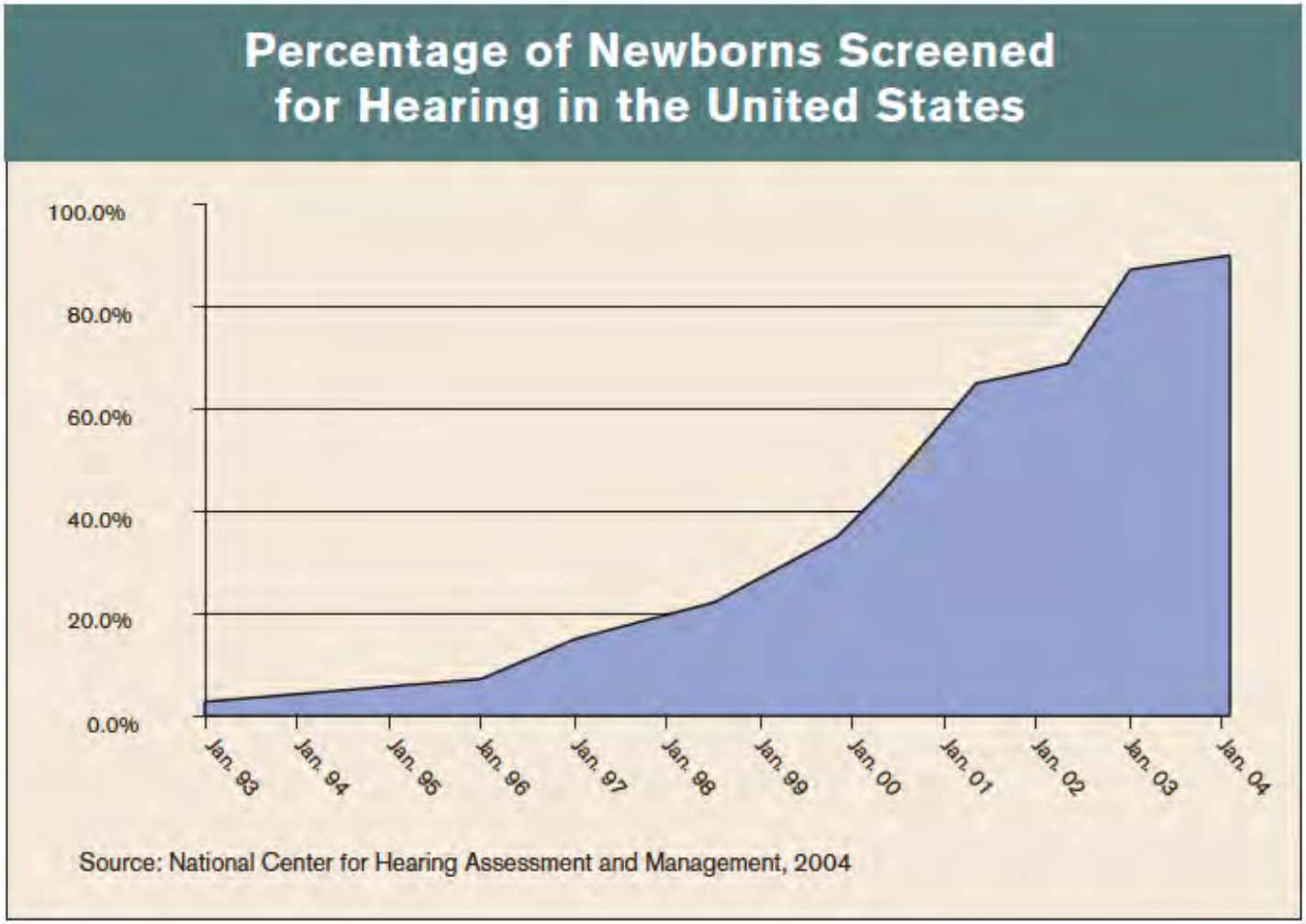
Answer to Q: How has early hearing loss detection changed over time?

