Barriers to and Facilitators of EHDI: Learning from our Past for a Better Future

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EHDI Virtual
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Meet the Team

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Learning Objectives

Identify	Identify barriers to timely early hearing detection and intervention
Discuss	Discuss successful facilitators of timely diagnosis and early intervention
Implement	Implement evidence-based quality improvement measures in programs to facilitate EHDI

Introduction

- The incidence of permanent, congenital hearing loss is estimated to be 1-3 per 1000 infants

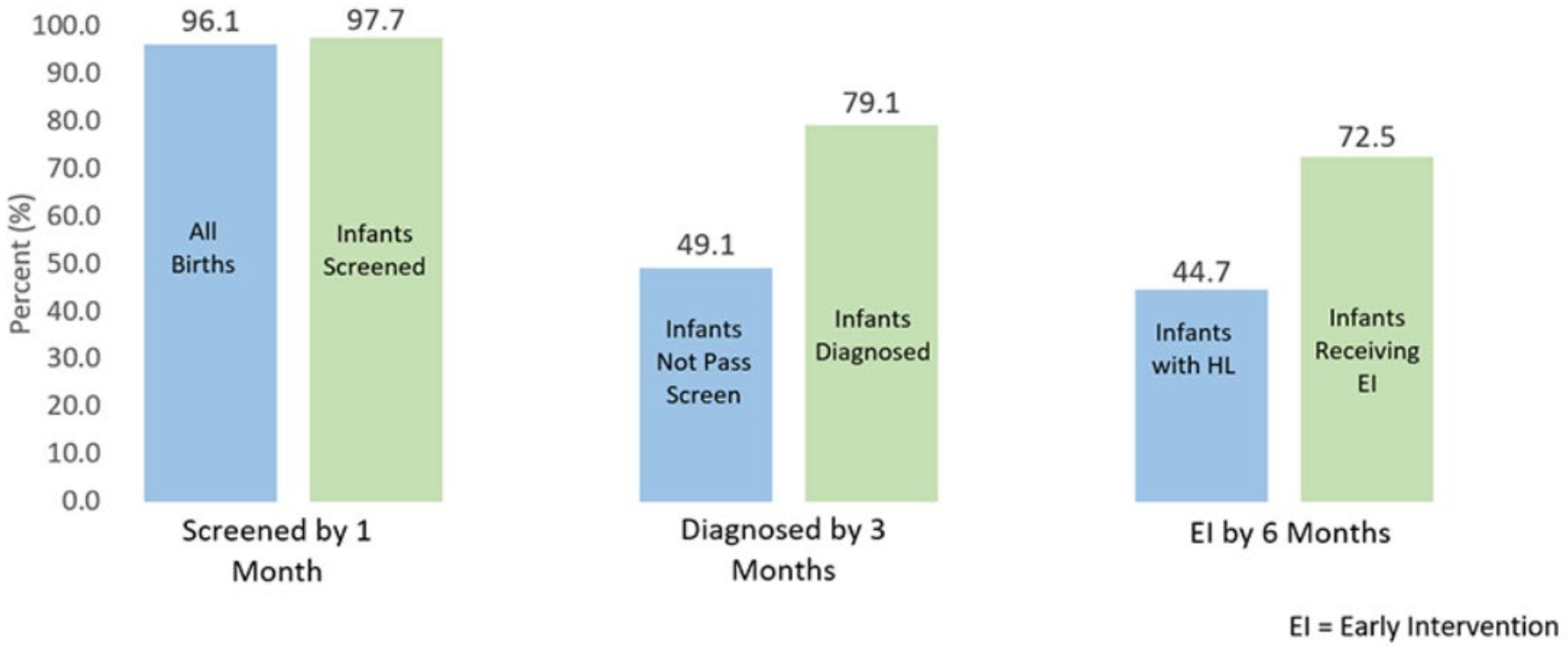
- Undiagnosed and/or late diagnosed congenital hearing loss can have significant developmental implications related to:
  - speech/language development
  - cognition
  - academic achievement
  - vocational opportunities
  - quality of life

