Data Source: 2021 CDC Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-up Survey (HSFS)

Background: 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 people 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, can delay a child's speech, language, social, and emotional development. To ensure children with permanent hearing loss are identified as soon after birth 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
- Are enrolled in early intervention (for those identified with permanent hearing loss), ideally before 6
 months of age²

The Hearing Screening and Follow-up Survey (HSFS) is a voluntary survey sent out annually by CDC to each jurisdictional EHDI program. It requests aggregated hearing information on infants born in a specified calendar year (e.g., 2021). 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 2021 HSFS highlights EHDI-related information for <u>babies born</u> <u>between January 1, 2021 and December 31, 2021</u>.

Number of Survey Respondents: **55** (*48 states, 6 territories, 1 district*) AK, AZ, AR, CA, CO, Commonwealth of the Northern Mariana Islands, CT, DE, District of Columbia, FL, GA, Guam, HI, ID, IL, IN, IA, KS, KY, LA, ME, 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, Virgin Islands, 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

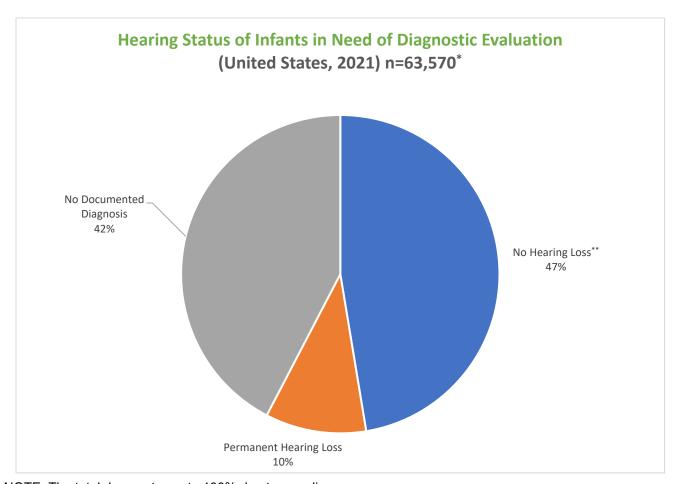
²Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs (2019). *Journal of Early Hearing Detection and Intervention*, 4(2), 1–44. https://digitalcommons.usu.edu/jehdi/vol4/iss2/1/

2021 Documented EHDI Data Items	
Total Occurrent Births (according to state and territorial EHDI programs)	3,578,511
Documented Hearing Screening	
Percent Screened (among births)	98.0% (n=3,508,393) (Range across jurisdictions: 79.6%–100.0%)
Percent Screened (excluding infant deaths and parental refusals)	98.6%
o Percent Screened before 1 Month of Age (among births)	95.5% (n=3,418,241)
Percent Not Passing final/most recent screening (among screened infants)	1.7% (n=60,894)
No Documented Hearing Screening	
Percent w. No Documented Screening:	2.0% (n=70,118)
Documented Diagnosis (among not passed screen + not screened because referred straight to diagnostic evaluation)	
Percent Diagnosed	57.6% (n=36,646) (Range across jurisdictions: 11.2%–100.0%)
o Percent with No Hearing Loss (i.e., normal hearing, transient hearing loss)	47.4% (n=30,128)
o Percent with Permanent Hearing Loss	10.3% (n=6,518)
 Percent Diagnosed (no hearing loss + transient hearing loss + permanent hearing loss) before 3 Months of Age 	42.7% (n=27,137)
Prevalence of Permanent Hearing Loss	1.8 per 1,000 births
No Documented Diagnosis (among not passed screen + not screened because referred straight to diagnostic evaluation)	
Percent with No Documented Diagnosis	42.4% (n=26,924)
Audiological Diagnosis in Process	2.0% (n=1,257)
o Infant Died	0.6% (n=358)
o Parents/Family Declined	2.9% (n=1,845)
Non-Resident/Moved	3.0% (n=1,901)
 Percent Loss to Follow-up (LFU)/Loss to Documentation (LTD) for Diagnosis LFU/LTD = # Parents/Family Contacted but Unresponsive (6,110) + # Unable to Contact (3,104) + # Unknown (11,351) 	32.4% (n=20,565) (Range: 0.0%–84.2%)
Other Cases of Hearing Loss	
Number of Additional Cases (e.g., late-onset hearing loss, infants not screened at birth)	n=353
Documented Referral to Early Intervention (EI) (among those with permanent hearing loss)	
Percent Referred to Part C El	88.1% (n=5,742)
Documented Enrollment in El (among those with permanent hearing loss)	
Percent Enrolled in El (Part C and Non-Part C) o Enrolled in El = # in Part C El (3,753) + # in Non-Part C El (173)	60.2% (n=3,926) (Range across jurisdictions: 0.0% - 100.0%)
Percent Enrolled in El before 6 Months of Age (Part C and Non-Part C)	42.2 % (n = 2,750)
No Documented Enrollment in El (among those with permanent hearing loss)	
Percent w. No Documented El Services	39.8% (n=2,592)
o Infant Died	0.6% (n=36)
o Parents/Family Declined	11.0% (n=717)
	2.7% (n=174)

0	Not Eligible for Part C Services	1.0% (n=67)
0	Percent Loss to Follow-up (LFU)/Loss to Documentation (LTD) for EI LFU/LTD = # Parents/Family Contacted but Unresponsive (203) + # Unable to Contact (362) + # Unknown (710)	19.6% (n=1,275) (Range across jurisdictions: 0.0%–100.0%)

Notes:

See pages 5–7 for an explanation of the calculations for the above EHDI data items. For summaries by jurisdiction, visit: www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