- Most babies born with hearing loss are identified within the first week of life
- We have improved but about a quarter of children are still not identified until they are one year or older
- Identification of newborns with hearing loss has changed very little since Federal hearing detection programs were initiated

Early Hearing Detection and Intervention Act (EHDI)

- Federal legislation passed in 1999 to address detection, diagnosis, treatment of newborns
- Prior to implementation of newborn hearing screening, >10% of newborns were screened (most children identified after age 2)
- Screening increased steadily with 98% screened in 2023

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5908a2.htm



EHDI Passed: 1999

2004: ~85%

2024: ~ 98%

What is loss to follow-up (LTF) in Early Hearing Detection and Intervention?

- Multiple orgs endorse universal newborn hearing screening
- EHDI 1-3-6 goals from Joint Committee on Infant Hearing (JCIH)

LTF

(1) Screen by one month

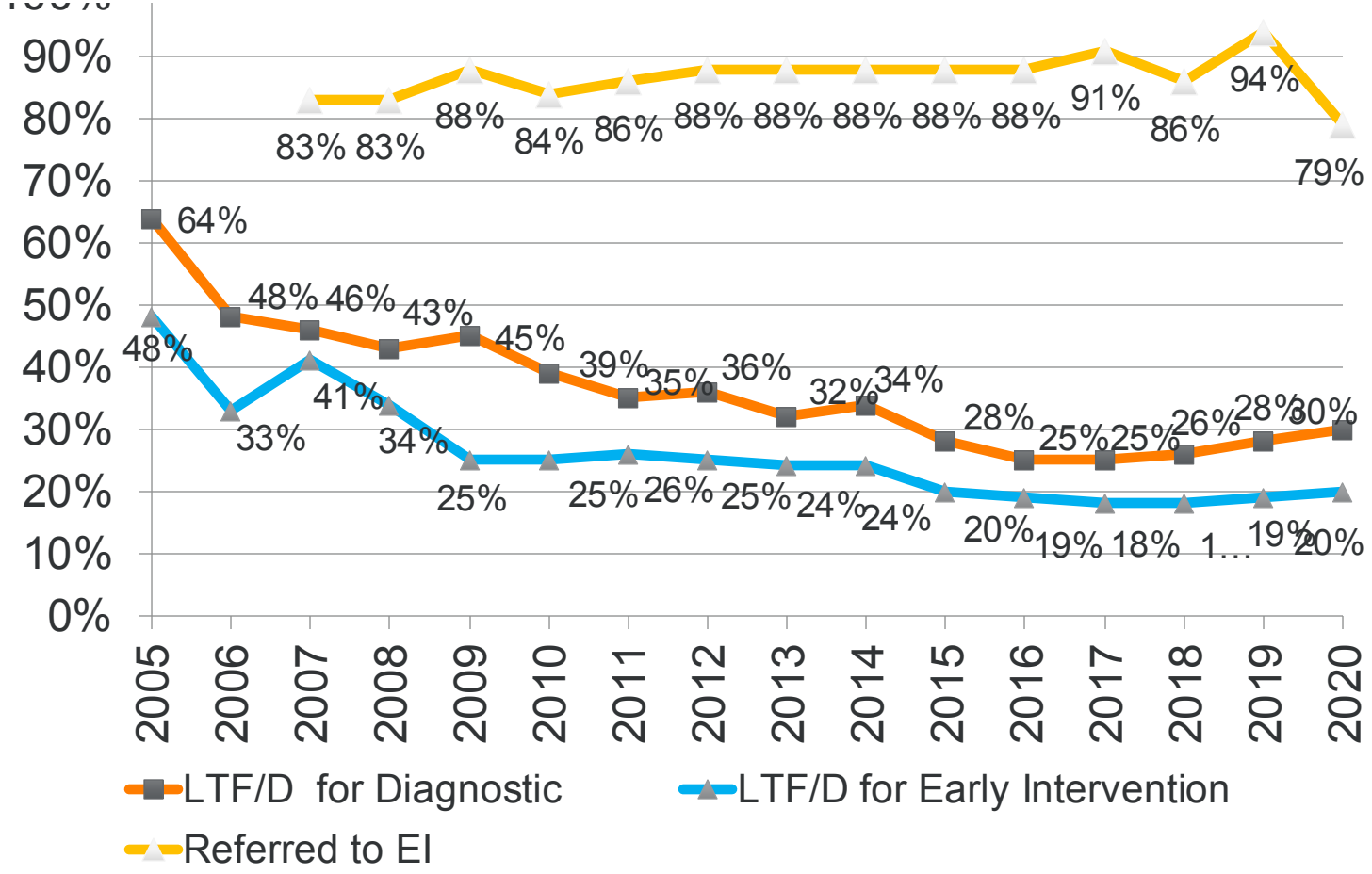
(3) Confirm/diagnose hearing loss by 3 months

