

# EHDI in Arizona

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AZAAP JULY 21, 2023

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AZAAP EHDI CHAPTER CHAMPION

# Disclosures

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No financial conflicts

# Acknowledgements

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Melissa Selbst – Executive Director, Ear Foundation

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General Overview of EHDI from national perspective

Arizona Data

Role of Pediatrician/Medical Home

Resources

## EHDI Overview

The American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) program is part of a cooperative agreement between the AAP and the Maternal and Child Health Bureau.

The goal of the AAP EHDI program is to improve the effectiveness of newborn hearing screening, diagnosis, and intervention by increasing the involvement of pediatricians, other physicians, and nonphysician clinicians in state EHDI programs.

## EHDI Overview



Early identification, diagnosis, and referral to early intervention for a child who is D/HH is critical for age-appropriate development of communication, language, and social skills that influence a child's overall well-being.

The purpose of early identification and intervention is to assure that all infants are identified as early as possible and appropriate referral to early intervention initiated no later than 3-6 months of age. Children and families reach optimal outcomes when these benchmarks are met.

# EHDI Legislative Authority

- 2022 Reauthorization:
  - Reauthorizes EHDI through 2027
  - Includes GAO study of EHDI programs



Early Hearing Detection and Intervention Act of 2022, Public Health Service Act, Title III, Section 399M (as added by P.L. 106-310, Sec. 702 and reauthorized by P.L. 117-241, Sec. 2)



# EHDI's Impact



**98 percent of U.S.-born infants are now screened for hearing loss usually before leaving the hospital**



**Since 2005 over 84,000 D/HH infants in the U.S. have been identified early**



**\$200 million in education costs are saved each year in the U.S. due to newborn hearing screening**



Center for Disease Control and Prevention. (2022). *CDC's Progress in Detecting Infant Hearing Loss* [Fact sheet]. <https://www.cdc.gov/ncbddd/hearingloss/documents/hearing-factsheet-508.pdf>



# Foundations for EHDI

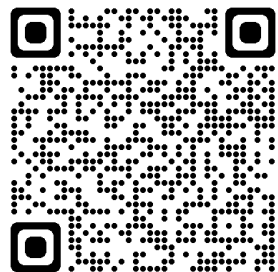
## JCIH 2019 Position Statement

- 1- Screen by one month
- 3- Diagnosis by three months
- 6- Early Intervention by six months
- + Parent to parent support

**Consensus document developed by a multi-organizational committee. [www.jcih.org](http://www.jcih.org)**

Includes:

- American Academy of Audiology
- American Speech Language and Hearing Association



## Public Health Principles

- Assess and monitor population health status, factors that influence health, and community needs and assets
- Investigate, diagnose, and address health problems and hazards affecting the population
- Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it
- Strengthen, support, and mobilize communities and partnerships to improve health
- Create, champion, and implement policies, plans, and laws that impact health
- Utilize legal and regulatory actions designed to improve and protect the public's health
- Assure an effective system that enables equitable access to the individual services and care needed to be healthy
- Build and support a diverse and skilled public health workforce
- Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement
- Build and maintain a strong organizational infrastructure for public health

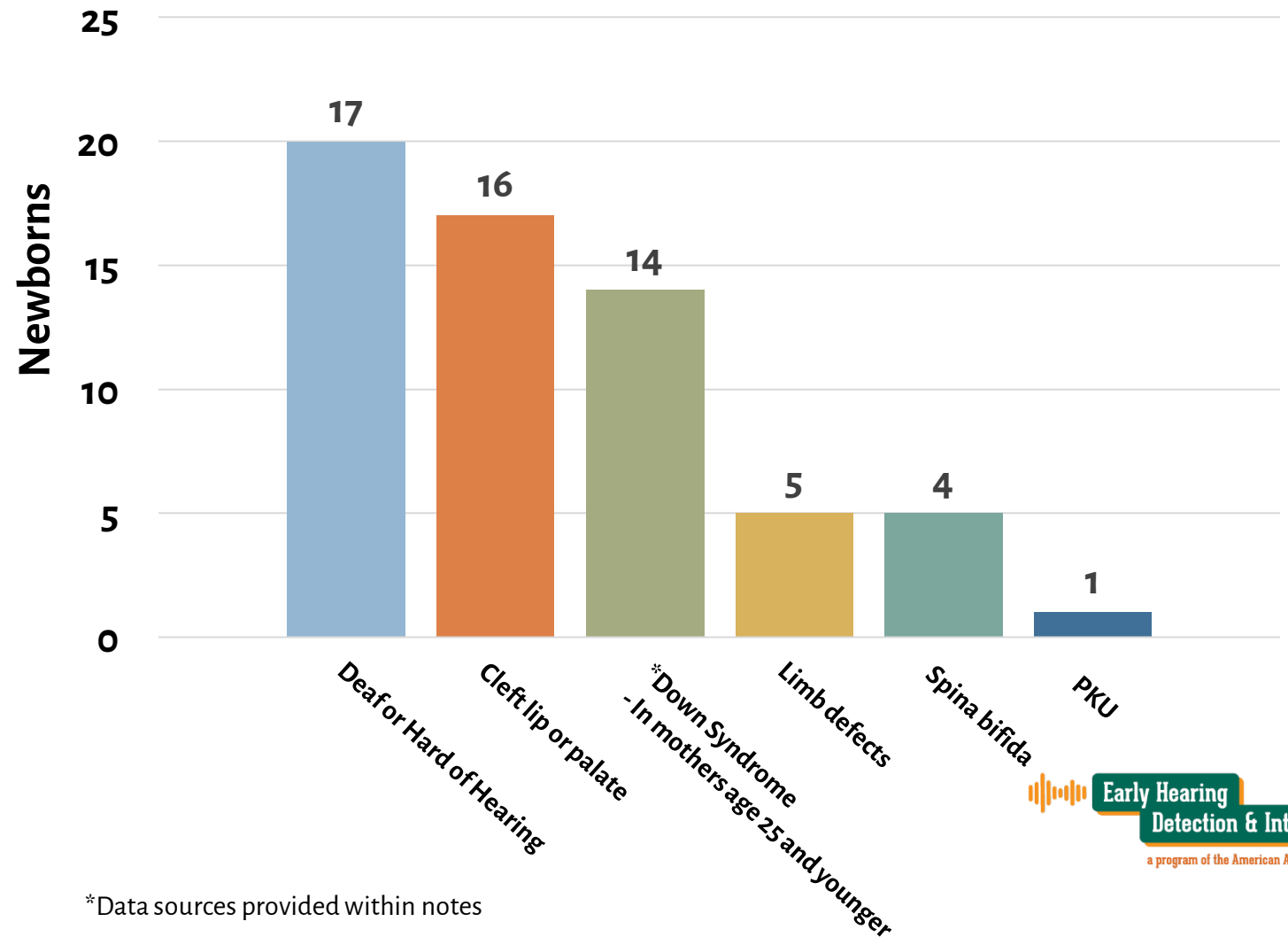


## 2019 Position Statement

“The goals of early hearing detection and intervention (EHDI) are to maximize language and communication competence, literacy development, and psychosocial well-being for children who are deaf or hard of hearing.”

# Comparison of Select Congenital Conditions

## Incidence per 10,000 of Congenital Conditions



\*Data sources provided within notes

# EHDI 1-3-6 Goals

## National EHDI Goals

- ❑ All infants born in a US hospital should receive a hearing screening before leaving the hospital and no later than 1 month of age
- ❑ Every infant who does not pass their newborn hearing screen sees a pediatric audiologist with the capability to perform a complete diagnostic evaluation no later than 3 months of age
- ❑ All infants identified as D/HH will begin receiving early intervention services as soon as possible and no later than 6 months of age

### Three Key Components of Early Hearing Detection & Intervention Programs

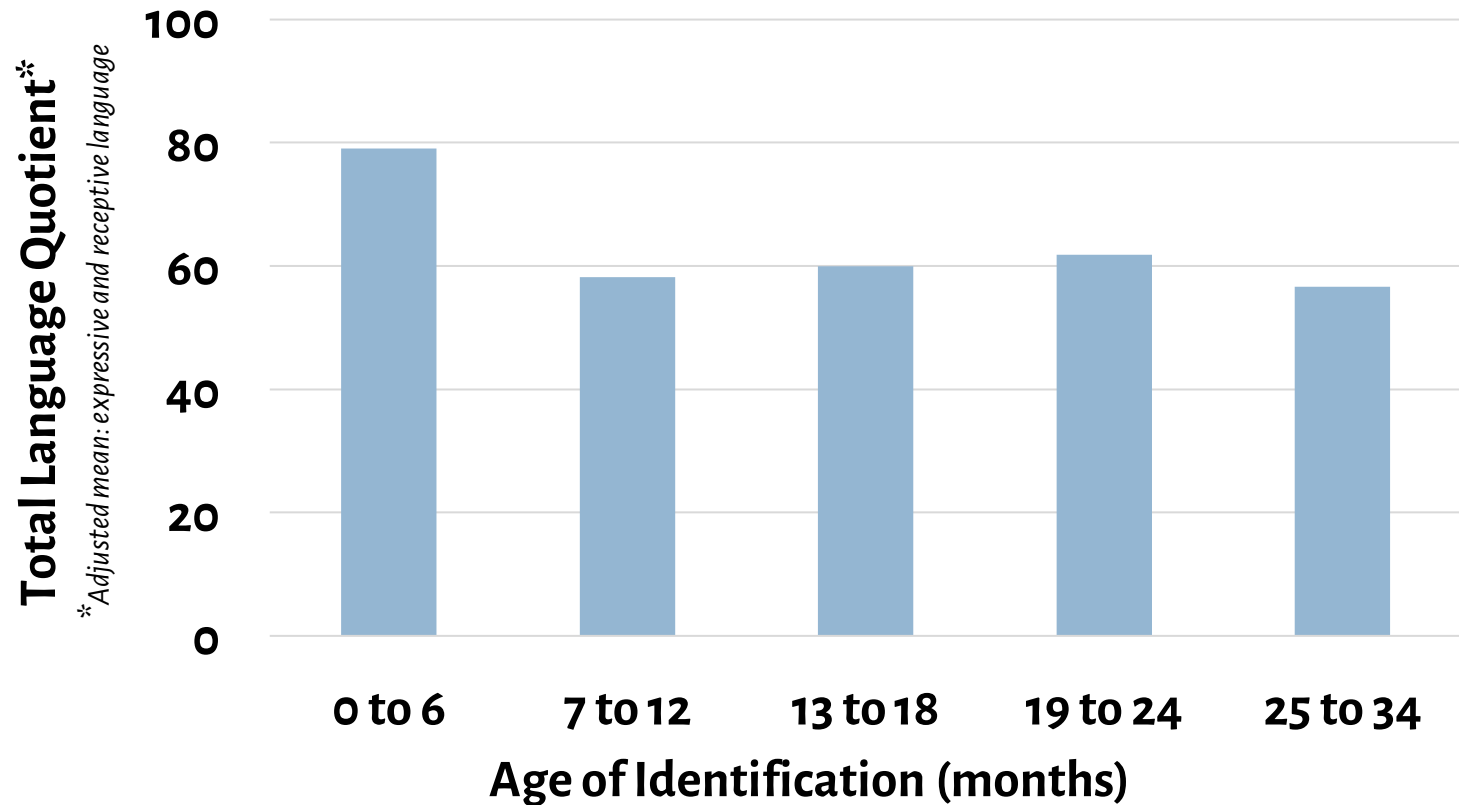


# Developmental Emergency

When a newborn is identified as D/HH it is a developmental emergency.