Introduction

- Completion rates for screening have been consistently high since the inception of universal newborn hearing screening programs in the US

- Success rates for both diagnostic follow-up and early intervention enrollment have lagged

Meeting EHDI Benchmarks



[2019 CDC Summary Data]

Project Purpose

- Undertake a systematic review of literature pertaining to the entire EHDI process
- Identify factors that serve as barriers to timely benchmarks
- Identify facilitators of timely benchmarks

Method

- Prospero Registration CRD42021257187 (pending review)
- Systematic search of PubMed, EMBASE, CINAHL, APA PsychINFO, and Google Scholar completed on May 9, 2021 and August 27, 2021
- Medical subject heading (MeSH) terms of hearing loss/diagnosis, early medical intervention, loss-to-follow-up, time-to-treatment, or early hearing detection and intervention

Method

Covidence Systematic Review Software (www.covidence.org) used to move through three stages:

Stage 1- Title & Abstract Screening:

- Two independent reviewers for potential relevance.
- Managing reviewer resolved conflicts
- Third reviewer to resolve any discrepancies.

Stage 2- Full-text Review:

- Two independent reviewers screened all potentially relevant full-text articles.
- Disagreements resolved by consensus or a third member of the research team.

Stage 3- Data Extraction:

- Pre-determined data extracted for each study: design, level of evidence, population characteristics, outcome measures, control or comparison groups, barriers, facilitators, conclusions.
- Critical Appraisal Skills Program (CASP, 2019) used for quality ratings.
- Third reviewer completed consensus to resolve any conflicts between first two reviewers.

Method- Criteria

Inclusion

- Empirical, peer-reviewed articles
- English language
- Population focus on children birth to 3 years of age
- Published 1990 to present
- Location focus within the US

Exclusion

- Grey literature (dissertations, conference proceedings)
- Non-empirical studies
- Non-English language articles
- Population focus on children older than 3 years
- Location focus outside of the US
- Abstract Only
- Did not address barriers specifically

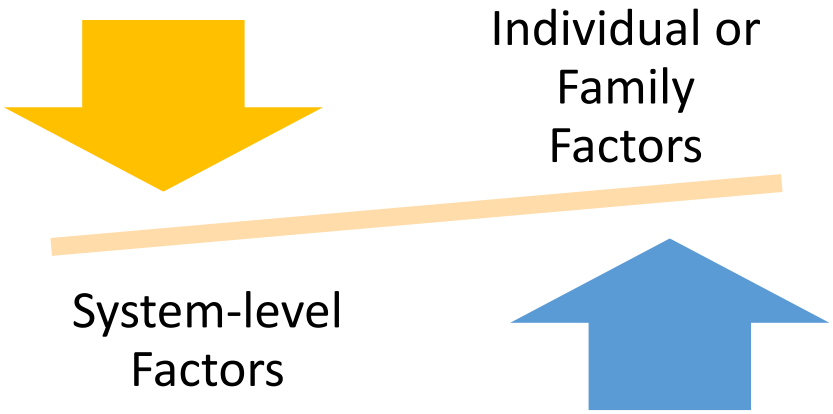
Method- Categorization

Analysis completed to categorize article content into:

