EHDI in Arizona

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Disclosures

No financial conflicts

- General Overview of EHDI from national perspective
 - Include info on JCIH and 1-3-6
- Arizona specifics
 - plans/implementation
 - AZ data
- Role of Pediatrician/Medical Home
- Resources

EHDI Overview



Early identification, diagnosis, and referral to early intervention for a child who is D/HH is critical for ageappropriate 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 through2027
 - Includes GAO study of EHDI programs

One Hundred Seventeenth Congress of the United States of America

AT THE SECOND SESSION

Begun and held at the City of Washington on Monday, the third day of January, two thousand and twenty two

An Act

To reauthorize a program for early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Early Hearing Detection and Intervention Act of 2022".

SEC. 2. REAUTHORIZATION OF PROGRAM FOR EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.





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







Joint Committee on Infant Hearing 2019 Position Statement (www.jcih.org)



- Consensus organization convened 1969
- 2019 Most Recent Position Statement
- Implications for Early Intervention
- 2013 Supplement to the 2007 Statement: Specific to Early Intervention

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 multiorganizational committee. <u>www.jcih.org</u> Includes:

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



Public Health Principles

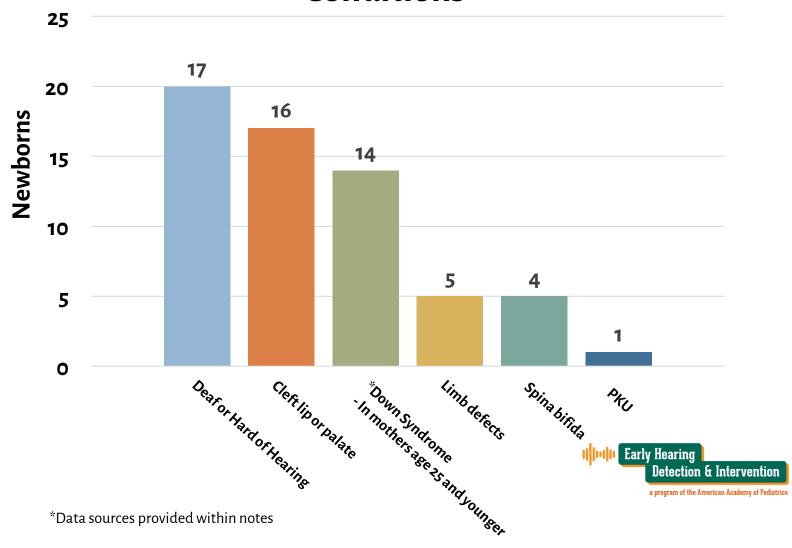
- Assess and monitor population health status, factors that influence health, and community needs and assets
- Investigate, diagnose, and address health problems and hazards affecting the population
- Communicate effectively to inform and educate people about health, factors that influence it, and how 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

JCIH 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

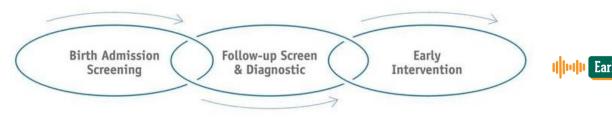


EHDI 1-3-6 Goals

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



Detection & Intervention

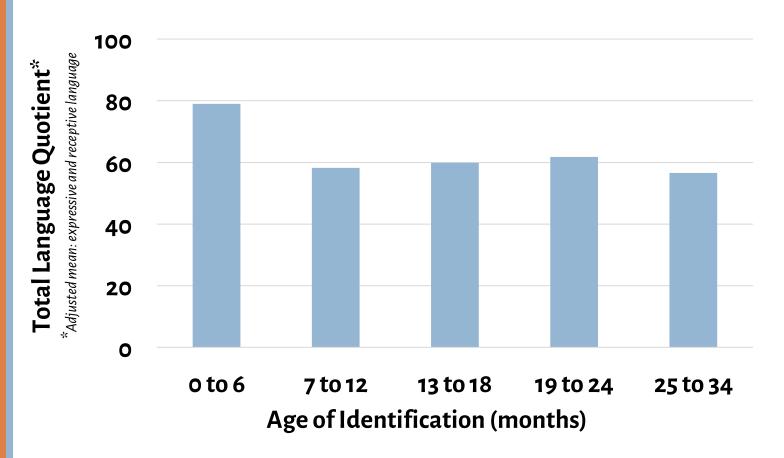
a program of the American Academy of Pediatrics