Early identification and intervention are critical for language outcomes.

## Language Quotient and D/HH Identification



# State EHDl Programs



- ❑ Every state and territory in the US has now established an EHDl program
- ❑ All 50 states and the District of Columbia have a law, regulation, or documented legislative intent about hearing screening and/or hearing screening guidelines
- ❑ EHDl program staff are responsible for creating, operating, and continuously improving a system of services which assures that the national EHDl goals are met
- ❑ State EHDl Laws and Regulations: [Federal Early Hearing Detection & Intervention Legislation | NCHAM \(infanthearing.org\)](#)
- ❑ NCHAM State Resource Page: [http://www.infanthearing.org/states\\_home/](http://www.infanthearing.org/states_home/)



- Home
- EHDI System
- Resources
- States
- Legislation
- About Us

### State EHDI Information

- [State Profiles](#)
- [EHDI Program Websites & Guidelines](#)
- [EHDI Contacts](#)
- [EHDI Program Toolbox](#)
- [State EHDI Grants](#)
- [State Parent Information](#)
- [Hearing Aid Loaner Bank Programs](#)
- [Home Visiting Resources](#)
- [EHDI-Related Employment Opportunities](#)

### ((( State EHDI Information

Every state and territory in the United States has now established an Early Hearing Detection and Intervention (EHDI) program. The EHDI program staff are responsible for creating, operating, and continuously improving a system of services which assures that:

- Every child born with a permanent hearing loss is identified before 3 months of age and provided with timely and appropriate intervention services before 6 months of age.
- Every family of an infant with hearing loss receives culturally-competent family support as desired.
- All newborns have a "medical home."
- Effective newborn hearing screening tracking and data management systems are linked with other relevant public health information systems.

This section provides information about the EHDI system in each state and territory.



National Center for Hearing Assessment and Management  
 Utah State University, 2615 Old Main Hill, Logan, Utah 84322  
 Tel: 435.797.3584 || [Questions and Comments](#)  
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EMMA ECCLES JONES  
 COLLEGE of EDUCATION  
 and HUMAN SERVICES  
 UtahStateUniversity.

Many of the resources on this site are offered in various formats, such as





- Home
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- Resources
- States
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- About Us

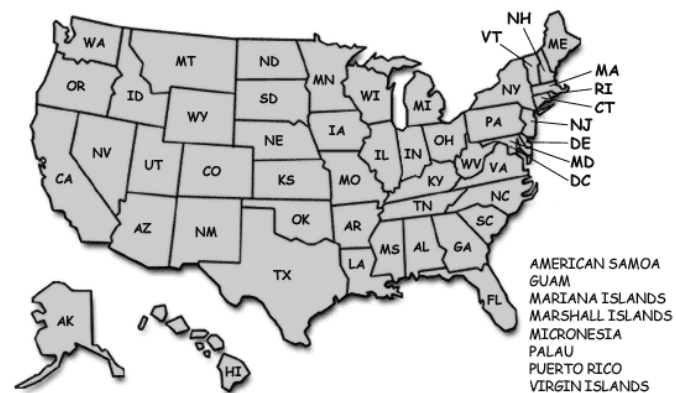
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## The "State" of Early Hearing Detection & Intervention in the United States

To find a state's EHDI summary click on that state on the map below.

[\(Skip to Text Links\)](#)



#### U.S. States

- [Alabama](#)
- [Alaska](#)
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- [Connecticut](#)
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- [Wisconsin](#)
- [Wyoming](#)

#### Territories and Jurisdictions

- [American Samoa](#)
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State Profiles (U.S. Map) > Arizona

## Arizona Early Hearing Detection & Intervention (EHDI) Information

### State EHDI Information

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- Home Visiting Resources
- EHDI-Related Employment Opportunities

#### State Website

- [Arizona Newborn Hearing Screening Program](#)
- State Stakeholder Meeting Agenda is not yet available. Please contact your state EHDI coordinator.

#### Early Hearing Detection & Intervention Contacts:

##### Lylis Olsen, MS, CCC-A

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 Lead on HRSA EHDI grant  
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 Fax: 602-364-1495  
[Email Fran Altmaier](#)

#### [Arizona EHDI Legislation](#)

#### [Arizona EHDI Guidelines](#)

#### [Arizona EHDI Grants](#)

#### Information for Families

- [Materials Available from Arizona EHDI Program](#)
- [Communicate With Your Child Website and Brochure](#)

#### [Involving Adults who are Deaf and Hard of Hearing](#)

#### For Health Care Providers

- [Diagnostic Audiology & Pediatric Rehabilitation Services \[PDF\]](#)
- [Medical Home](#)
- [EHDI PALS](#)



# EHDI Program Components

- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Pediatric Audiology
- Specialty Referrals
- Early Intervention
- Family-to-Family
- D/HH Adult-to-Family Support
- Tracking and Data Management