EHDI Journey Benchmark

SCREENING DIAGNOSIS MANAGEMENT EI JOURNEY

Factor Type



Results

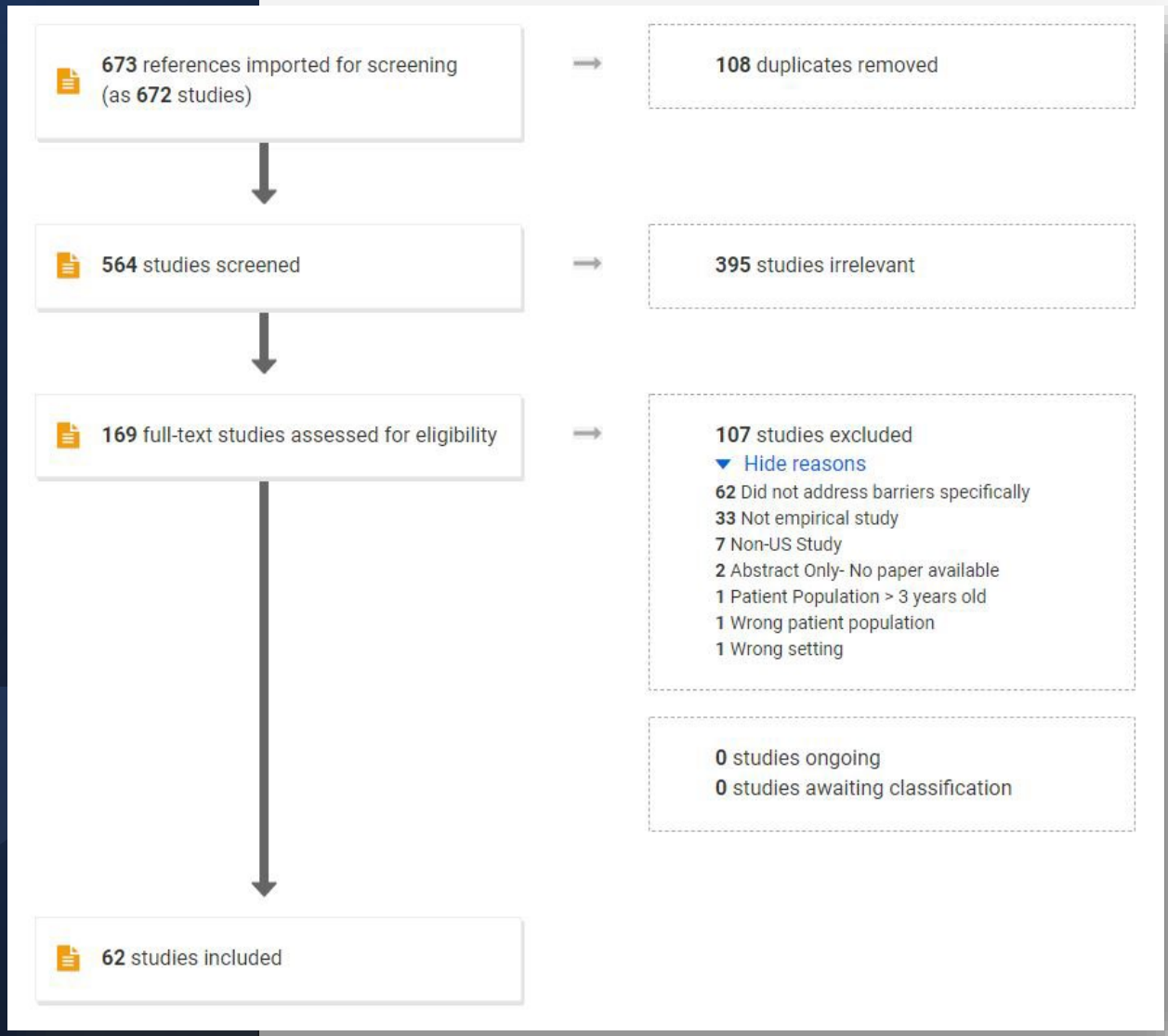
But first…A Poll

What barriers have you identified that hinder families moving through the 1-3-6 EHDI Process?

When poll is active, respond at **PollEv.com/ursulafindle591**

Text **URSULAFINDLE591** to **22333** once to join

Results


673 references imported for screening (as 672 studies)
108 duplicates removed
564 studies screened
395 studies irrelevant
169 full-text studies assessed for eligibility
107 studies excluded
Hide reasons
62 Did not address barriers specifically
33 Not empirical study
7 Non-US Study
2 Abstract Only- No paper available
1 Patient Population > 3 years old
1 Wrong patient population
1 Wrong setting
0 studies ongoing
0 studies awaiting classification
62 studies included

Categorization Analysis

	SCREENING	DIAGNOSIS	MANAGEMENT	EI	JOURNEY
Individual/Family Factors	9	27	9	7	5
System-level Factors	10	27	6	5	14

