

EQUITY OF EARLY HEARING DETECTION & INTERVENTION (EHDI)

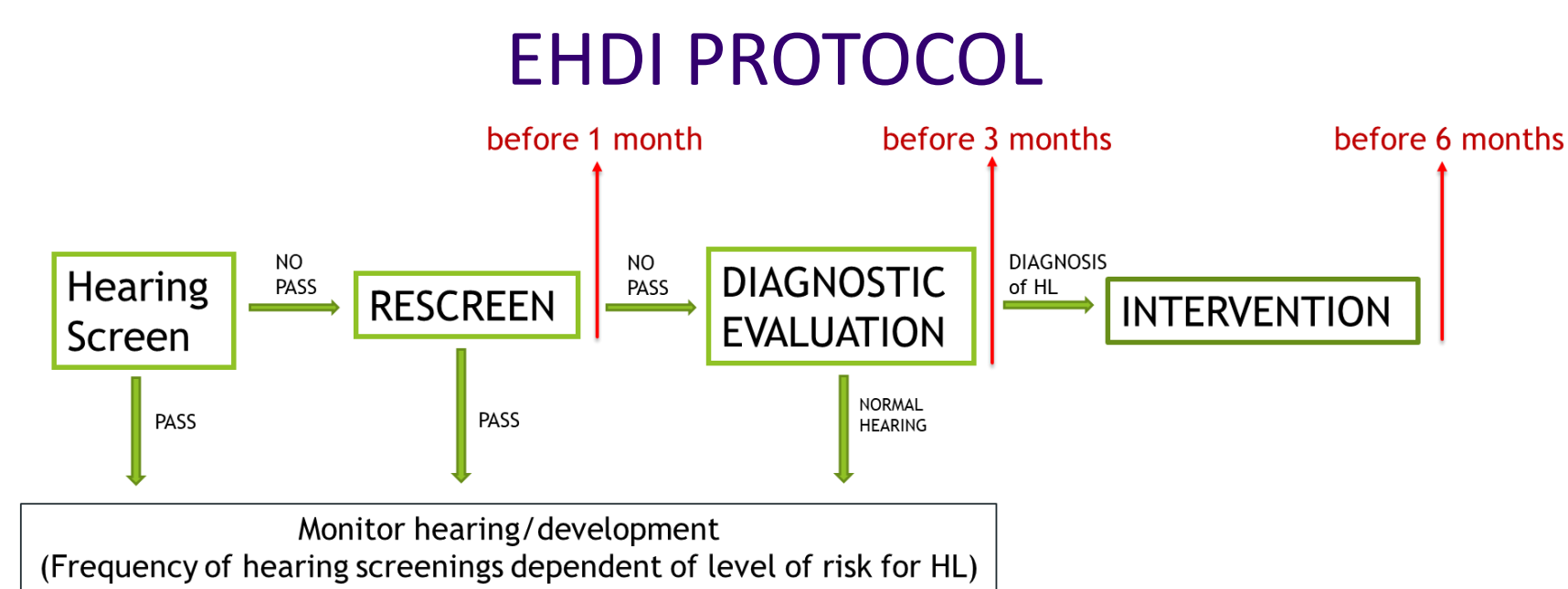
Exploring Barriers & Solutions



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INTRODUCTION



References: ASHA, 2008

EHDI STATISTICS: NATIONALLY

- > **Prevalence of permanent childhood hearing loss (HL) at birth: 3 in 1000**
- > **Successes**
 - 95% of infants born in U.S. receive newborn hearing screening (NHS)
- > **Challenges**
 - 59% of U.S. infants who did not pass NHS did not receive a diagnosis by 3 months of age
 - 64% of infants with permanent HL enrolled in early intervention (EI) programs; only 69% of those enrolled start by 6 months of age

References: ASHA, 2008; Bush, Kaufman, & McNulty, 2017; Tran et al., 2016

EHDI STATISTICS: WA STATE 2018

- > **Successes**
 - 96% screened by 1 month (99% overall)
 - 174 infants identified with permanent HL (2 in 1000)
- > **Challenges/Barriers**
 - Many children born outside of a hospital are not receiving hearing screenings
 - 64% received a diagnosis by 3 months

References: WA State Department of Health

MY LEND LEADERSHIP PROJECT

> What I know:

- Not all children receive the benefits of early identification of hearing loss.
- Not all children receive the benefits of early intervention of hearing loss.