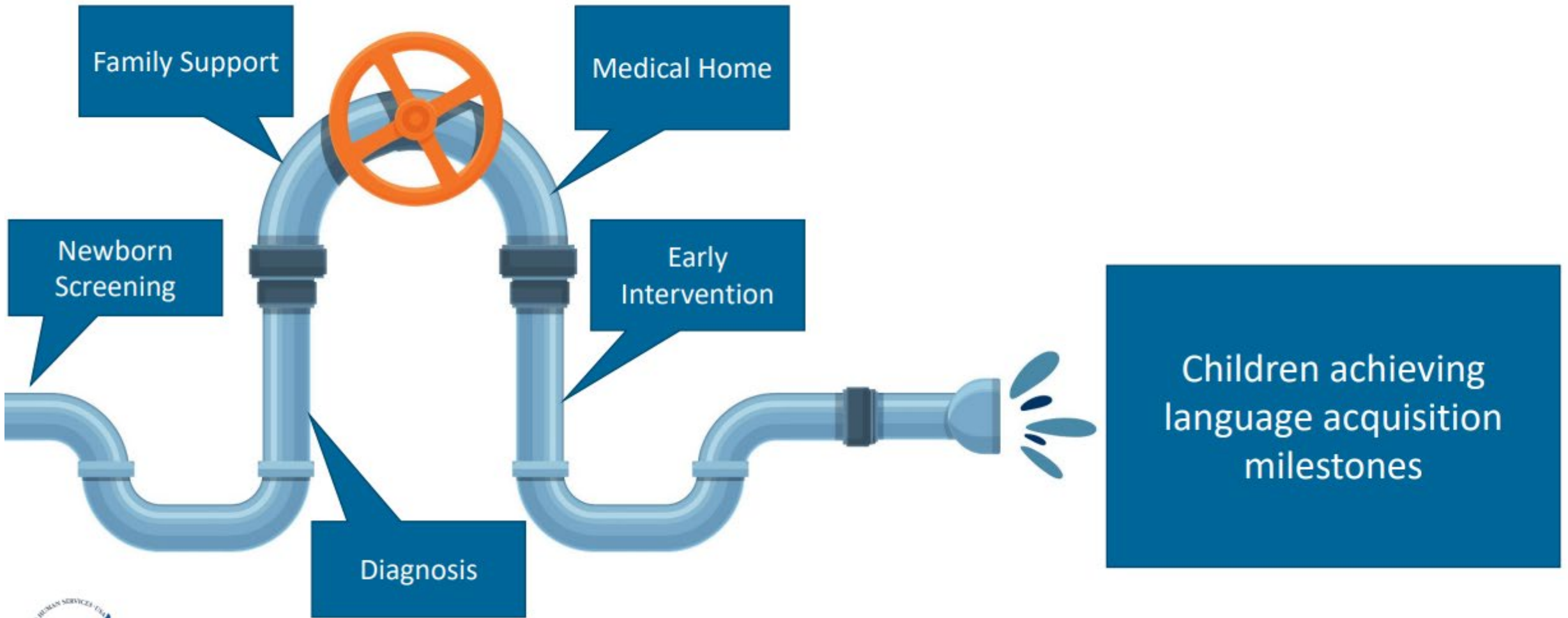
# Hearing Screening Process

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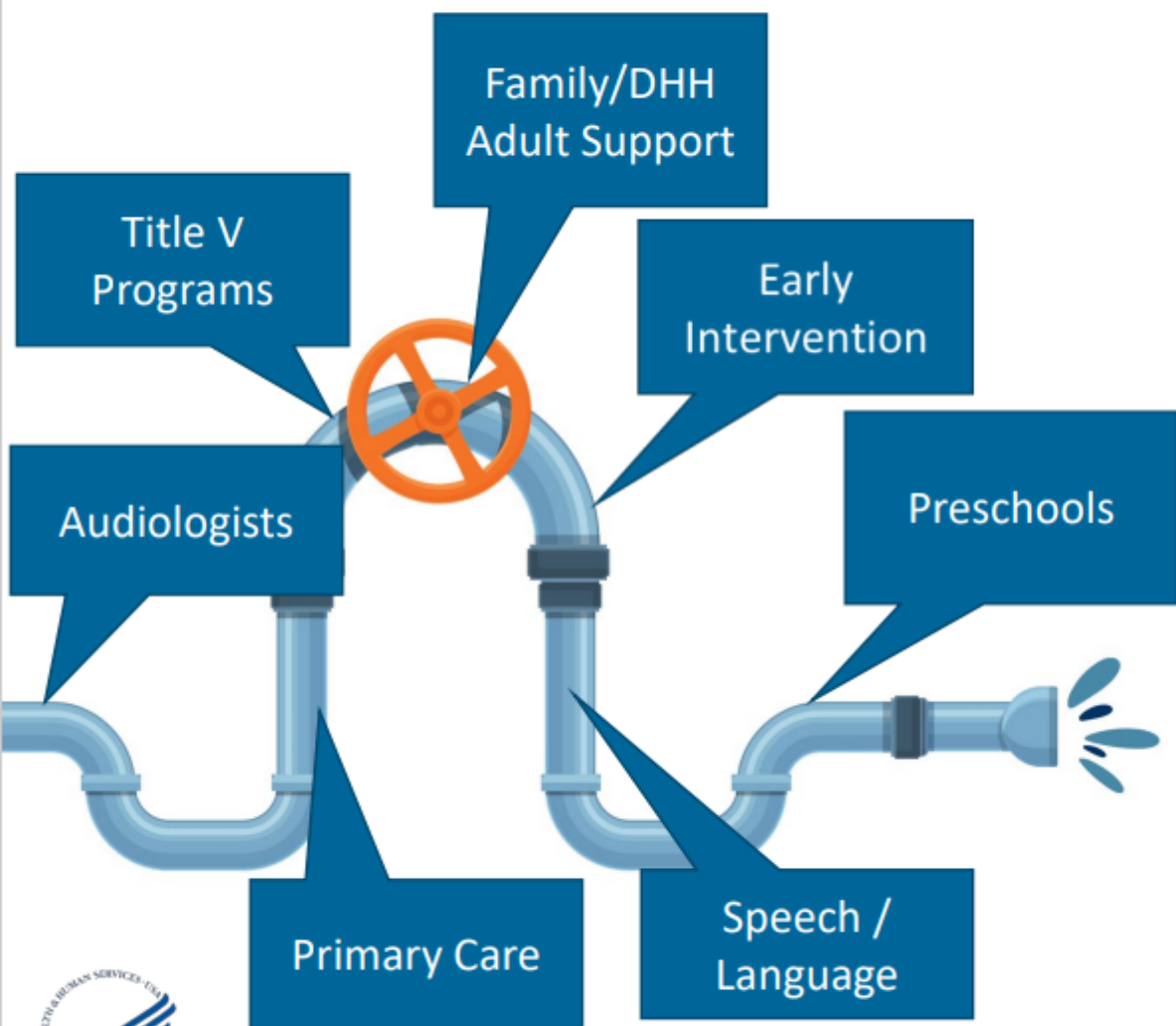
1. Inpatient newborn screening
2. Outpatient repeat screening
3. Diagnostic testing (by pediatric audiologist)
4. Specialty referral (ENT, genetics, ophthalmology)
5. Early Intervention referral



# EHDI Pipeline



# Everyone Helps Identify/Address the Leaks



## SYSTEMS LEVEL

Health equity, legislative support, financing systems, care integration . . .

## PROVIDER LEVEL

1-3-6 knowledge, workforce capacity, communication with families, guidance available, database capacity . . .

## PATIENT / FAMILY LEVEL

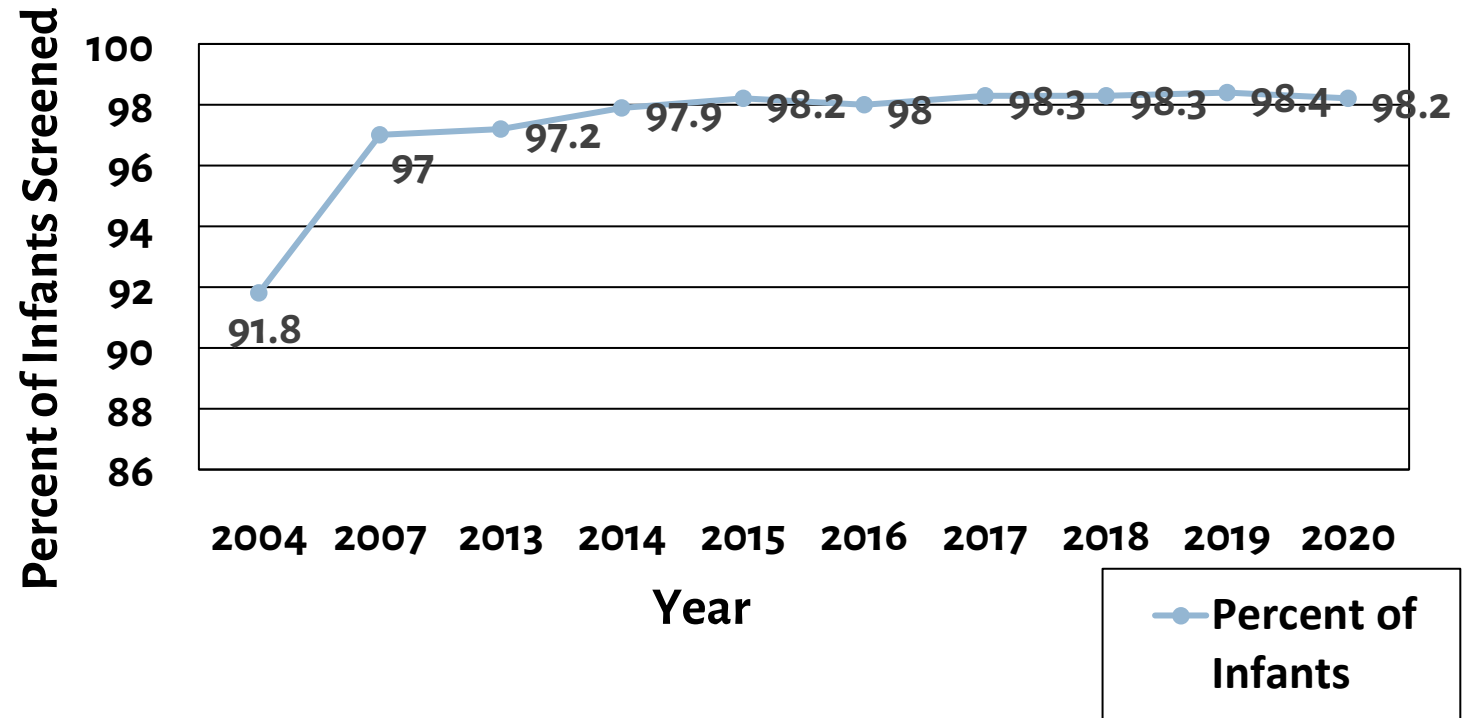
Competing needs, support network, financial support . . .



# National EHDI Data

Universal Newborn Hearing  
Screening

## Percent of Infants Receiving Hearing Screening: 2004-2020

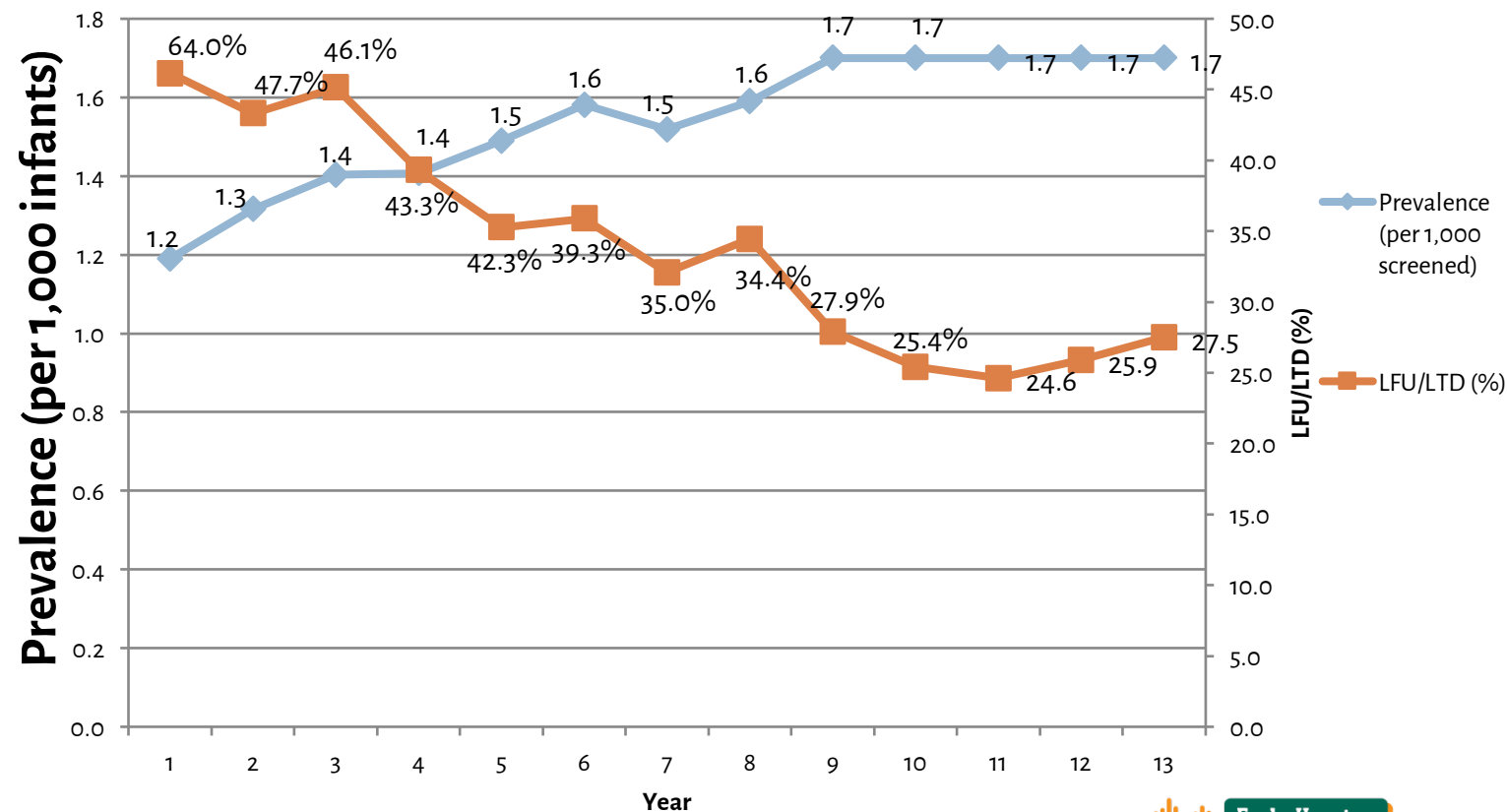


Source: 2020 Annual Data Early Hearing Detection and Intervention (EHDI) Program. Centers for Disease Control and Prevention. Accessed March 21, 2023. <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html>

# National EHDI Data

Incidence of Children who are D/HH

## Prevalence of Infants Identified as D/HH and Loss to Follow-up/Documentation, US, 2007-2019



Source: 2019 CDC Early Hearing Detection and Intervention (EHDI) Hearing Screening & Follow-up Survey (HSFS). Centers for Disease Control and Prevention. Accessed January 31, 2023. <https://www.cdc.gov/ncbddd/hearingloss/2019-data/01-data-summary.html>



