

Summary of 2019 National CDC EHDI Data

Data Source: 2019 CDC Early Hearing Detection and Intervention (EHDI) Hearing Screening & Follow-up Survey (HSFS)

Background: The CDC's National Center on Birth Defects and Developmental Disabilities promotes the health of babies, children, and adults, with a focus on preventing birth defects and developmental disabilities and optimizing the health outcomes of those with disabilities. As part of these efforts the Center is actively involved in addressing the early identification of permanent hearing loss among newborns and infants. Hearing loss affects between 1 and 2 per 1,000 infants in the United States and when left undetected, it can delay a child's speech and language, social, and emotional development.¹ To ensure children with permanent hearing loss are identified as soon as possible, states and territories have implemented Early Hearing Detection and Intervention (EHDI) programs. These EHDI programs work to ensure all infants are screened for hearing loss, ideally before 1 month of age, receive diagnostic audiologic evaluation (for those not passing the screening), ideally before 3 months of age, and enrolled in early intervention (for those identified with permanent hearing loss), ideally before 6 months of age.² The Hearing Screening & Follow-up Survey is a voluntary survey sent out annually by the CDC to each state and territorial EHDI program that requests, non-estimated hearing screening, diagnostic, and intervention information on infants born in a specified calendar year (e.g., 2019). The survey helps to assess the progress of EHDI efforts to identify infants with permanent hearing loss across the United States. This summary of the 2019 HSFS highlights EHDI related information for babies born between January 1, 2019 and December 31, 2019.

Number of Survey Respondents: 55^a (47 states, 7 territories, 1 district) AK, American Samoa, AZ, AR, CA, Commonwealth of the Northern Mariana Islands, CT, DE, District of Columbia, FL, GA, Guam, HI, ID, IL, IN, IA, KS, KY, LA, ME, Marshall Islands, MD, MA, MI, Micronesia, MN, MO, MT, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OK, OR, Palau, PA, Puerto Rico, RI, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY

¹American Speech-Language-Hearing Association (ASHA). Effects of hearing loss on development. Available at: <https://www.asha.org/public/hearing/effects-of-hearing-loss-on-development>. Accessed April 8, 2021

²Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs (2019). *Journal of Early Hearing Detection and Intervention*, 4(2), 1-44. <https://digitalcommons.usu.edu/jehdi/vol4/iss2/1/>

Summary of 2019 National CDC EHDI Data

2019 Documented EHDI Data Items	
Total Occurrent Births (according to state & territorial EHDI programs)	3,604,761
Documented Hearing Screening	
Percent Screened	98.4% (n = 3,545,388) (Range: 88.9% - 99.9%)
o Percent Screened (excluding infant deaths & parental refusals)	98.9%
o Percent Screened before 1 Month of Age	97.7% (n = 3,463,600)
Percent Not Passing final / most recent screening	1.7% (n = 61,475)
No Documented Hearing Screening	
Percent w. No Documented Screening:	1.6% (n = 59,373)
Documented Diagnosis	
Percent Diagnosed	62.0% (n = 38,127) (Range: 0.0 - 100.0%)
o Percent with No Hearing Loss (i.e., no diagnosed hearing loss)	52.4% (n = 32,193)
o Percent with Permanent Hearing Loss	9.7% (n = 5,934)
o Percent Diagnosed (normal hearing + permanent hearing loss) before 3 Months of Age	79.1% (n = 30,170)
Prevalence of Permanent Hearing Loss	1.7 per 1,000 screened
No Documented Diagnosis	
Percent w. No Documented Diagnosis	38.0% (n = 23,348)
o In Process	2.1% (n = 1,306)
o Infant Died / Parents Declined	3.3% (n = 2,038)
o Non-Resident / Moved	3.0% (n = 1,817)
o Overall Percent Loss to Follow-up (LFU) / Loss to Documentation (LTD) for Diagnosis*	27.5% (n = 16,893) (Range: 0.0 - 91.4%)
▪ LFU/LTD = # Parents/Family Contacted but Unresponsive (5,219) + # Unable to Contact (3,723) + # Unknown (7,951)	
▪ Percent LFU / LTD for Diagnosis : Due to Unable to Contact and Unknown	19.0% (n = 11,674)
▪ Percent Unresponsive for Diagnosis : Due to Parents/Family Contacted but Unresponsive	8.5% (n = 5,219)
Other Cases of Hearing Loss	
Number of Additional Cases (e.g., late-onset hearing loss & infants not screened at birth)	n = 395
Number of Cases of Non-Permanent / Transient Hearing Loss	n = 930
Documented Referral to Early Intervention (EI)	
Percent Referred to Part C EI (of those with hearing loss)	84.8% (n = 5,034)
Percent Not Referred to Part C and Unknown (of those with hearing loss)	9.0% (n = 533)
Documented Enrollment in EI	
Percent Enrolled in EI (Part C & Non-Part C)	61.7% (n = 3,662) (Range 0.0% - 82.4%)
o Enrolled in EI = # in Part C EI (3,564) + # in Non-Part C EI (98)	
o Percent Enrolled in EI before 6 Months of Age (Part C & Non-Part C)	72.5% (n = 2,654)
No Documented Enrollment in EI	
Percent w. No Documented EI Services	37.8% (n = 2,241)
o Infant Died / Parents Declined	10.0% (n = 594)
o Non-Resident / Moved	2.4% (n = 140)
o Not Eligible for Part C Services	2.3% (n = 139)
o Overall Percent Loss to Follow-up (LFU) / Loss to Documentation (LTD) for EI*	19.1% (n = 1,135) (Range 0.0 - 98.3%)
▪ LFU/LTD = # Parents/Family Contacted but Unresponsive (124) + # Unable to Contact (282) + # Unknown (729)	
▪ Percent LFU / LTD for EI: Due to Unable to Contact and Unknown	17.0% (n = 1,011)
▪ Percent Unresponsive for EI: Due to Parents/Family Contacted but Unresponsive	2.1% (n = 124)