> What I wanted to learn:

- What are the barriers to early identification & intervention in Seattle?
- What are the solutions to improve equity of EHDI?

> What I did:

- Interview WA EHDI stakeholders.
- Identified barriers.
- Found solutions.

BARRIERS IN SEATTLE

WA EHDI STAKEHOLDERS* INVOLVED IN DIVERSE CULTURAL COMMUNITIES



An organization dedicated to ensuring that families with family members with developmental/intellectual disabilities have equal access to culturally & linguistically appropriate information, resources, & services.



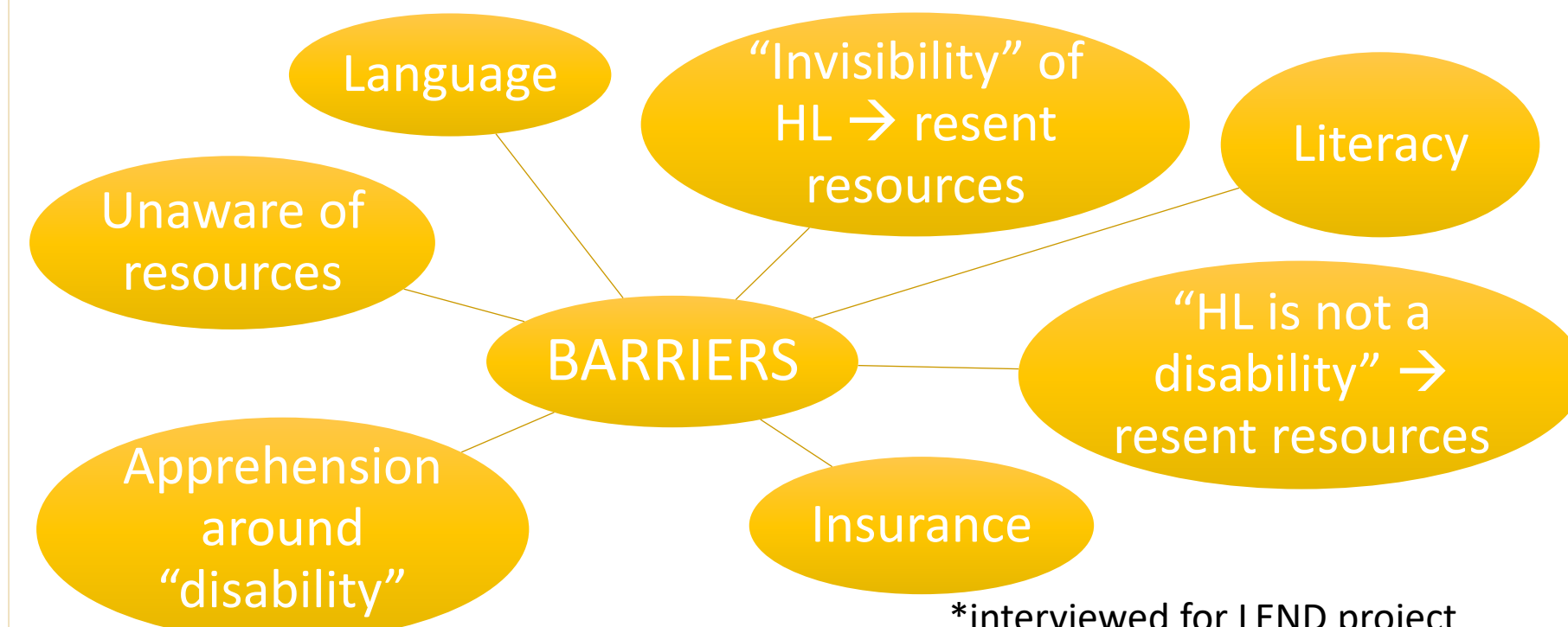
Provide childbirth education, doula & midwife services for clients. Clients are predominately people of color, immigrants/refugees, & low-income families. NHS is available.