## Status on Meeting 1-3-6 Goals



### 2020 National EHDI Data

- ❑ 97.2% screened before 1 month of age (n=3,413,238)
- ❑ 60.6% diagnosed before 3 months of age (n=25,466)
- ❑ 72.4% receiving Intervention before 6 months of age (n=2,797)
- ❑ 29.9% loss to follow-up or documentation for early intervention (n=20,970)



# EHDI in Arizona

1-3-6

Total births: 78,481

Screened: 76,952 (98%)

Passed screen: 75,687 (96.4%)

- 1839 passed after 1 month of age (2.4%)

Did not pass screen: 1312

- 232 normal hearing (18%)
- 192 permanent hearing loss (15%)
- 851 No diagnosis (64%)

Total not screened: 1529 (1.9%)

- 312 deceased (20%)
- 173 refused (11%)
- 864 unable to contact (57%)

192 hearing loss

- 113 diagnosed by 3 months (59%)
- 56 by 6 months
- 23 after 6 months

Referred to EI

- 143 by 6 months (74%)
- 11 after 6 months
- 38 not referred

2021

# Arizona Data

1

Screened  
98%

## 1265 Screened did not pass

- 686 Refer IP no OP-
- 308 Refer IP and OP
- 246 Refer IP direct Dx
- 20 No IP refer OP

3

1312 Refer for Dx  
-1265 Referred  
-47 Direct to Dx

## 461 Documented Dx

- 232 No Hearing Loss (135 <3 Mo, 97 >3 mo)
- 192 Permanent Loss (113 <3 mo, 79 >3 Mo)

6

192 Perm Loss  
154 Refer to EI

## 111 Enrolled

- 83 before 6 mo
- 28 age unknown

+

Parent to Parent  
192 Perm Loss  
173 Refer AZHV

66 Enrolled with  
written consent

## 1529 Not Screened

- 47 Direct to Dx
- 312 Infant Died
- 173 Parent declined
- 67 Parent Contacted unresponsive
- 867 No Contact

## 851 No Dx

- 14 Infant died
- 41 Non Resident
- 26 Parents Declined
- 97 Parent Contacted Unresponsive
- 673 No Contact

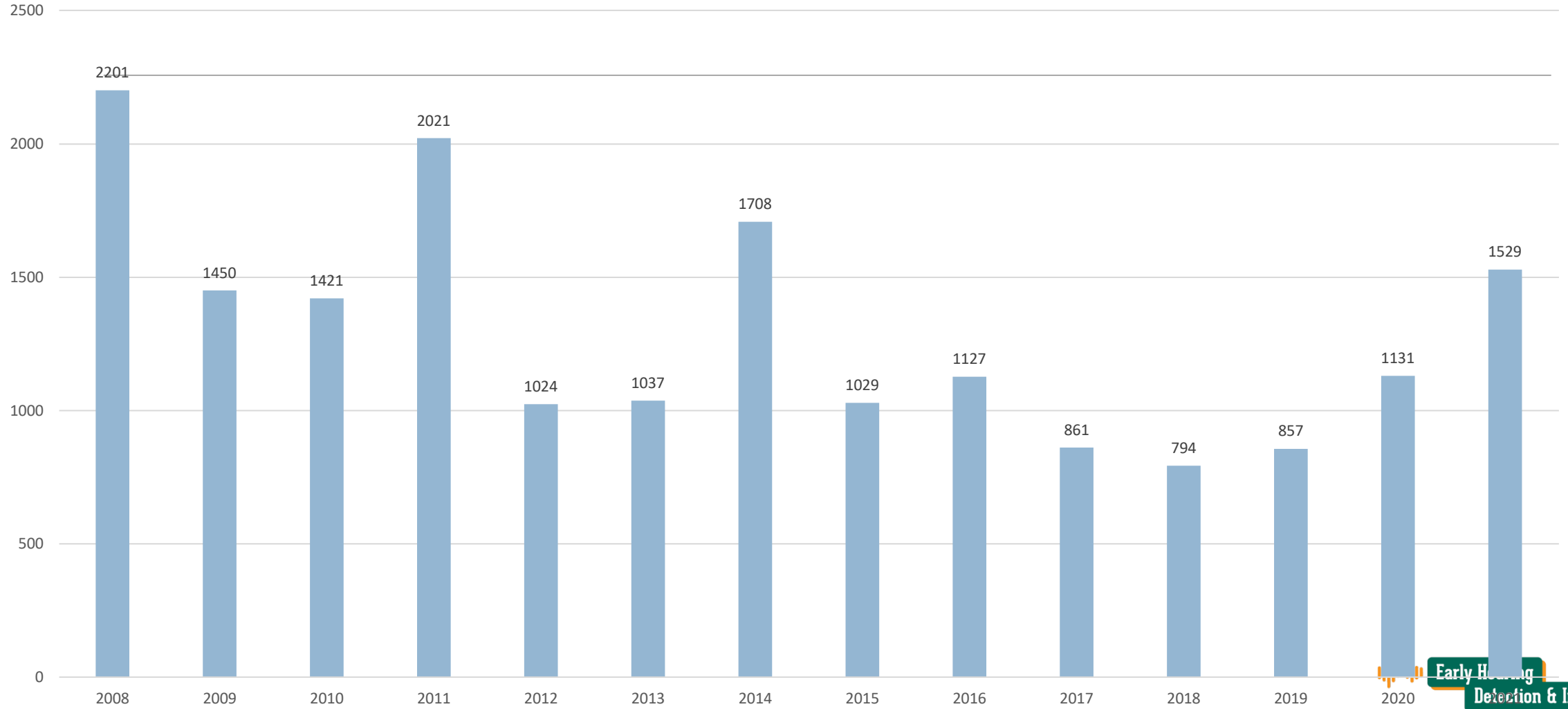
## 81 No EI

- 9 Dx changed no loss
- 12 Contacted Unresponsive
- 47 No Contact

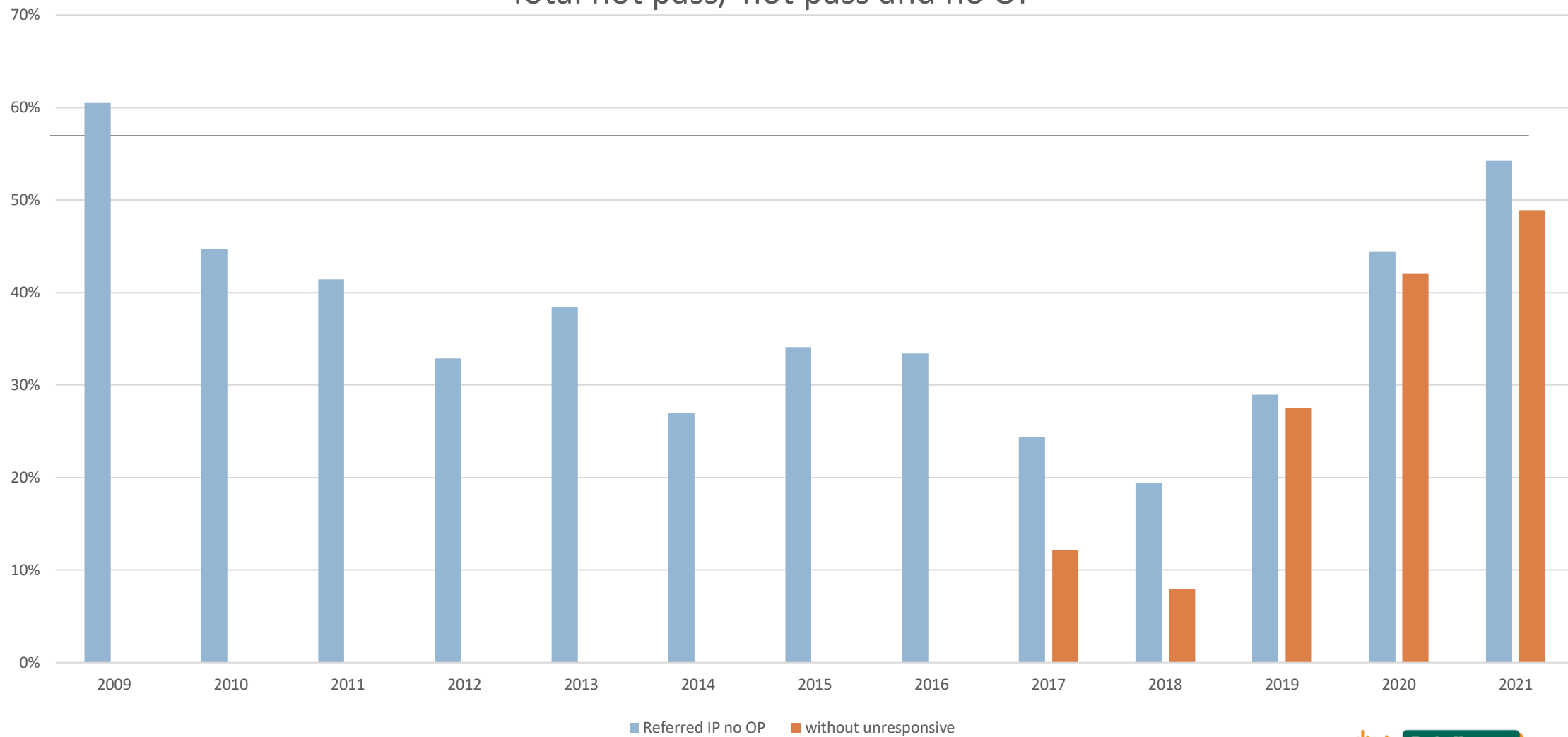
## 107 Not Enrolled

- 15 declined
- 4 Unresponsive
- 3 verbal consent only
- 53 No Contact (20 Incorrect or no contact info)