Notes:

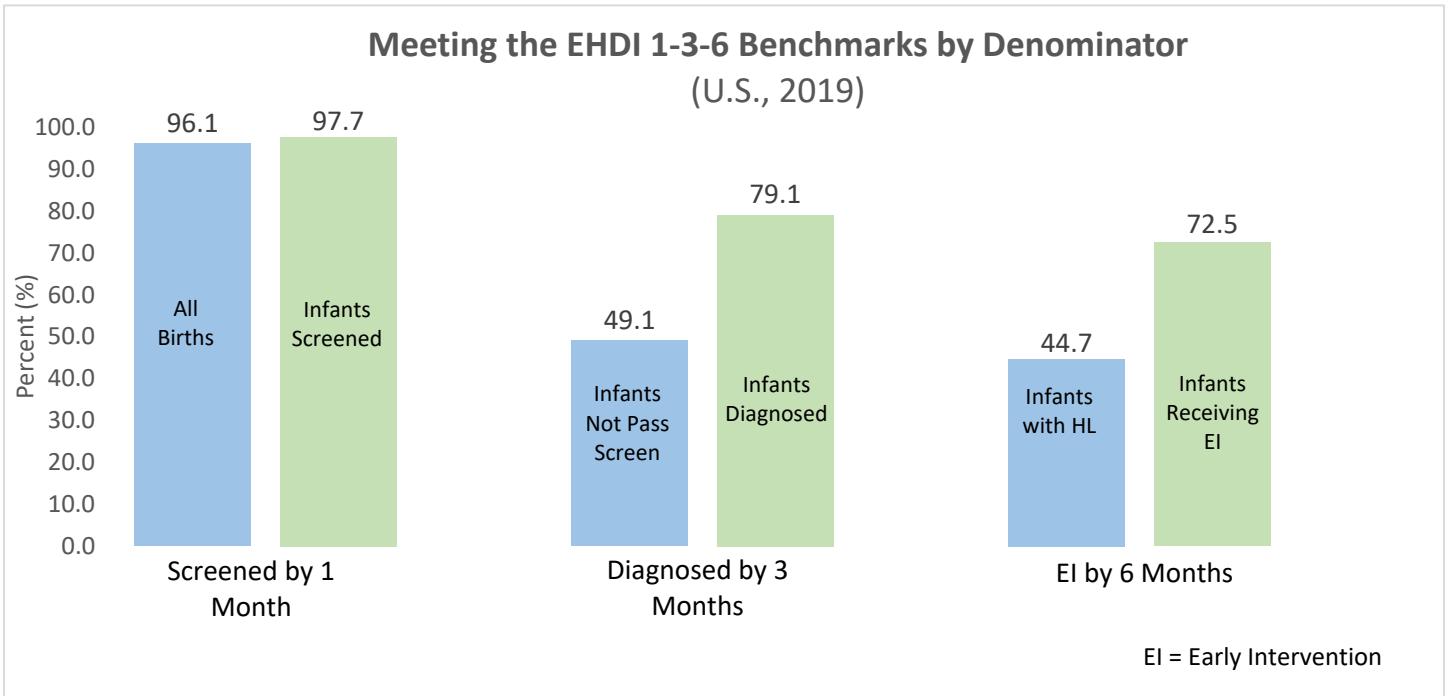
-In many regions the COVID-19 pandemic interrupted the delivery of health care services in 2020, including newborn hearing screening and follow-up services. As a result, infants born in late 2019 and needing hearing screening and/or follow-up services in 2020 may have had difficulties obtaining these services.