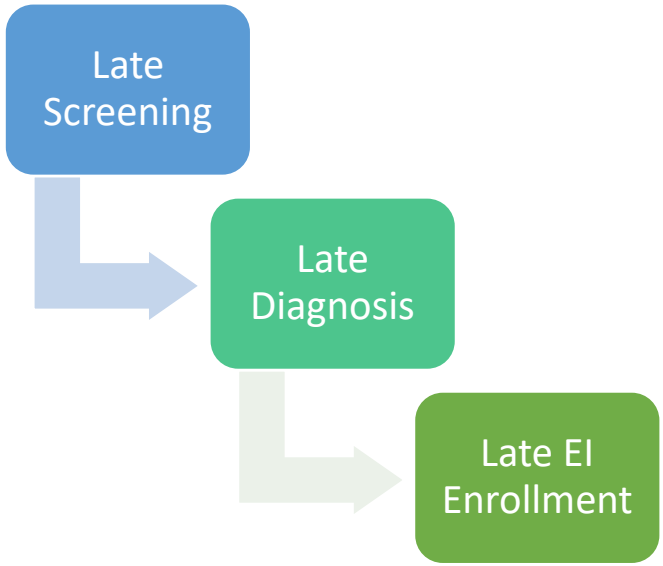
Social Determinants of Health (SDOH)

Barriers

The Entire EHDI Journey

32% of infants not passing the NBHS actually meet 1-3-6 benchmarks (Holte 2012)

- Denominator changes when looking at CDC data
- Cascading Effect of Delays



Some factors impact the entire journey wholistically…

The EHDI Journey- Social Determinants

Economic Stability

- **Low-income-** Families with limited income struggle to complete the EHDI process

Social/Community Contexts

- **Race/ethnicity-** families of color, Hispanic, or Native descent experience more barriers to completing EHDI

- **Smoking-** positive smoking during pregnancy

- **Family responsibilities** of childcare/work/school

The EHDI Journey- Social Determinants

Health Care Access & Quality

- **Public insurance –** families struggle to complete the EHDI process
- **Access to/Distance to Healthcare Facility**

Neighborhood & Built Environment

- **Rurality-** access to services
- **Transportation-** can be an issue in both rural and urban areas

The EHDI Journey- Maternal Factors

- **Maternal Education Level:** Lower education level → less likely process will be finalized → more likely benchmarks protracted beyond 1-3-6
- **Maternal Age-** lower maternal age associated with lower completion rates
- **Marital Status-** unmarried mothers associated with lower completion rates
- **Maternal Depression:** Mothers who endorse more depression symptoms → delayed or lack of follow-up

The EHDI Journey- Medical Factors

- **Medical Issues/NICU Stay:** Multiple medical needs leads to protracted EHDI timelines

**Except in programs where there is strong Inpatient Audiology

- **Transient Middle Ear Issues:** Middle ear fluid/CHL complicates timely diagnosis, follow-up, and management

The EHDI Journey- Family Knowledge

- **Knowledge of Results and Resources-** families are not provided the knowledge they need to be successful which causes →

- **Confusion** about the process, often related to →

- **Language Barriers/Cultural Competence**

The EHDI Journey- Family Knowledge

- **Knowledge of results and recommendations**
  - Families who did not know the screening or diagnostic results and recommendations are less likely to follow-up
  - Families often don't know where to follow-up

- **Knowledge of Impact of Hearing Loss**
  - Families who know less about the developmental impact of hearing loss are less likely to follow-up

The EHDI Journey- Provider Knowledge

- **Physician Dismissal-** families continue to report that their pediatricians dismiss the need for follow-up
  - PCP- 95% of PCPs had documentation of screening results, but not necessarily associated with successful follow-up
  - About 30% of PCPs do not feel that referral on NBHS should prompt referral to an audiologist for diagnostic testing
  - There is significant variability in knowledge about hearing loss and EHDI among physicians (Pediatricians vs. Family Practice)