## # Not Screened by Birth Year

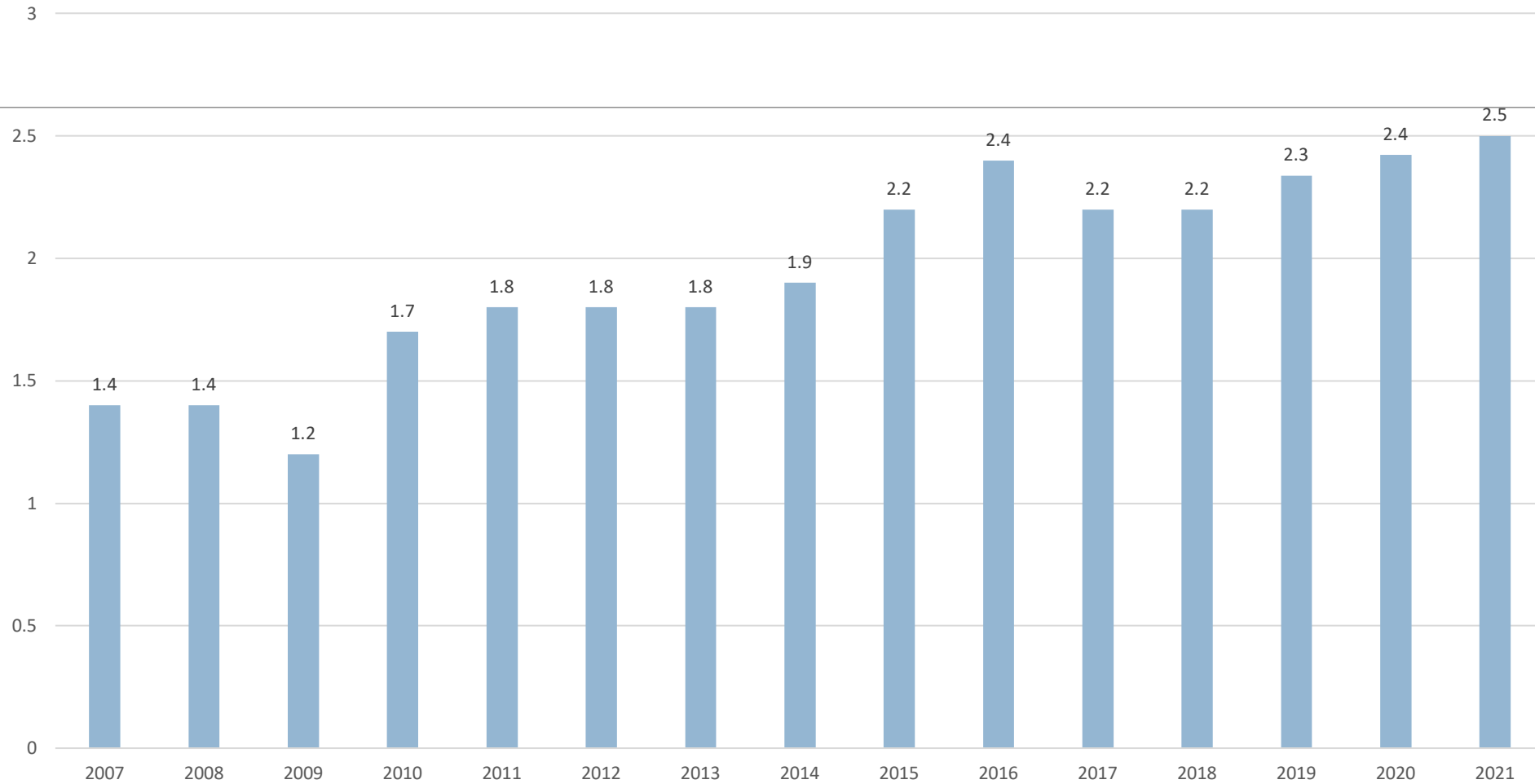


## Lost to Follow up Between IP and OP screen Total not pass/ not pass and no OP

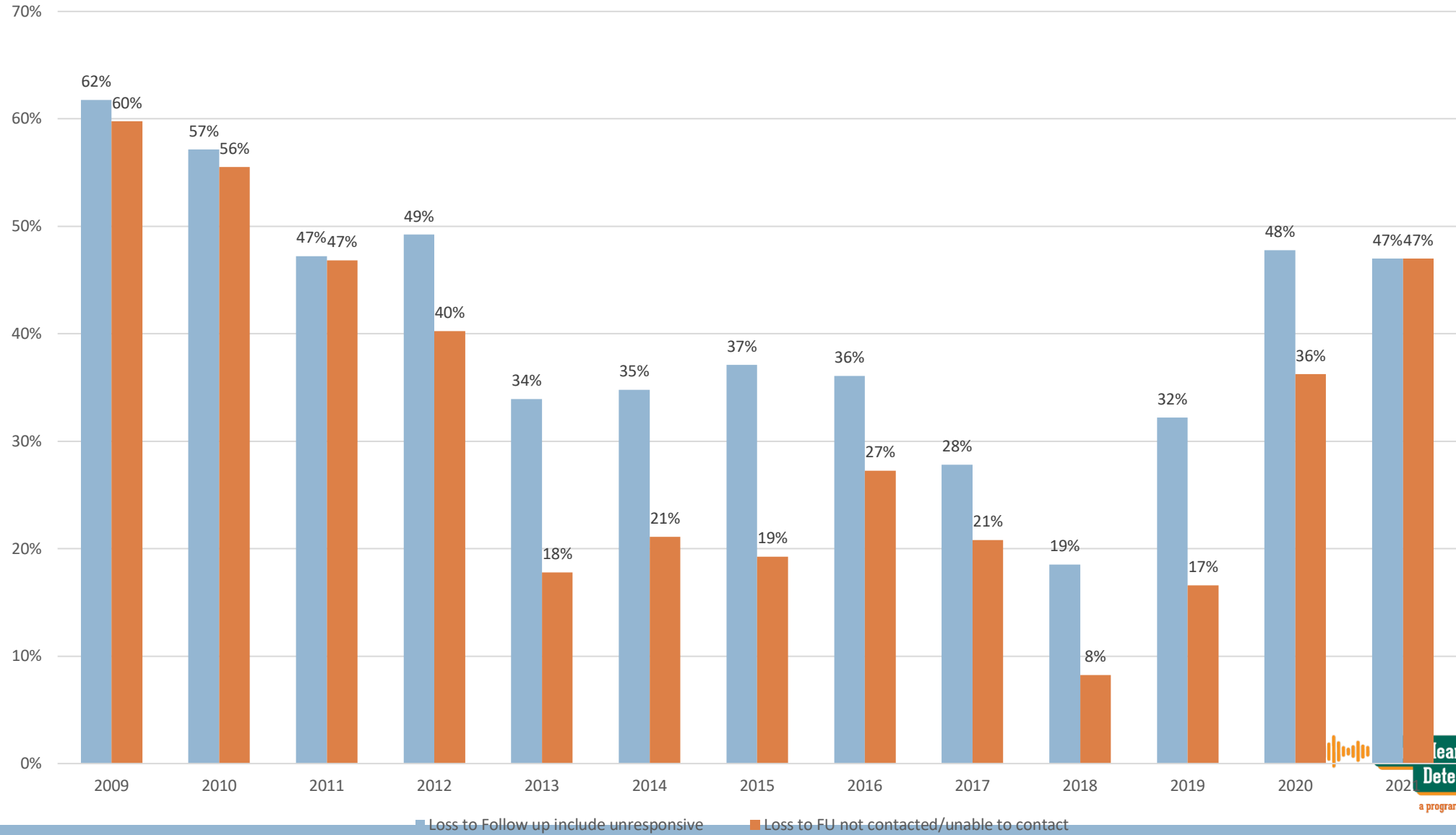


	2016	2017	2018	2019	2020	2021
Not contacted/ unable to contact	534	205	146	36	123	864

Prevalence- # of ID per 1000 births

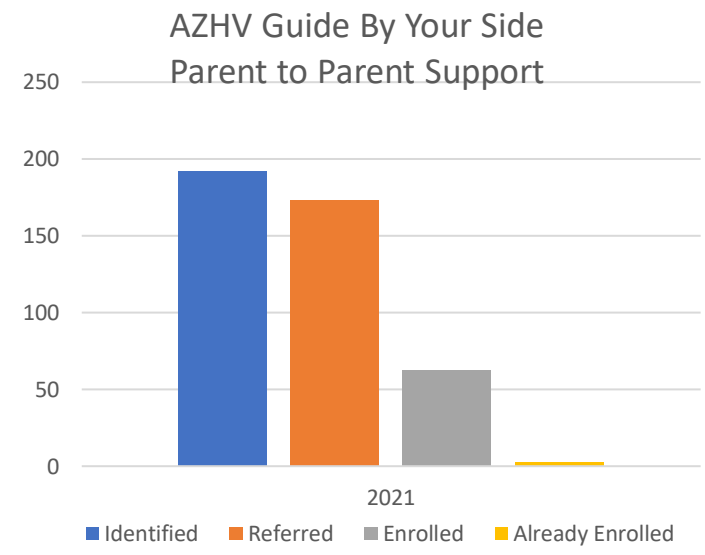
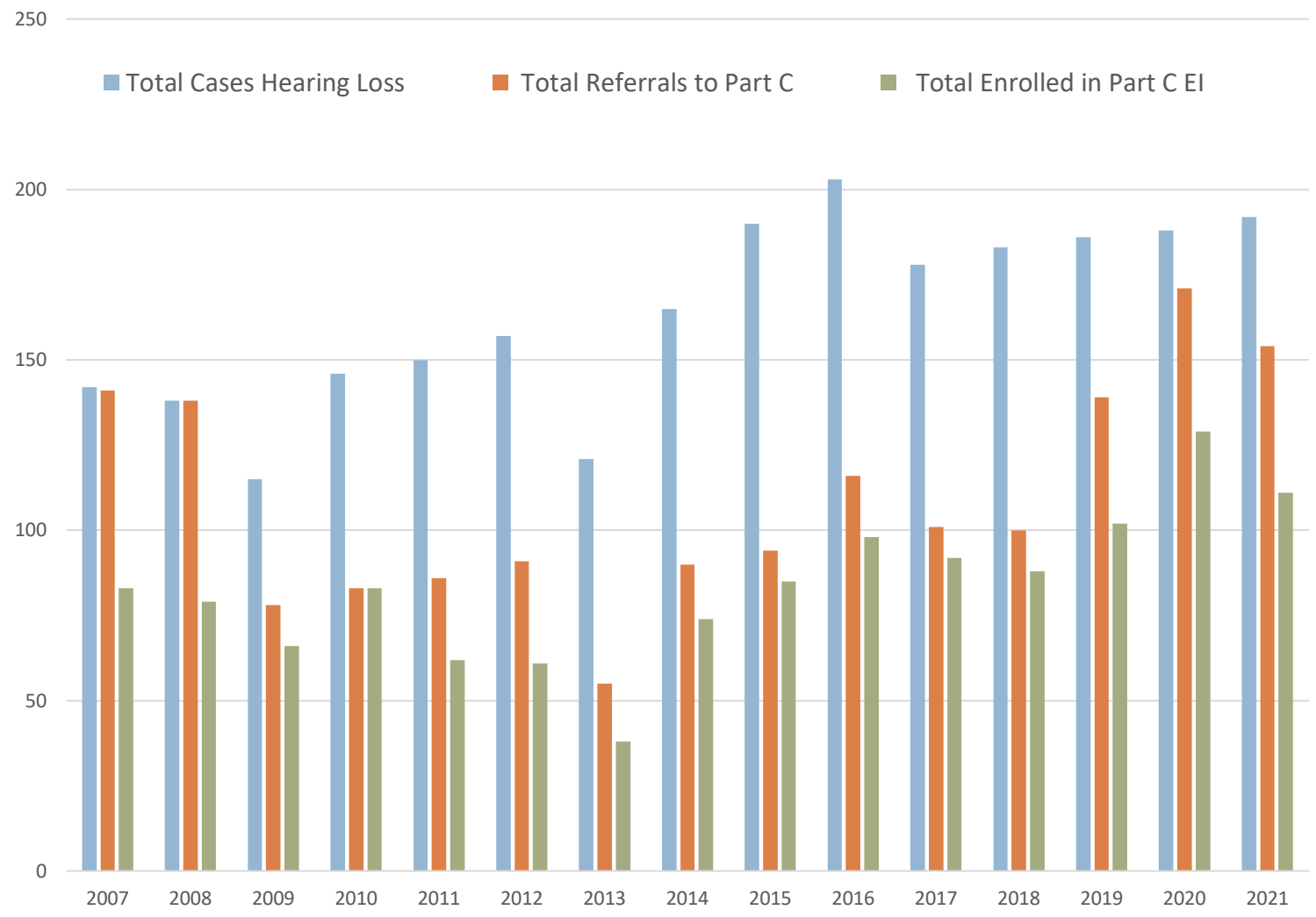