*All of the 55 states and territories responded to each part of the survey ∞ Respondents had the option to either use the revised definition or previous version for the field "Parents/Family Contacted but Unresponsive." 46 jurisdictions used the revised definition for the 2019 HSFS.

-Please see pages 5-6 for an explanation of the calculations for the above EHDI data items.

For summaries by jurisdiction, please visit: www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

Summary of 2019 National CDC EHDl Data



Note: Label inside each bar represents the denominator used (e.g., All Births or Infants Screened). Please see below for calculations.

1-3-6 Formulas (different denominators allow for review of status and progress based on different but relevant criteria)

Screened by 1 Month (*Denominator*: of all births):
 $3,463,600$ (# pass before 1 month + # not pass before 1 month) / $3,604,761$ (births reported by EHDl) x 100 = 96.1%
 Mean: 95.8
 IQR: (95.3-97.2)

Screened by 1 Month (*Denominator*: of infants screened):
 $3,463,600$ (# pass before 1 month + # not pass before 1 month) / $3,545,388$ (# screened) x 100 = 97.7%
 Mean: 97.6
 IQR: (97.3-98.4)

Evaluated by 3 Months (*Denominator*: of infants not pass screen):
 $30,170$ (# diagnosed with no hearing loss before 3 months + # with permanent hearing loss before 3 months) / $61,475$ (infants not pass screen) = 49.1%
 Mean: 39.6
 IQR: (26.4-56.2)

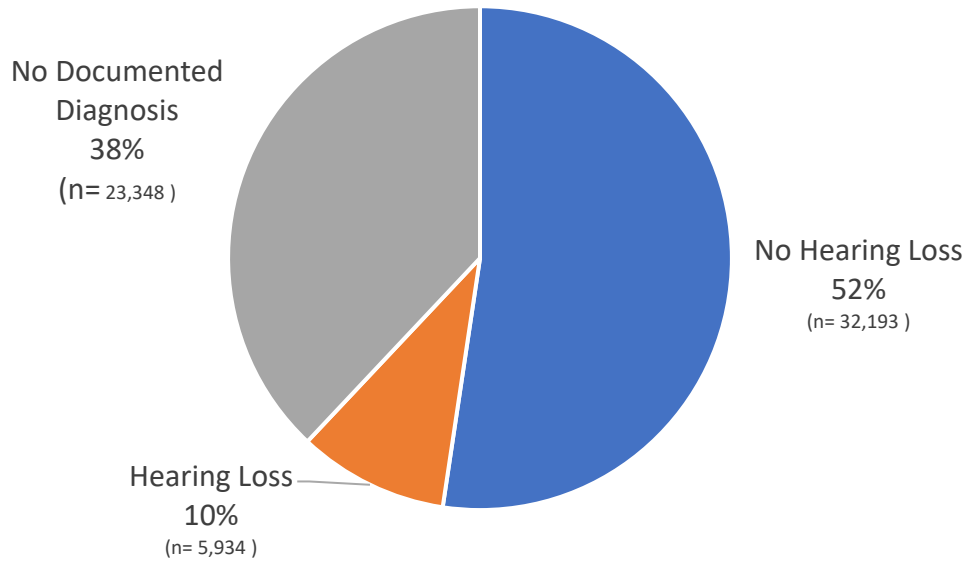
Evaluated by 3 Months (*Denominator*: of infants evaluated):
 $30,170$ (# diagnosed with no hearing loss before 3 months + # diagnosed with permanent hearing loss before 3 months) / $38,127$ (# w. documented diagnostic evaluation) x 100 = 79.1%
 Mean: 71.1
 IQR: (60.4-81.8)

Early Intervention by 6 Months (*Denominator*: of infants with permanent hearing loss):
 $2,654$ (# enrolled in Part C EI before 6 months + # in Non-Part C EI before 6 Months) / $5,934$ (with permanent hearing loss) x 100 = 44.7%
 Mean: 41.5
 IQR: (36.0-50.0)