(6) Appropriate intervention by 6 months

Follow-up impacted by various factors including NICU status, maternal education, poverty, insurance type, maternal race/ethnicity, geography/access, parental knowledge, maternal support networks

Percentage of EHDI Children LTF/D for Diagnostic Testing, Referred to EI, and EI Enrollment in the US

Slide Courtesy Karl White



Source: Centers for Disease Control and Prevention, http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

Poll: What proportion of children who would benefit from hearing aids have them?

- Close to 90%
- 50-60%
- We have no idea

Answer: What proportion of children who would benefit from hearing aids have them?

- Close to 90%
- 50-60%
- We have no idea

Poll: What proportion of US children who qualify for cochlear implantation have one or two CIs?

- 90%
- 35%
- 50%

Answer: What proportion of US children who qualify for cochlear implantation have one or two CIs?

- 90%
- 35%
- 50%

Compared with 90% in many European countries

The Opportunity of Early ID

- Early intervention for hearing loss facilitates access to language and social interaction
- Hearing aids, cochlear implants, bone anchored devices
  - Better auditory skills
  - Language development broadly
  - Social interaction
  - Cognitive benefits
  - Long-term benefits with all of the above
  - Kral, Sininger, Hamilton, Cejas
- Early sign language for those who chose it

Cejas. *JAMA Oto*. Cochlear Implantation and Educational Quality of Life Outcomes in Adolescence. 2023.

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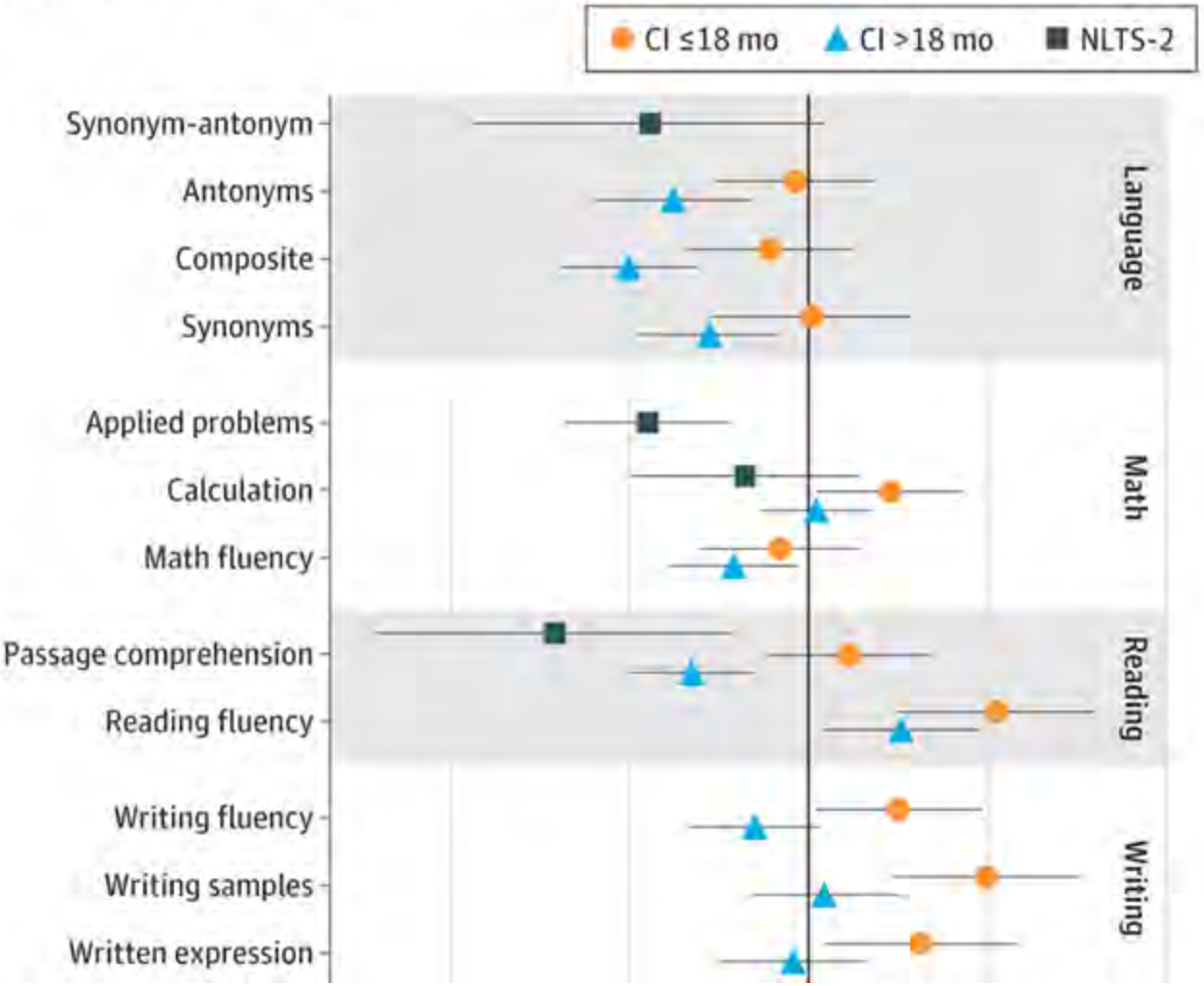
Figure 1. Comparison of Academic Achievement in Samples With and Without Cochlear Implants (CIs)