- **Insufficient/Lack of qualified Providers/Programs-** spans screeners, diagnostic audiologists, and EI providers

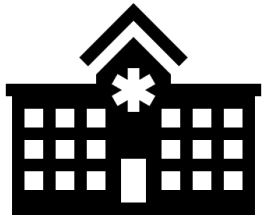
The EHDI Journey- Care Coordination

- **Lack of EHDI Care Navigator/Resources**
  - Programs that experienced time without EHDI staff for care coordination saw a decrease in follow-up rates

- **Information gaps** throughout the system can hinder families' journey

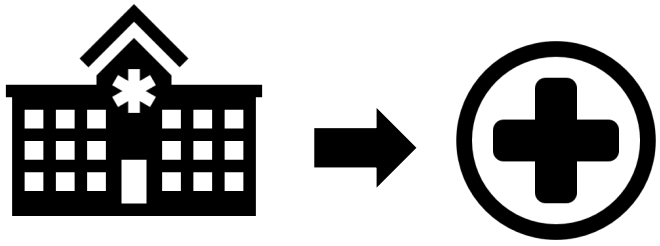
Screening is Highly Variable

Multiple approaches across states:



<u>Inpatient Only Screenings</u>

- Baby receives 2 screenings in birth hospital before discharge



<u>Inpatient to Outpatient Screenings</u>

- Baby receives 1-2 screenings in birth hospital before discharge
- Final screening occurs at an outpatient clinic, health department, or at PCP office

Screening – System Factors

- **NBHS Program Quality**
  - **Data Fidelity-** incomplete contact information complicates outreach for follow-up
  - **Screening Rate-** programs with lower overall screening rates have higher LTFU
  - **Access to screening equipment** (midwives/homebirths)
  - **Provider Involvement**
    - Audiologist Involvement- lack of involvement hinders re-screenings
    - Provider Time/Commitment and Competency- limited resources and lower volume associated with lower quality

- **Re-screenings**
  - Multiple re-screenings prior to diagnostic phase
  - Having an OP step in the process

Diagnosis – Family Factors

- **Missed/Cancelled Appts-** multiple missed appointments or rescheduling of diagnostic evaluations protracts the diagnostic process
- **Parent refusals-** often leads to significantly late diagnosis and significant developmental delays

Diagnosis – Provider Knowledge

- **Physician Knowledge**
  - Monitoring hearing due to risk factors for infants who pass UNHS

- **Inadequate reporting** – providers not reporting diagnostic results properly

Diagnosis – System Factors

- **Multiple re-screenings-** even when a diagnostic is indicated
- **Lack of evidence-based assessment/test battery-** incomplete testing to establish hearing status
- **Multiple Tests** to confirm results- sometimes related to medical factors or lack of appropriate test battery
- **Inadequate scheduling availability-** inconvenient appointment times for families
- **Equipment or sleep state issues** complicating testing

Management – Social Determinants

- **Financial Concerns about Cost**
  - Management via devices can be cost-prohibitive for families even with insurance
  - Navigating finding funding for devices is often frustrating

Management – Medical Factors

- **Type/Severity of Hearing Loss-** Infants with mild, unilateral, or permanent conductive hearing loss are less likely to be fit with amplification despite need

Management – Family Factors

- **Missed/Cancelled Appointments-** often related to other factors of family obligations, inconvenient appointment times, or lack of transportation

- **Family Acceptance**- some families need time to come to terms with the diagnosis

Management – System Factors

- **Appointment Availability**
  - Audiologic/Fitting- appointment constraints for specialty appointments
  - Medical Clearance- added step can protract the process
  - Both appointment types can be geographically specific and not available everywhere

- **Inadequate audiologist support-** Insufficient information provided or confusion about process

EI Enrollment- Medical Factors

- **Type/Degree of Hearing Loss**
  - Children with mild and/or unilateral hearing loss are less likely to be enrolled in EI

  **The role of developmental need warrants further exploration

- **Family Choice**
  - Choosing to wait for enrollment
  - Choosing to seek out private EI services not reported

What have we learned?