# Diagnostic-Lost to Follow up





### Total Bilateral Confirmed Loss, Referrals and Enrollment in Early Intervention - Part C of IDEA





# Delayed onset and Progressive Hearing Loss

Prevalence increases from 1.2:1000 newborns to 3:1000 by early school age

- Delayed onset or progressive hearing loss
- Missed conductive, sensory or neural hearing loss
  - Minimal or mild loss, unilateral loss
  - Loss to follow-up after refer on newborn screen

Patchwork of screening available (No universal objective screening)

- Often part of eligibility for Early Intervention
- Some home visiting programs offer hearing screening
- Early Head Start requires hearing screening
- Some primary care providers have equipment and screen as part of EPSDT
- Many ChildFind programs offer hearing screening

Risk Factors for late onset and progressive hearing loss

- #1 is caregiver concerns
- JCIH discusses high risk factors and recommendations for evaluation frequency
- Hearing loss can occur without known risk factors





# For Medical Home Providers

EHDI Algorithm  
1-3-6 Guidance

## 1-3-6 Guidance For Medical Home Providers





# For Medical Home Providers

EHDI Do's  
1-3-6 Guidance  
For Medical Home Providers

- DO** confirm that you receive hearing screening results from the hospital for every newborn you see.
- DO** ask about risk factors which can affect hearing levels when babies pass their newborn hearing screen and develop a plan for following these babies.
- DO** remember that a stay in the NICU is a risk factor and these babies should be followed closely even if they passed their hearing screen in the NICU.
- DO** confirm that every baby who refers on their newborn hearing screen sees a pediatric audiologist with the capability to perform a complete diagnostic evaluation by 3 months of age.
- DO** know where to turn to get EHDI resources in your state.

# For Medical Home Providers

EHDI Don'ts  
1-3-6 Guidance  
For Medical Home Providers

- ❑ **DON'T** delay referral for diagnostic testing if a baby has middle ear fluid.
- ❑ **DON'T** ignore a parent's concern that their baby may not be hearing or responding to sounds, even if that baby has passed their newborn hearing screen.



1-3-6 Guidance For Medical Home Providers:

[https://downloads.aap.org/AAP/PDF/EHDI%20Algorithm%20and%20ChartDoDont.pdf?\\_ga=2.251080846.985652545.1662640540-898940546.1543324236](https://downloads.aap.org/AAP/PDF/EHDI%20Algorithm%20and%20ChartDoDont.pdf?_ga=2.251080846.985652545.1662640540-898940546.1543324236)

# The Role of the Medical Home



## If there is any suspicion that an infant is D/HH...

- Do listen to parents concerns and refer immediately for full audiology evaluation for any parental worries about hearing or language development
- Encourage prompt follow-up with rescreens and diagnostic evaluations
- Make sure diagnostic evaluations are done by a pediatric audiologist
- Set up electronic medical record (EMR) system to include results of newborn hearing screening
- Flag all patient charts for children that:
  - require follow-up from a referral on newborn hearing screen
  - are at risk for late onset hearing loss



# The Role of the Medical Home

Risk Factor Identification and  
Management for Medical Home  
Providers

- The incidence of hearing loss increases after the newborn period
- Physicians are responsible for identifying risk factors and developing a follow-up plan
- A list of risk factors can be found in the JCIH statement **The Journal of Early Hearing Detection and Intervention 2019**
- Congenital cytomegalovirus is a common risk factor, and many states have screening programs
  - Know the expectations for your state  
**<https://www.nationalcmv.org/about-us/advocacy>**



# What is CMV?

Cytomegalovirus  
(sy·toe·MEG·a·low·vy·rus)

- Common virus that is usually harmless to healthy kids and adults but can cause cold-like symptoms (sore throat, fever, fatigue and swollen glands)
- Most adults have been infected with CMV by the time they are 40 years old
- **Common in children ages 1-3 years old**, especially if they attend day care
- *Herpesvirus*: Once you are infected, CMV stays in your body in an *inactive* (latent) state that *reactivates* (lytic state) throughout your life.

You or your child can have a **hidden infection with no signs or symptoms** (*asymptomatic*)



# When does CMV become a concern?

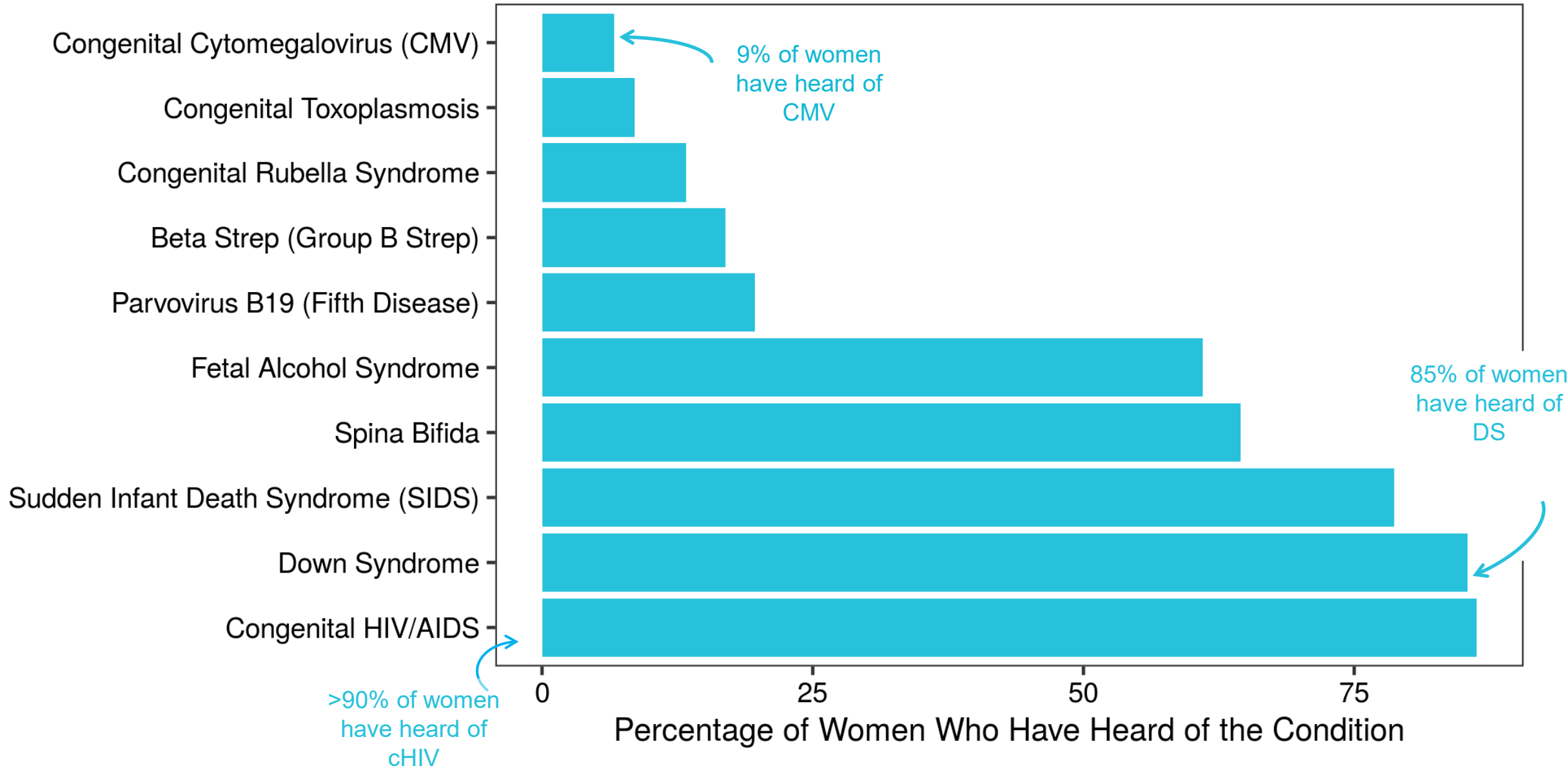
## Congenital CMV (cCMV)

- when a baby catches CMV before birth
- contact with the **saliva** or **urine** of a young child is a common cause CMV infection in pregnant women
- CMV can **survive on objects** long enough to be transmitted between people by touching surfaces



**CMV is preventable by following universal precautions (especially during pregnancy) (wash hands & clean surfaces often, kiss on top of head, use only your own utensils/cups)**