Children, Hearing Technology, Medicaid

Medicaid Overview

- Health care for persons of all ages whose income and resources are insufficient to pay for healthcare
- Medicare and Medicaid were created in 1965 as part of The Great Society programs
  - Separate programs/operate differently
- Medicaid is a joint program, funded primarily by the federal government and carried out at state level
- All states cover hearing care for eligible children (specifics determined by each state)

Medicaid Role in Serving Deaf & Hard of Hearing Children

- Established 1967 by US Congress to ensure children received appropriate healthcare services / EPSDT added later to ensure states were responding across board
- Covered 37% of US children aged 19 and under in 2023*
- CMS guidance on EPSDT (9/26/2024)
  - Improve outcomes by identifying and addressing health care in children—specifically mentions hearing
  - Acknowledges impact of poverty on health during childhood and beyond, EPSDT intended to guarantee services needed
  - Clarifies rules apply to all states

*Statista.com

Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

- EPSDT services were part of a broad effort to comprehensively address children's healthcare
- Began with the War on Poverty and legislation that gave rise to Medicaid & Medicare
- Added to original Medicaid Act of 1965 (1967)
- Special needs of low-income children at risk for conditions that could impose lifelong disabilities
- Looked beyond adult treatments – *issues that impact on growth and development of children*

EPSDT Provisions Apply to All States

- Congress found disparities in way states carryied out the Act
- EPSDT added provision to screen children to ascertain "physical or mental defects" provide appropriate treatment
- Bottom line: States cannot decide they won't provide specific services that fall under medical services definition
  - Required services include hearing assistance
- If a clinician says a specific service is the best option for hearing restoration, Medicaid must provide it
- Will enforcement change in current environment?

Children and Technology

- Children must be covered for devices under Medicaid
- All states cover children, but issues remain related to how services are provided
- Replacement parts, upgrades, batteries, therapy
- Candidacy criteria including age at time of CI may differ from FDA (FL uses 12 months for CI)
- Second device has been an issue in some states, but clinicians should be able to argue this (and all of the above) based on EPSDT