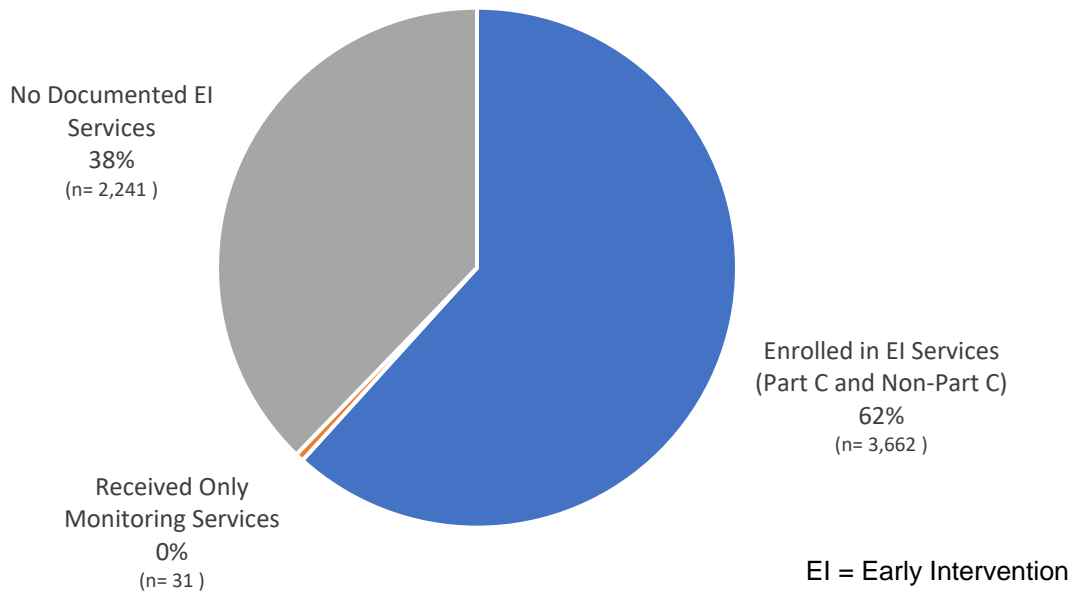
Early Intervention by 6 Months (*Denominator*: of infants enrolled in early intervention):
 $2,654$ (# enrolled in Part C EI before 6 months + # in Non-Part C EI before 6 Months) / $3,662$ (# enrolled in Part C + # in non-Part C EI) x 100 = 72.5%
 Mean: 71.6
 IQR: (65.7-80.2)

Summary of 2019 National CDC EHDI Data

**Hearing Status of Infants Not Passing Hearing Screening
(U.S., 2019) N = 61,475**



**Documented Intervention Status of Infants with Permanent Hearing Loss
(U.S., 2019) Total w. Permanent Hearing Loss = 5,934**



Summary of 2019 National CDC EHDI Data

Explanation of 2019 EHDI Data Item Calculations (*from page 1*)*

Data Notes

- Hearing Screening and Follow-up Survey data reflect information that states and territories have reportedly **documented** without estimation. As a result, data reported by CDC EHDI may differ from other sources.
- Some respondents only provided partial data (e.g., hearing screening data only). As a result, the number of reporting states and territories and denominators varies for some of the data sections.
- These data are subject to change if additional states and/or territories report data for year 2019.
- **In Process:** Respondents were advised that to be reported in this category, each infant must have been seen for diagnostic evaluation at least one time and have a follow-up appointment already scheduled.
- **LFU (Loss to Follow-up) / LTD (Loss to Documentation):** Sub-group of “No Documented Diagnosis / Undetermined” and “No Intervention Services / Undetermined” include cases where infants’ families were *Contacted but Unresponsive, Unable to Contact, and Unknown*.

Documented Hearing Screening

Percent Screened

$$3,545,388 \text{ (\# screened)} / 3,604,761 \text{ (occurrent births reported by EHDI programs)} \times 100 = 98.4\%$$

Percent Screened (*excluding infant deaths & parental refusals*)

$$3,545,388 \text{ (\# screened)} / 3,584,904 \text{ (occurrent births excluding infant deaths & parental refusals)} \times 100 = 98.9\%$$

Percent Screened Before 1 Month of Age

$$3,463,600 \text{ (\# pass before 1 month + \# not pass before 1 month)} / 3,545,388 \text{ (\# screened)} \times 100 = 97.7\%$$

Percent Not Passing final / most recent hearing screening

$$61,475 \text{ (\# not pass)} / 3,545,388 \text{ (\# screened)} \times 100 = 1.7\%$$

No Documented Hearing Screening

Percent with No Documented Hearing Screening

$$59,373 \text{ (\# w. no documented screening)} / 3,604,761 \text{ (\# occurrent births reported by EHDI programs)} \times 100 = 1.6\%$$

Documented Diagnosis

Percent Diagnosed

$$38,127 \text{ (\# w. documented diagnosis)} / 61,475 \text{ (\# not pass screen)} \times 100 = 62.0\%$$