# Awareness of Congenital Conditions



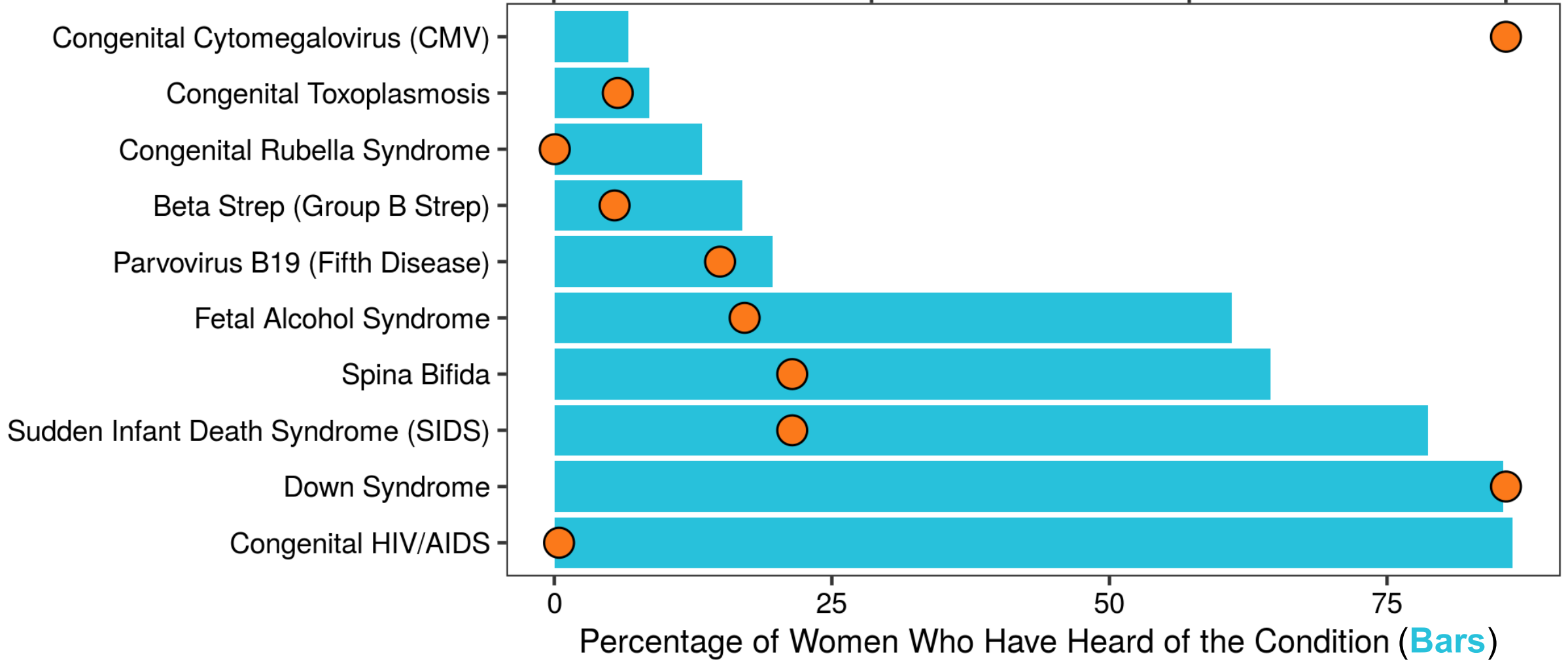
Based on US data from Doutré SM *et al.* (2016) Losing Ground: Awareness of Congenital Cytomegalovirus in the United States. *Journal of Early Hearing Detection and Intervention* 1:39-48. Chart by Artful Analytics, LLC (@\_sethdobson).



# Awareness vs Incidence of Congenital Conditions

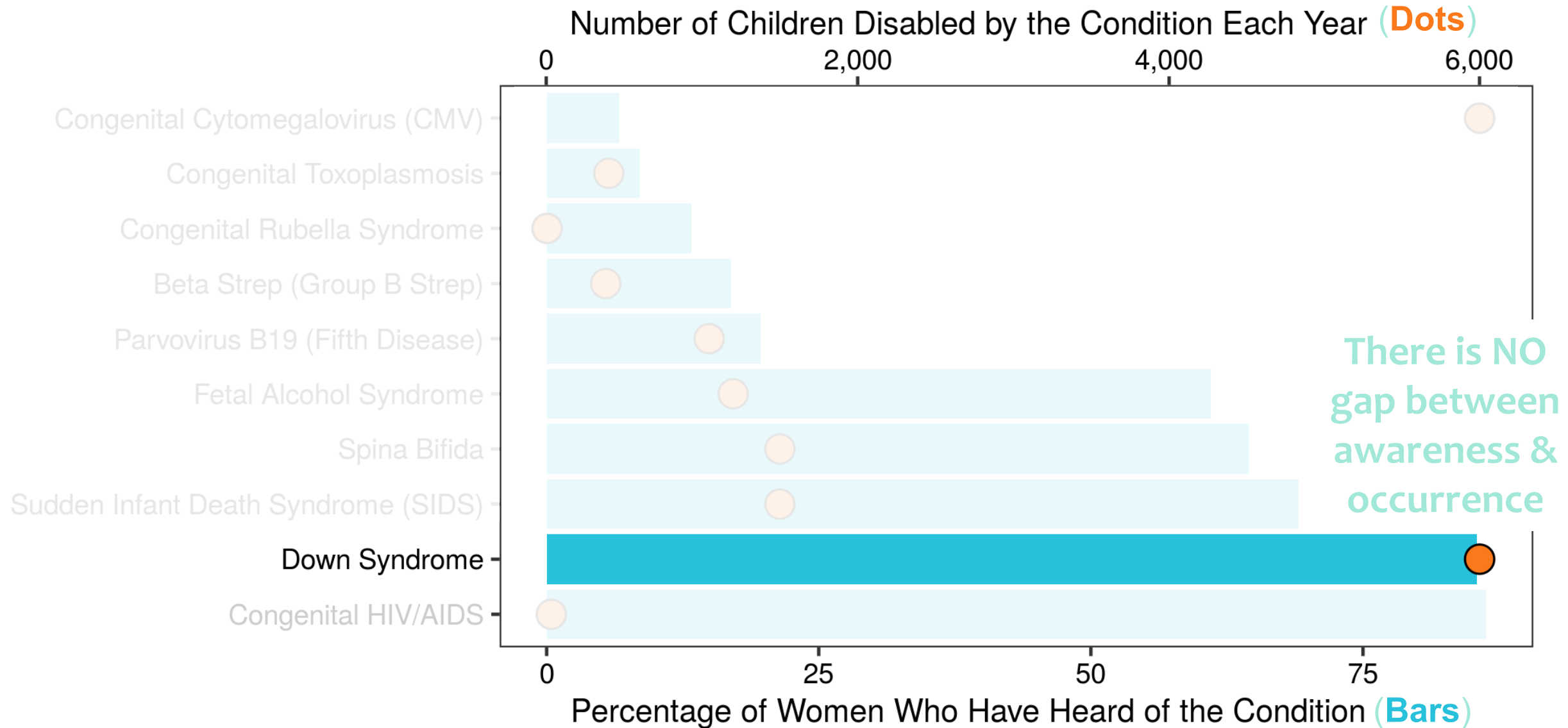
Number of Children Disabled by the Condition Each Year (**Dots**)

0 2,000 4,000 6,000



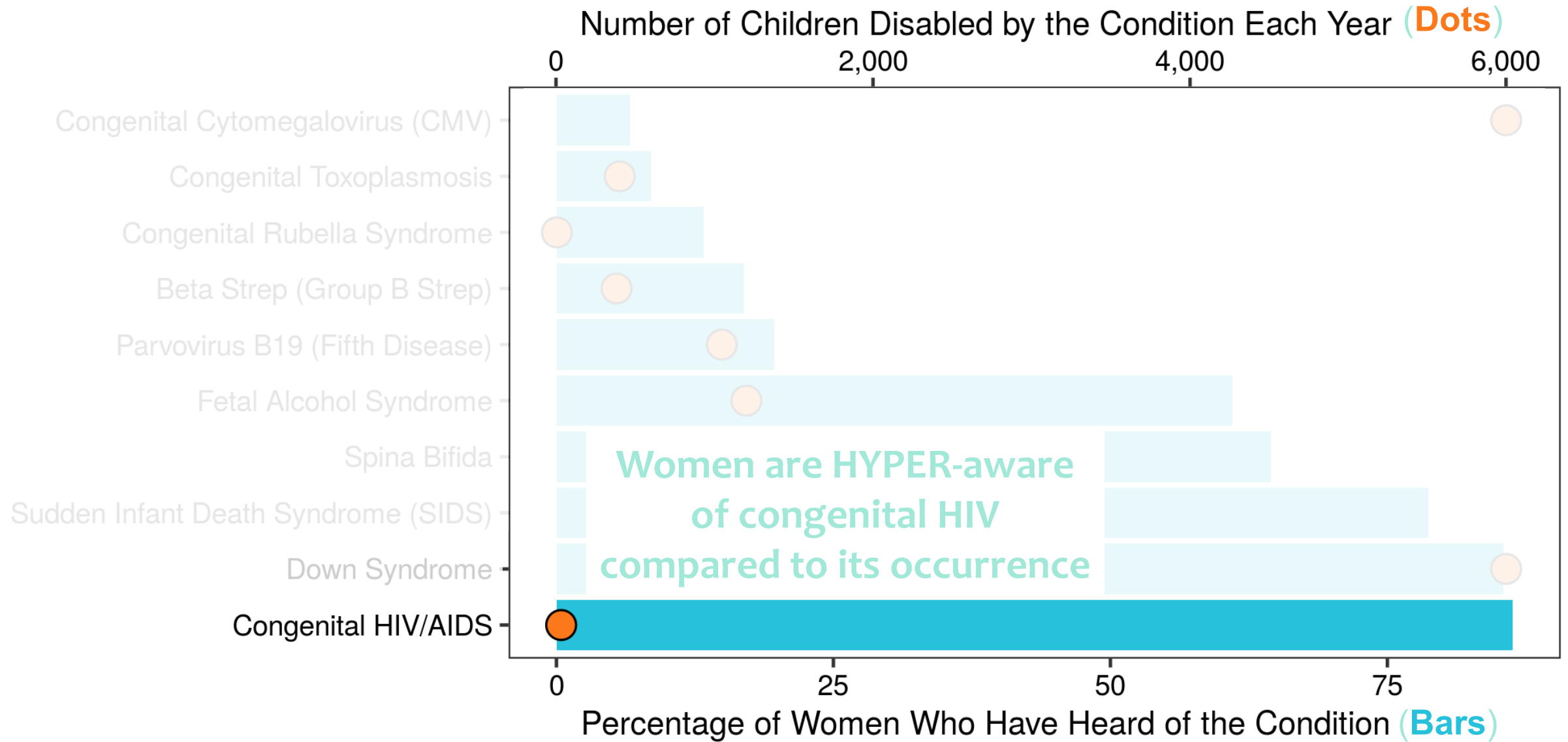
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# Awareness vs Incidence of Congenital Conditions

Number of Children Disabled by the Condition Each Year (**Dots**)

0 2,000 4,000 6,000

Congenital Cytomegalovirus (CMV)