- Many barriers exist for timely, effective, early hearing detection and intervention
- Some barriers exist for all steps in the process
- Some barriers are specific to a particular step (e.g.: funding for amplification, not enough qualified EI providers)
- Social Determinants of Health have a significant impact on the success of our EHDI programs

Evidence to the Contrary

In some studies, SDOH were NOT factors associated with delayed or loss-to-follow-up!

- Awad 2019- Public insurance status was NOT associated with delays in diagnosis, management (HA fitting), and EI Enrollment
- Smith 2019- None of the SES factors studied related to delays in treatment of hearing loss via speech therapy, eventual speech outcomes, HA uptake and compliance, and LTFU. Children on Medicaid had equal access to services and similar outcomes for speech/language development
- Razak 2021- 17% of children LTFU for diagnosis was related to having multiple children in the family (childcare needs) and history of NICU stay, NOT poverty indicators of maternal education, maternal age, public insurance, ethnicity, etc.

Evidence to the Contrary

Commonality across these studies is that they were completed in settings where system-level/hospital-wide programs were in place to potentially mitigate SDOH

- Awad 2019- Metropolitan Children's Hospital/8 sites in Metro and adjacent areas
- Smith 2019- 3 major metropolitan health facilities in different states with large low SES populations
- Razak 2021- Urban Safety-Net Hospital; mission-driven to provide services regardless of ability to pay/insurance status

Facilitators

Another Poll

What facilitators have you identified that help families move through the 1-3-6 EHDI Process?

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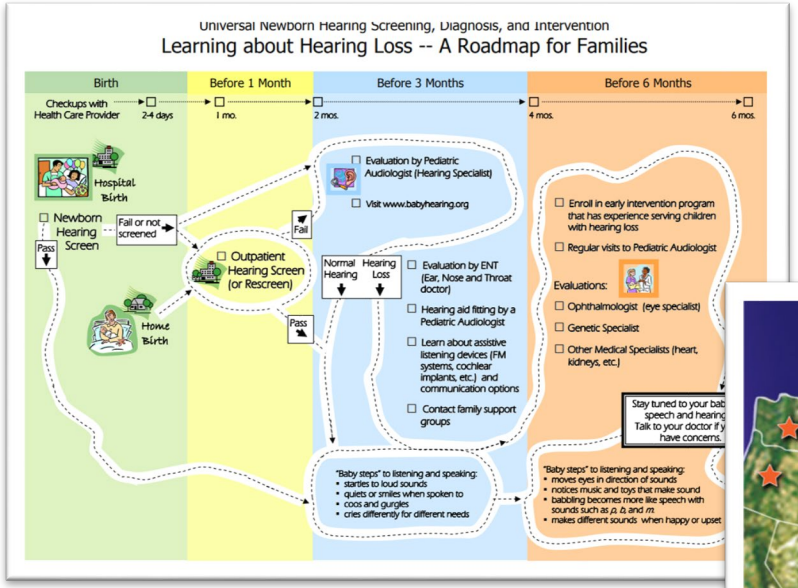
The EHDI Journey

Favorable SDOH…

The EHDI Journey- Family Support

- Resources for Family Support



[Infanthearing.org Roadmap]

[handsandvoices.org]

The EHDI Journey- Care Coordination

- **Care Navigation**
  - Shepherding families through the process of EHDI at any level can help with follow-up at any step

- **Co-locating Services**- well-baby appointments, WIC appointments, back to the familiar birth nursery, etc.