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 EHDI Programs



- Every state and territory in the US has now established an EHDI 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
- EHDI program staff are responsible for creating, operating, and continuously improving a system of services which assures that the national EHDI goals are met
- State EHDI Laws and Regulations: Federal Early Hearing Detection & Intervention Legislation | NCHAM (infanthearing.org)
- NCHAM State Resource Page: http://www.infanthearing.org/states_home/

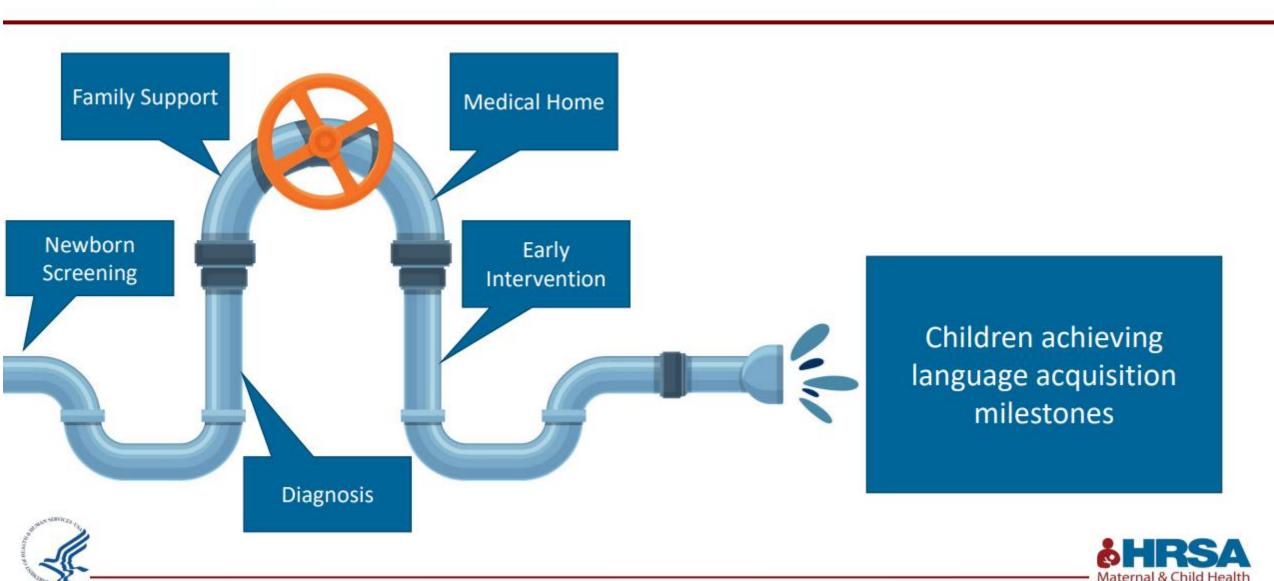


EHDI Program Components

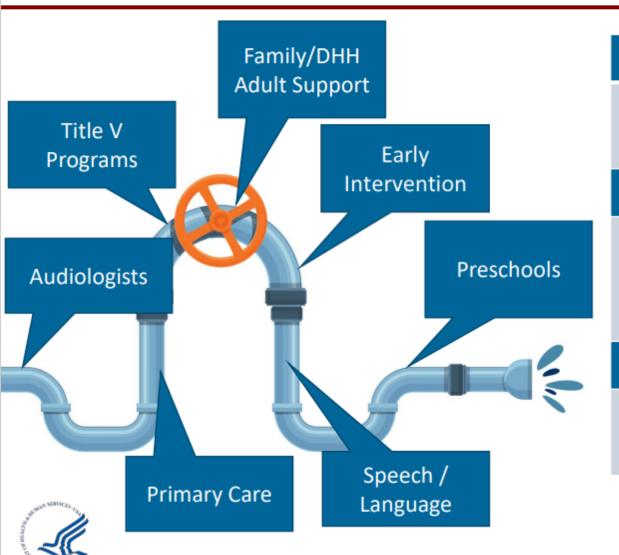
- Universal Newborn Hearing Screening
- Medical Home
- Diagnostic Pediatric Audiology
- Specialty Referrals
- Early Intervention
- ☐ Family-to-Family
- □ D/HH Adult-to-Family Support
- Tracking and Data Management