Congenital Toxoplasmosis

Congenital Rubella Syndrome

Beta Strep (Group B Strep)

Parvovirus B19 (Fifth Disease)

Fetal Alcohol Syndrome

Spina Bifida

Sudden Infant Death Syndrome (SIDS)

Down Syndrome

Congenital HIV/AIDS

**CMV awareness gap**  
is a **public health crisis**

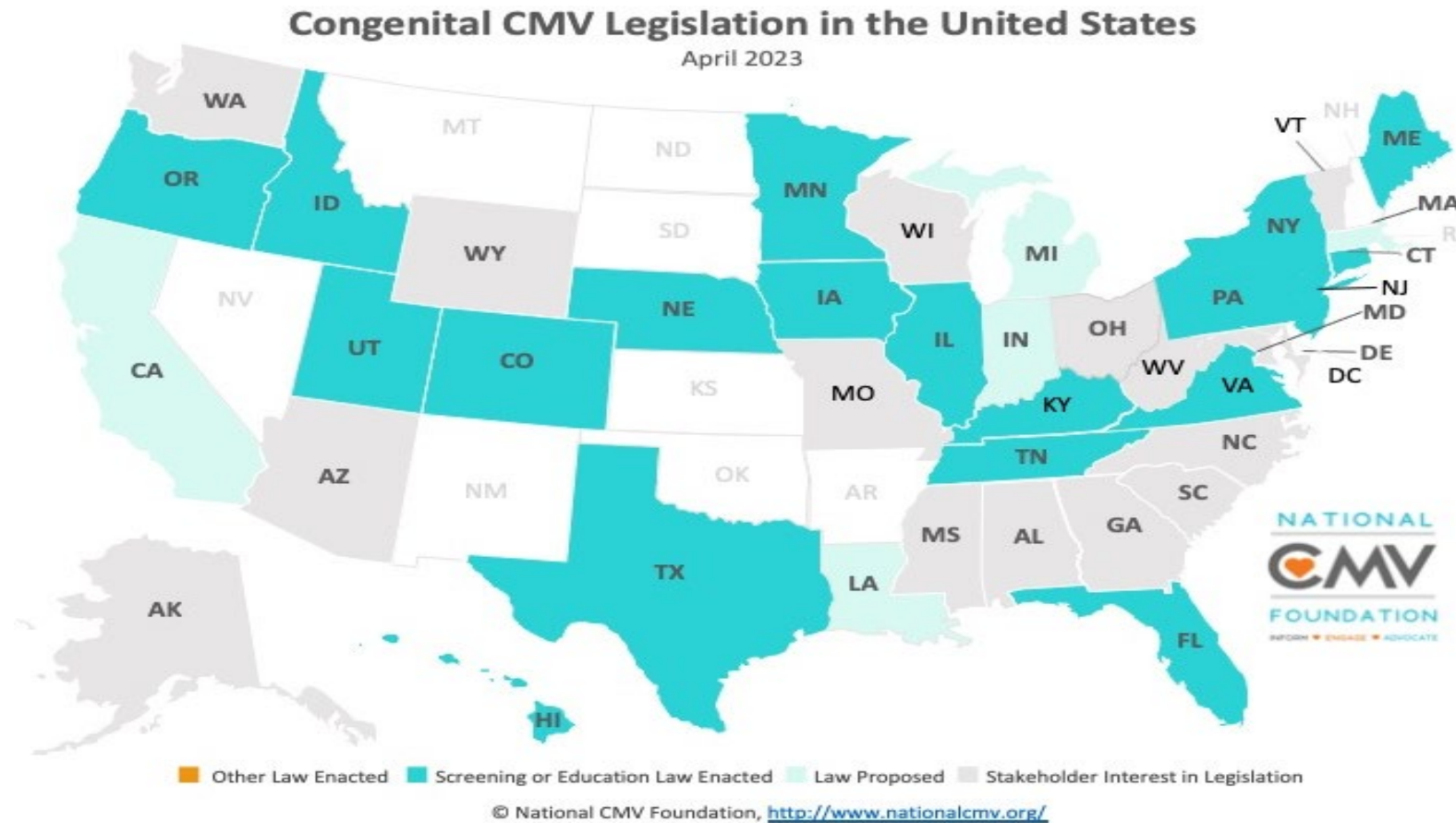
0 25 50 75  
Percentage of Women Who Have Heard of the Condition (**Bars**)



CMV Awareness Gap

Based on US data from Doutré SM *et al.* (2016) Losing Ground: Awareness of Congenital Cytomegalovirus in the United States. *Journal of Early Hearing Detection and Intervention* 1:39-48. Chart by Artful Analytics, LLC (@\_sethdobson). For more information, visit [nationalcmv.org](http://nationalcmv.org).

# cCMV Screening



# cCMV Screening

## Congenital CMV Legislation in the United States

April 2023



■ Other Law Enacted ■ Screening or Education Law Enacted ■ Law Proposed ■ Stakeholder Interest in Legislation

© National CMV Foundation, <http://www.nationalcmv.org/>





# The Role of the Medical Home

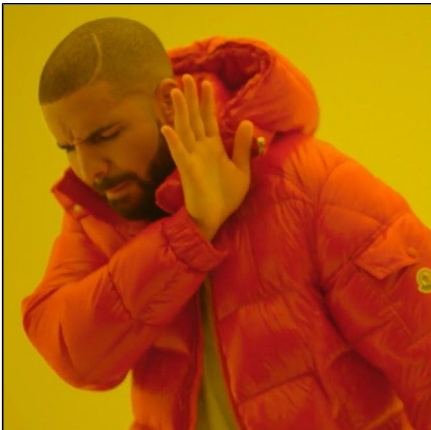


## Infants identified as D/HH

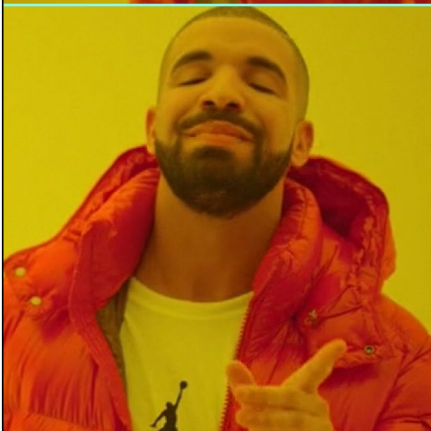
- Address the family's concerns
- Facilitate connection between family and an experienced pediatric audiologist
- Refer the family to appropriate specialists, such as
  - Otolaryngology, Genetics, Ophthalmology
- Help the family enroll in early intervention services and connect with family support
- Monitor developmental milestones paying particular attention to receptive and expressive language

# Pitfall Scenarios

## 1. “False positive”

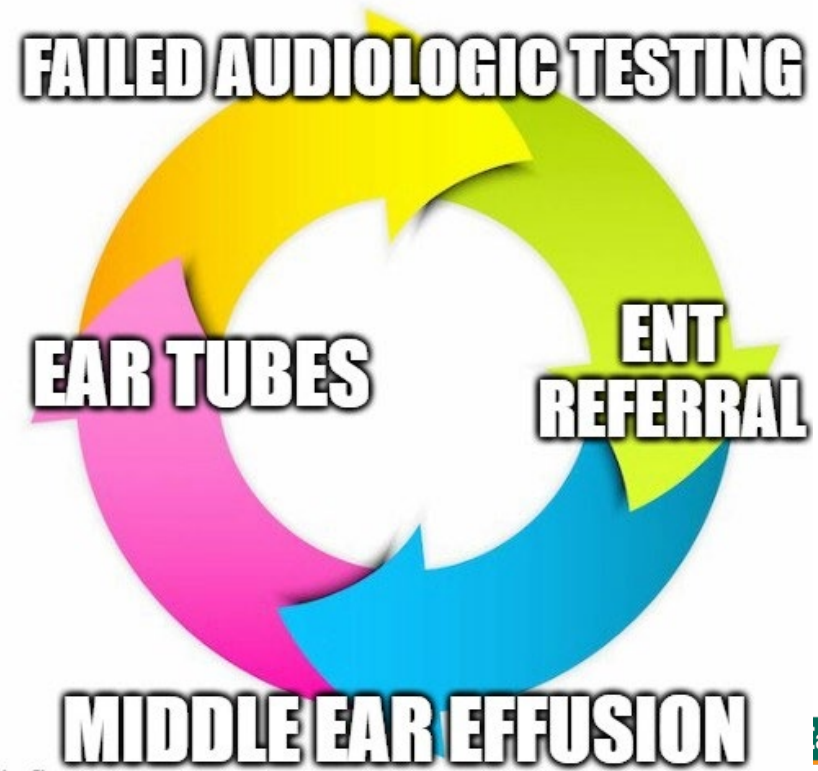


Reassure parents whose child failed their newborn hearing screen.



Ensure they get appropriate follow up testing

## 2. “ENT Loop”





# If your family needs more help

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Arizona Hands & Voices

Parent to parent support

Experts at

- Identifying resources
- Coaching parents on next steps
- Reassuring parents

[executivedirector@azhv.org](mailto:executivedirector@azhv.org)

**1-866-685-1050**



[www.ehdipals.org](http://www.ehdipals.org)

National Pediatric Audiology Links to Services

Web-based

Resources

- Finding audiology facilities
- Links to other helpful websites

# HEAR for Kids

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A program of the EAR Foundation

Funded by private donations and Vitalyst

Provides

- Loaner and permanent hearing aids
- Medical voucher to provide medical clearance
- Voucher for pediatric audiology assessment

[hearforkids@earfoundationaz.com](mailto:hearforkids@earfoundationaz.com)

602-690-3975



# Arizona Dept. of Health Services Office of Newborn Screening

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## Phone

(602) 364-1409

(800) 548-8381 - (outside Maricopa County)

## Fax

(602) 364-1495

## Website

<http://www.aznewborn.com/>

# EHDI Resources

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## AAP - [Early Hearing Detection and Intervention \(aap.org\)](http://www.aap.org)

- [EHDI The Role of the Medical Home presentation](#)
- [The EHDI Case Study presentation](#)

## JCIH - [www.jcih.org](http://www.jcih.org)

- Position statements and supplements

## EHDI Pals – [www.ehdipals.org](http://www.ehdipals.org)

- Directory of pediatric audiology resources

## EHDI National Technical Resource Center – [www.infanthearing.org](http://www.infanthearing.org)

- Technical assistance, training, evidence-based practices, family resources
- Run by NCHAM – National Center for Hearing Assessment and Management

## Hands and Voices – [www.handsandvoices.org](http://www.handsandvoices.org)

- Parent-led family support