The EHDI Journey- Care Coordination

- **Proactive appointment scheduling**
  - Appointments for re-screening or diagnostics should be made at the time of newborn screening referral

- **Data Linking**
  - Linking EHDI data to vital statistics can reduce data entry errors and facilitate contact information confirmation
  - Linking EHDI data to other data management systems (ie: Medicaid billing) can identify loss-to-documentation

Screening – Quality

- **Screening Program Quality**
  - Audiologist Involvement
  - Provider/Screener Education, especially counseling
  - Access to Equipment – midwives for homebirths

- **Positive social supports-** Additional support for families can mitigate PPD impact

- **Inpatient Only Screening Program-**
  - Reduces a possible LTFU pinch point
  - Some states have very successful inpatient-outpatient programs because of infrastructure set in place

Screening –Cost

- **Funding/free rescreening services**
  - Some EHDI programs serve as the payer of last resort for screening and diagnostic services

- **Favorable Reimbursement**
  - Having a known payment pathway can reduce family reticence to follow-up

Diagnosis – Coordination/Outreach

- **Teleaudiology or Outreach Programs**
  - Bringing diagnostic assessments to underserved areas via telehealth or training local educational audiologists helps reduce loss to follow-up for families unable to travel

- **Medical Outreach**
  - Partner with local physicians and audiologists to confirm follow-up appointments and results
  - Education of local physicians about EHDI importance and pathways to referrals

Diagnosis – Family Support

- **Tailored Family Education**
  - Education families through family support programs and information specific to their situation can facilitate diagnosis

- **Positive social support**
  - Families who had more support from other family members or knew healthcare providers to reach out to had better follow-up

Diagnosis – Knowledge/Technology

- **Evidence-based Diagnostic Protocols**- thorough testing of a well-prepared baby expedites timely diagnosis
- **Audiologist Knowledge-** supporting training programs for pediatric audiologists
- **Instrumentation/Technology**
  - Newer signal processing technology can facilitate faster and more accurate diagnosis
- **Risk Factor Monitoring**
  - Plan for long-term monitoring of infants who pass UNHS but have risk factors for hearing loss

Management- Family Support

- **Financial Support/Loaner HA Programs**
- **Parent-to-parent support**
  - Speaking with and learning from other families is often the resource families ask for in retrospect
- **Evidence-based National Standard for EHDI**
  - In the absence of standardization, differences across states in terms of Medicaid coverage could impact outcomes

EI Enrollment- Medical Factors

- **Degree of Hearing Loss**
  - Children with profound hearing loss more likely to be enrolled
  - Family and provider education about developmental impact of lesser degrees of hearing loss

- **Other Medical Issues**
  - Children with comorbid medical issues can facilitate EI enrollment due to addressing multiple needs

EI Enrollment- System Consideration

- **National Standard for EHDI**
  - JCIH 2019 provides national guidelines, but individual state differences in execution and insurance coverage could significantly impact outcomes
  - Until there is a truly universal system with universal standards, variability will continue (Kingsbury 2022- SDOH review article)

What have we learned?

- Social Determinants of Health and other individual factors can serve as barriers while system-level changes have been shown to be facilitators of EHDI

- Some system-level changes have served to mitigate SDOH factors
  - Our role in EHDI will be to apply system-level changes in order to mitigate SDOH impact

- System-level changes will be location-specific across the county and within each state
  - Urban vs. Rural considerations- different system-level changes will be necessary

Facilitator Theme

Meeting the family where they are:

- **Co-locating services**
  - Pairing re-screenings with well-child visits, WIC visits, etc.
- **Teleaudiology services and Outreach Programs**
  - Expanding access, reducing travel
  - Training professionals in underserved areas
- **Educational materials tailored to Families**
  - Language
  - Reading level
  - Cultural Competence

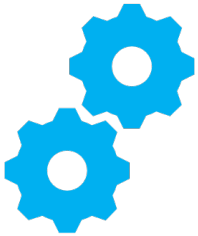
Limitations

- Most studies included are not Randomized Control Trials (actually, only 1 was!)
  - Limits conclusions drawn and increasing likelihood of different biases (selection, recall, etc.) which can limit generalizability
- So many factors, not all have been included in each study
  - Limits ability to understand complex interactions of factors
- Only included studies completed within the US due to specific programmatic factors and differences in health insurance coverage that may or may not be factors elsewhere.
  - However, much can be learned from programs in other countries

We need more research…

Expand understanding of management and EI enrollment phase factors

Expand understanding of family support/parent-to-parent support on the EHDI Journey



Understand complex interactions between factors

Thank you! Questions?

Contact:

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