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

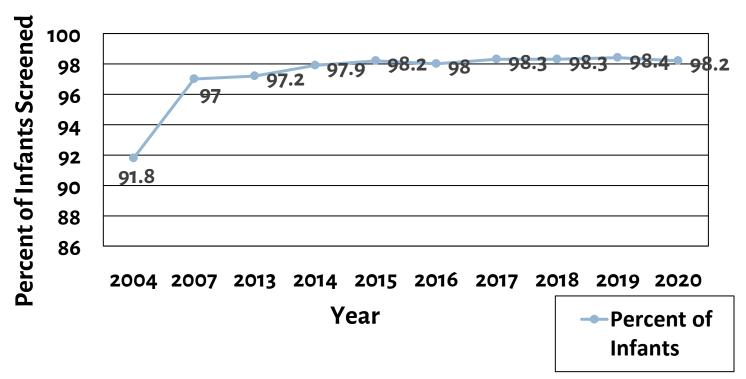
Competing needs, support network, financial support . . .



National EHDI Data

Universal Newborn Hearing Screening

Percent of Infants Receiving Hearing Screening: 2004-2020



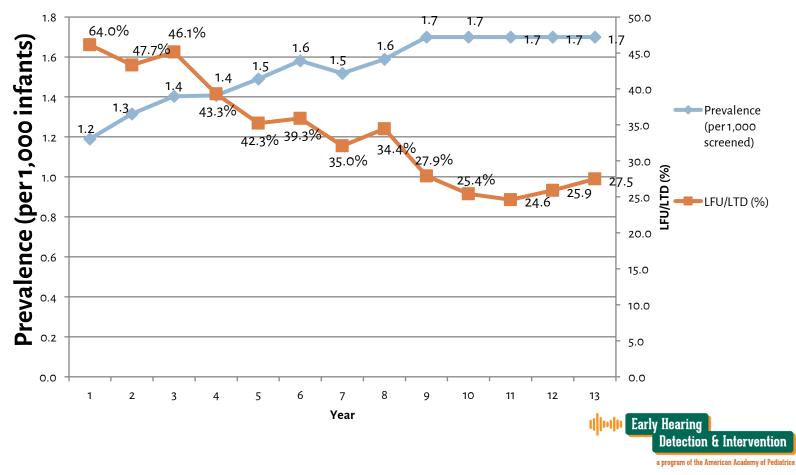


Source: 2020 Annual Data Early Hearing Detection and Intervention (EHDI) Program. Centers for Disease Control and Prevention. Accessed March 21, 2023. https://www.cdc.gov/ncbddd/hearingloss/ehdidata.html