The WA Dept of Health EHDDI program:

- > Supports NHS process
- > Collects NHS results
- > Provides monitoring of follow-up of infants who did not pass
- > Provides education for WA stakeholders

BARRIERS IDENTIFIED BY WA EHDI STAKEHOLDERS



*interviewed for LEND project

NATIONAL BARRIERS

BARRIERS LEADING TO LOSS OF FOLLOW-UP



Lack of Communication

Unclear communication of hearing screening results in hospital^{3,4}
 PCP not receiving NHS info/incoordination among service providers^{1,4}



Educational Disparities^{2,4}

Families finding the hearing process difficult to navigate^{1,2}
 Inconsistencies in healthcare info from providers^{3,4}
 Parent uncertainty in ability to make healthcare decisions for child due to lack of resources²



Healthcare Delays

Protocol drift⁵
 Difficulty to obtain outpatient testing^{3,4,5}
 Insurance-related healthcare delays^{3,4}



Lack of Resources^{2,3,4,5}

Distance to travel
 Transportation/parking
 Time off work
 Childcare for siblings



Competing Needs

Competing healthcare needs^{2,4}
 Conflict with family or work duties^{2,3,4}



Cultural Barriers^{4,5}

Mistrust⁵
 Concerns regarding the impact of a disability to a family's identity⁵
 Misunderstanding of EHDI process⁵
 Varying awareness of HL⁵

References: ASHA, 2008¹; Bush, Kaufman, & McNulty, 2017²; Elpers et al., 2016³; Ravi et al., 2016⁴; Campbell & Hyde⁵

STATEGIES TO IMPROVE ACCESS

SUGGESTIONS FROM WA EHDI STAKEHOLDERS

| |
|--|
| RAISE AWARENESS OF RESOURCES |
| > Diverse cultural communities need more resources to support raising a child who is DHH |
| OTHER WAYS TO PROVIDE RESOURCES |
| > WhatsApp - A place to post resources |
| > Videos with voice over in other languages to support those with reading challenges |
| > Provide links to EHDI resources on community organization websites |
| > Resources/information in various languages |
| IMPROVE PROVIDER SKILLS |
| > Consider impact of diagnosis and "disability" among cultures |



IMPROVE HEALTHCARE SYSTEMS

Closely monitor high-risk families^{4,7,9}
 Provide appointment reminders¹⁰
 NHS report sent to primary care doctor¹⁰
 Collaborate with other state programs^{7,10}



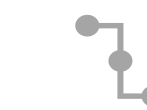
EDUCATE HEALTHCARE PROVIDERS

Educate midwifery programs⁸, PCPs^{7,9}, & other service providers^{3,10} about NHS process, EHDI importance, & to provide resources to them
 Discuss EI services & enroll families as soon as possible after diagnosis¹¹



EDUCATE FAMILIES

Provide info to mothers about NHS prior to birth^{5,10}
 Provide clear information about NHS^{5,7,10} with culturally-appropriate information^{4,7}
 Provide increased patient support¹



IMPROVE ACCESS TO CARE^{3,4,5,7}

Remote services/telehealth^{1,2}
 Centralized screening facility¹⁰

References: Bush, Kaufman, & McNulty, 2017²; Campbell & Hyde⁵; Cheek-Zamora & Thullen, 2017³; Cunningham et al., 2017⁴; Elpers et al., 2016³; Liu et al., 2016⁷; Palmer et al., 2016⁸; Prince, 2016⁹; Ravi et al., 2016⁴; Tran et al., 2016¹⁰; Tran et al., 2016¹¹

SUMMARY

BARRIERS IN SEATTLE

- > Uncertainty with diagnosis
 - Uncertainty with the label of "disability"
 - Cultural reaction to disabilities
 - Invisibility of HL
- > Resources
 - Lack of awareness of resources/information about EHDI among families from diverse cultural backgrounds
 - Lack of culturally-appropriate resources

BARRIERS SEEN NATIONALLY

- > Communication
 - Lack of communication with health care providers
 - Miscommunications between providers & families
 - Families misunderstanding or uncertainty
- > Healthcare system delays
- > Family barriers
 - Lack of financial resources for family
 - Competing needs within the family
 - Cultural barriers

IMPROVING ACCESS

- > Reach out to local organizations to determine the needs in the community
- > Identify languages used most in the community, to improve access to resources
 - Closed captions in multiple languages
 - Video resources in multiple spoken languages
- > Partner with organizations in your field to obtain resources & increase access to these resources

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