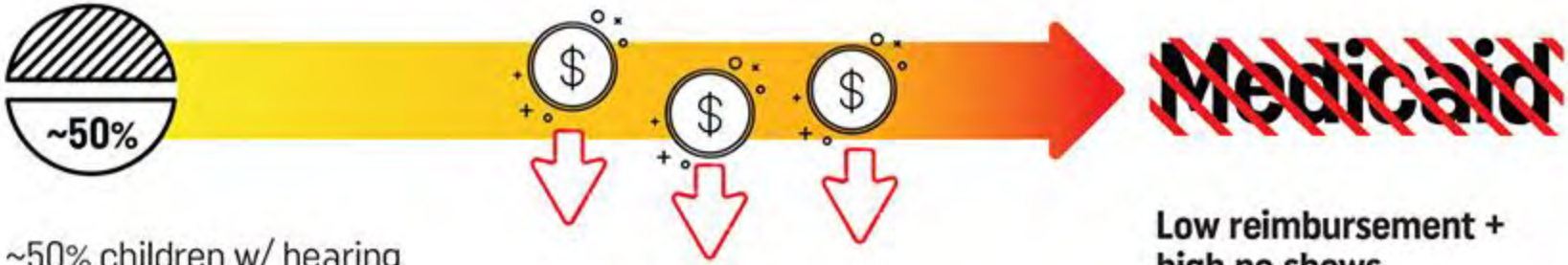
EPSDT Guidance issued by CMS:
Additional Details on Awareness + Access

- Services provided to children (even if specific services not provided for adults) to allow child to reach development milestones
- Full range of covered services “must” be provided
  - Caregivers must be made aware and have access
  - Services must meet child’s individual needs
- States must use a range of written and oral methods to inform
  - Social media platforms, electronic communications along with beneficiary handbooks, text messages for reminders

Transportation, Care Coordination, Case Management

- Families are supposed to be informed: Transportation assistance is available
- Systems are complex and children/families need help negotiating the system
- Care coordination can be covered under Medicaid rehabilitation services benefit in section 1905

How does Medicaid Impact Early Intervention Access?



~50% children w/ hearing loss **covered by Medicaid for hearing related care**

Across states: **low, variable payment rates**

~~Medicaid~~

Low reimbursement + high no shows leads some providers to not accept Medicaid

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Illustrative Reimbursement Rates

Medicaid Reimbursement Rates by State

Code	KY	FL	SC	CA	VA	NE	Medicare Hospital Outpatient
69930 Cochlear device implantation, w/ or w/out mastoidectomy	$990	$920	$34,416	$1127	$1039	$1662	$33,148
L8614 (CI device)	0	$16,580	$582	0	$17,993	$18,368	Reimburses 80% of cost (~$40k)
92591 Binaural HA exam & selection	$65	?	$36	$34	$79	$75	
92650 AABR at hearing rescreening	$23	$55	$67	$31	$23	$6	
92652 threshold ABR at diagnostic appointment	$94	$81	$88	$105	$95	$82	

How does this impact access?

- Reimbursement amount for specific services determined by state Medicaid programs
- *On average*, Medicaid reimburses providers 60% less than Medicare or private insurance
- In some instances, reimbursement is negligible (15% or less of Medicare payment rates)
- When that occurs, hospitals may terminate pediatric programs or put other pressures on hearing programs

More Medicaid Impacts on Access to EHDI

- 50+% D/HoH children covered by Medicaid
- Variable payment & rules across states
  - Candidacy may be more restrictive
- Low reimbursement → provider pool → may result in program closures
- Delays pre-authorization
- Managed Care Plans may not track straight Medicaid guidelines
- Difficult/complex enrollment process can be overwhelming → delays care

Barriers to Early Intervention: Provider, Patient, Family

Provider

- *Limited access to audiologists with pediatric experience*
- *Rural location*
- *Wait times*
- *Delay in diagnosis*

Patient

- *Comorbidities*
- *Unilateral, mild hearing loss, or otitis media*
- *General health and/or NICU stay (complicated birth)*
- *Birth state not same as state of residence*

Family

- *Lack of understanding of follow-up need (PCP, fathers)*
- *Subjective observation of child's response to sound and/or acceptance of hearing loss*
- *Work schedule*
- *Socioeconomic (lower income, education, language)*
- *Type of insurance*
- *Comprehensive options information*

Provider / System-Related Barriers

- Availability of qualified:
  - Pediatric audiologists
  - Early interventionists skilled in working with infants and children who are D/HH
- Use of general EI personnel w/out specific HL experience
- Availability of apt for diagnostic ABR within 3 months
- Few pediatric otolaryngologists
- Many (most?) pediatricians unfamiliar with hearing loss
  - “Let’s wait and see”
- Who? What? When?