Percent with No Hearing Loss

$$32,193 \text{ (\# w. no hearing loss)} / 61,475 \text{ (\# not pass screen)} \times 100 = 52.4\%$$

Percent with Permanent Hearing Loss

$$5,934 \text{ (\# w. diagnosed permanent hearing loss)} / 61,475 \text{ (\# not pass screen)} \times 100 = 9.7\%$$

Percent Diagnosed Before 3 Months of Age

$$30,170 \text{ (\# w. no hearing loss before 3 months + \# w. permanent hearing loss before 3 months)} / 38,127 \text{ (\# w. documented diagnosis)} \times 100 = 79.1\%$$

Prevalence of Hearing Loss

$$5,934 \text{ (\# w. diagnosed permanent hearing loss)} / 3,545,388 \text{ (\# screened)} \times 1,000 = 1.7 \text{ per } 1,000 \text{ screened}$$

No Documented Diagnosis

Percent with No Documented Diagnosis (*of those not passing hearing screen*)

$$23,348 \text{ (\# w. no documented diagnosis)} / 61,475 \text{ (\# not pass screen)} \times 100 = 38.0\%$$

Percent in Process

$$1,306 \text{ (\# in process)} / 61,475 \text{ (\# not pass screen)} \times 100 = 2.1\%$$

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Percent Infant Died / Parents Declined Services

2,038 (# infant died + # parents declined services) / 61,475 (# not pass screen) x 100 = 3.3%

Percent Non-Resident or Moved Out of Jurisdiction

1,817 (# non-resident + # moved out of jurisdiction) / 61,475 (# not pass screen) x 100 = 3.0%

Overall Percent LFU / LTD for Diagnosis (*i.e., Unable to Contact / Unresponsive / Unknown*)

16,893 (# unable to contact + # unresponsive + # unknown) / 61,475 (# not pass screen) x 100 = 27.5%

Percent LFU/LTD for Diagnosis: Due to Unable to Contact and Unknown

11,674 (# unable to contact + # unknown) / 61,475 (# not pass screen) x 100 = 19.0%

Percent Unresponsive for Diagnosis: Due to Parents/Family Contacted but Unresponsive

5,219 (# parents/family contacted but unresponsive) / 61,475 (# not pass screen) x 100 = 8.5%

Documented Referral to EI

Percent Referred to Part C EI (*of those with permanent hearing loss*)

5,034 (# referred to Part C EI) / 5,934 (# w. permanent hearing loss) x 100 = 84.8%

Percent Not Referred to Part C and Unknown (*of those with permanent hearing loss*)

533 (# not referred to Part C + # unknown) / 5,934 (# w. permanent hearing loss) x 100 = 9.0%

Documented Enrollment in EI

Percent Enrolled in EI (*Part C & Non-Part C*)

3,662 (# enrolled in Part C + # in non-Part C EI) / 5,934 (# w. permanent hearing loss) x 100 = 61.7%

Percent Enrolled in EI before 6 Months of Age (*Part C & Non-Part C*)

2,654 (# enrolled in Part C EI before 6 months + # in Non-Part C EI before 6 Months) /

3,662 (# enrolled in Part C + # in non-Part C EI) x 100 = 72.5%

No Documented Enrollment in EI

Percent with No Documented EI Services (*of those with permanent hearing loss*)

2,241 (# not receiving any EI services) / 5,934 (# w. permanent hearing loss) x 100 = 37.8%

Percent Infant Died / Parents Declined (*of those with permanent hearing loss*)

594 (# infant died + # parents declined services) / 5,934 (# w. permanent hearing loss) x 100 = 10.0%

Percent Non-Resident / Moved (*of those with permanent hearing loss*)

140 (# non-resident + # moved out of jurisdiction) / 5,934 (# w. permanent hearing loss) x 100 = 2.3%

Percent Not Eligible for Part C Services (*of those with permanent hearing loss*)

138 (# not eligible for Part C services) / 5,934 (# w. permanent hearing loss) x 100 = 2.3%

Percent LFU / LTD for EI

1,135 (# unable to contact + # unresponsive + # unknown) / 5,934 (# w. permanent hearing loss)
x 100 = 19.1%

Percent LFU/LTD for EI: Due to Unable to Contact and Unknown

1,011 (# unable to contact + # unknown) / 5,934 (# w. permanent hearing loss) x 100 = 17.0%

Percent Unresponsive for EI: Due to Parents/Family Contacted but Unresponsive

124 (# parents/family contacted but unresponsive) / 5,934 (# w. permanent hearing loss) x 100 = 2.1%

*Based on data from 55 respondents (47 states, 7 territories, 1 district)