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

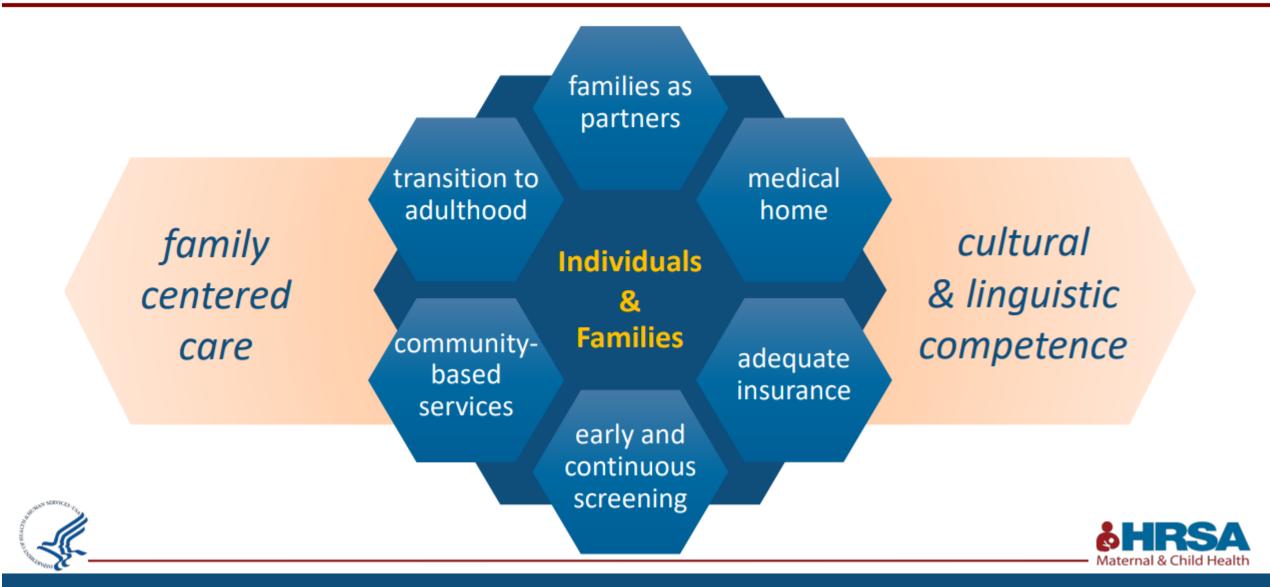


2020 National EHDI Data

- \square 97.2% screened before 1 month of age (n=3,413,238)
- \square 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)



Six Indicators of a Well-Functioning System



EHDI in Arizona

EHDI in Arizona

- Flowchart
 - Total births: screened/not screened
 - Screened: Passed/failed
 - Failed: Followed up/Lost
 - Followed up: Confirmed hearing loss/Normal
 - Other categories I am missing?

Screened 98%

1312 Refer for Dx

- -1265 Referred
- -47 Direct to Dx

6 192 Perm Loss 154 Refer to El

Parent to Parent 192 Perm Loss 173 Refer AZHV

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

461 Documented Dx

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

111 Enrolled

- -83 before 6 mo
- -28 age unknown

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 El

- -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)

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

Newborn Hearing Screening

- 1 Screen for hearing loss by one month of age
- 3 Diagnose hearing loss by three months of age
- 6 Enroll in early intervention programs before six months of age



Expectations of Medical Home

- AAP says EHDI is priority and 1-3-6 is still the expectation
- Help family (well baby) get second screen
- Coordinate referrals for Audiology/ENT
 - Appropriate Pediatric Audiology practice
 - Assure rule out Sensorineural hearing loss (Deaf kids have Otitis Media too)

If your family needs more help

Arizona Hands & Voices

- Parent to parent support
- Experts at
 - Identifying resources
 - Coaching parents on next steps
 - Reassuring parents

executivedirector@azhv.org

gbys@azhv.org

1-866-685-1050



- www.ehdipals.org
- National Pediatric Audiology Links to Services
- Web-based
- Resources
 - Finding audiology facilities
 - Links to other helpful websites





- 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
- 602-690-3975

Arizona Dept. of Health Services Office of Newborn Screening



Phone

- (602) 364-1409
- (800) 548-8381

(outside Maricopa County)

Fax

• (602) 364-1495

Website

http://www.aznewborn.com/

EHDI Resources

www.jcih.org

Position statements and supplements
 Add sentence description instead of bullets

www.ehdipals.org

Directory of pediatric audiology facilities and family resources

www.infanthearing.org

- National Center for Hearing Assessment and Management
- National Technical Assistance Center for EHDI

www.handsandvoices.org/fl3

- Hands & Voices
- Family Leadership in Language and Learning Center
- Parent lead family support