Patient (Child) Barriers

- Comorbidities
- Unilateral, mild hearing loss, otitis media
- General health and/or NICU stay (complicated birth)
- Birth state not same as state of residence

Family-Related Factors

Family Factors

- Lack of understanding of follow-up need (PCPs, fathers)
- Subjective observations of child's response to sound/non-acceptance of hearing loss
- Work schedule
- Socio-economic factors (lower income, education, language)
- Type of insurance
- Comprehensive options information


CASE
STUDY

Case Study: Texas

- Language barrier for re/enrolling key issues
  - Esp after automatic renewal ended
- Concerns about physicians/others not providing full information or urgency for follow up
- Fees not issue in larger hospitals

Case Study: Texas Continued

- Missed apts due to lack of transportation
  - Distance to appointments
  - Reliance on public transportation
  - Only one vehicle in family
- Solution: Utilizing Medicaid transportation
  - Must request 3-5 days in advance
  - Physician approval sometimes needed
  - Not always able to find a driver esp. in rural settings

Case Study: California

- Low reimbursement
  - Does not cover most costs (screenings, etc.)
- Hospitals run programs at a loss
- Limited # providers accept Medicaid

Case Study: California Cont.

- Complications for enrollment in California Children's Services (CCS)/Medicaid
  - Can be complicated/delayed for enrollees (language barriers)
  - Complicated for providers to be approved
  - LA County, ~80% of D/HoH children have CCS but only a few centers accept (One MRI takes CCS)
  - Location matters: short turn-around in urban vs 3-4 months in rural areas
  - Service coverage may not follow from county to county

Case Study: Florida

- Procedures/appointments not always reimbursed
- CI surgery coverage starts at 12 months
  - Earlier needed if child had meningitis
  - FDA guideline: 9 months
- Sheer numbers of Medicaid HMO plans with large coverage differences (no straight Medicaid)
- Lack of knowledge on importance of follow up from key providers
- Plan of care must be signed off by pediatrician and can delay process

Case Study: Florida Continued

- Some recent challenging elements
  - Bias in perspective about choice of modality: "ASL is the language of choice" based on interpretation by some EI professionals
  - Processor upgrade declined if child uses ASL

Case Studies Summary

- Issues with reimbursement across states
- Complicated re-enrollment w/ Medicaid
  - Language not English
  - Multiple Steps
- Impact of early intervention personnel and pediatricians not understanding goals/urgency for follow up

Possible Solutions

- Strengthen relationships with Medicaid staff
- Work to increase reimbursement
- Implement approaches that helped in other states
- Utilize:
  - Medicaid Provided Transportation
  - Medicaid Care Coordinators
- Opportunities for mentoring and peer to peer

Parent Support

- Facilitate connections to others
- Noted in EHDI legislation but frequently interpreted to mean Deaf adult mentors
- Parents wish to have access to a range of perspectives especially parents of deaf and hard of hearing children
- Organizations, clinics, online communities
  - Hands and Voices
- Fostering parent sensitivity is undervalued yet maternal sensitivity linked to language outcomes

Online Communities

- Parents of Children with Cochlear Implants Facebook Group (20k members)
- Moderated by parent volunteers
- Discussion group/questions posed
- Supportive environment with all modalities represented
- Mostly US but also some from other countries

- Families of Children with Hearing Loss (Family Facebook Group)
- Offered through Hearing First (2k members)
- Only members can see posts
- Staffed, materials offered
- Members are by design LSL focused and positive

Resources

- Medicaid Background related to hearing health https://www.acialliance.org/page/MedicaidMedicare
- Barriers Graphic https://www.acialliance.org/page/EarlyIntervention
- Impact of Medicaid on Cochlear Implant Access
  - Otology & Neurotology 40(3):p e336-e341, March 2019. | DOI: 10.1097/MAO.0000000000002142
- Guidance from Medicaid and CHIP on best practices for adhering to EPSDT Requirements 9/26/2024 https://www.medicaid.gov/federal-policy-guidance/downloads/sho24005.pdf

Thank you

Donna L. Sorkin, MA

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