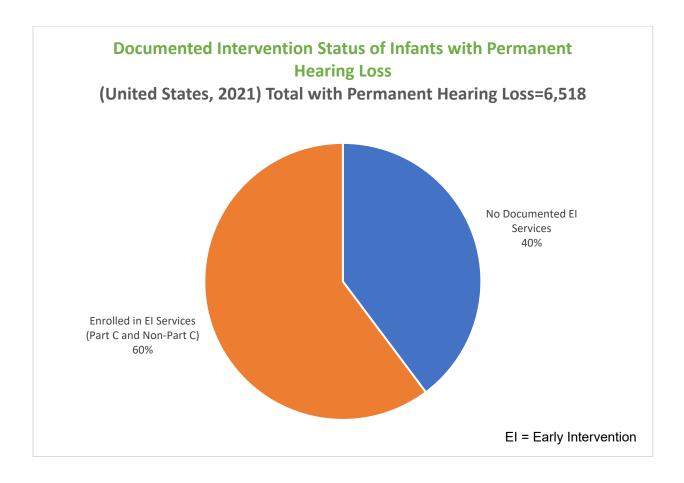


NOTE: The total does not sum to 100% due to rounding.

the hearing screen due to being referred straight to diagnostic evaluation.

^{*}Infants in need of diagnostic evaluation includes infants not passing the hearing screen and infants who missed

^{**}No Hearing Loss includes infants diagnosed with normal hearing and infants diagnosed with transient hearing loss.



Explanation of 2021 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 <u>provided only</u> 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.
- Audiological Diagnosis in Process: Respondents were advised that to be reported in this category, each
 infant <u>must</u> 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): Subgroup of "No Documented Diagnosis/Undetermined" and "No Intervention Services/Undetermined" includes cases where infants' families were Contacted but Unresponsive, Unable to Contact, and Unknown.

Documented Hearing Screening (55 jurisdictions)

Percent Screened

3,508,393 (# screened) / 3,578,511 (# occurrent births reported by EHDI programs) x 100 = 98.0%

Percent Screened (excluding infant deaths and parental refusals) 3,508,393 (# screened) / 3,559,695 (# occurrent births excluding infant deaths [10,785] and parental refusals [8,031]) x 100 = 98.6%

Percent Screened Before 1 Month of Age

3,418,241 (# pass before 1 month + # not pass before 1 month) / 3,578,511 (# total occurrent births reported by EHDI program) x 100 = 95.5%

Percent Not Passing final / most recent hearing screening 60,894 (# not pass) / 3,508,393 (# screened) x 100 = 1.7%

For source of numbers used in these calculations, see "2021 Summary of Hearing Screening Among Total Occurrent Births" and "2021 Summary of Infants Screened Before 1 Month of Age" on CDC EHDI webpage.

No Documented Hearing Screening (55 jurisdictions)

Percent with No Documented Hearing Screening

70,118 (# with no documented screening) / 3,578,511 (# occurrent births reported by EHDI programs) x 100 = 2.0%

For source of numbers used in these calculations, see "2021 Summary of Reasons for No Documented Hearing Screening Among Total Occurrent Births" on <u>CDC EHDI webpage</u>.

Documented Diagnosis (among not passed screen; 51 jurisdictions)

Percent Diagnosed

36,646 (# w. documented diagnosis) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 57.6%

Percent with No Hearing Loss

30,128 (# with no hearing loss [28,052] + # transient hearing loss [2,076]) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 47.4%

Percent with Permanent Hearing Loss

6,518 (# with diagnosed permanent hearing loss) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 10.3%

Percent Diagnosed Before 3 Months of Age

27,137 (# with no hearing loss before 3 months [22,885] + # with permanent hearing loss before 3 months [4,252]) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 42.7%

Prevalence of Hearing Loss

6,518 (# with diagnosed permanent hearing loss) / 3,573,446 (# occurrent births reported by EHDI programs) x 1,000 = 1.8 per 1,000 births

For source of numbers used in these calculations, see "2021 Summary of Diagnostics Among Infants Not Passing Hearing Screening" and "2021 Summary of Infants Not Passing Hearing Screening Diagnosed Before 3 Months of Age" on CDC EHDI webpage.

No Documented Diagnosis (among not passed screen; 51 jurisdictions)

Percent with No Documented Diagnosis (of those not passing hearing screen and not screened because referred straight to diagnostic evaluation)

26,924 (# with no documented diagnosis) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 42.4%

Percent Audiological Diagnosis in Process

1,257 (# audiological diagnosis in process) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 2.0%

Percent Infant Died

358 (# infant died) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 0.6%

Percent Parents / Family Declined Services

1,845 (# parents / family declined services) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 2.9%

Percent Non-Resident or Moved Out of Jurisdiction

1,901 (# non-resident + # moved out of jurisdiction) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 3.0%

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

20,565 (# unable to contact [3,104] + # unresponsive [6,110] + # unknown [11,351]) / 63,570 (# not pass screen [60,824] + not screened because referred straight to diagnostic evaluation [2,746]) x 100 = 32.4%

For source of numbers used in these calculations, see "2021 Summary of Reasons for No Documented Diagnosis Among Infants Not Passing Screening" on CDC EHDI webpage.

<u>Documented Referral to EI</u> (among those with permanent hearing loss; 51 jurisdictions)

Percent Referred to Part C EL

5,742 (# referred to Part C EI) / 6,518 (# with permanent hearing loss) x 100 = 88.1%

For source of numbers used in these calculations, see "2021 Summary of Infants Identified with Permanent Hearing Loss Enrolled in Early Intervention (EI) Before 6 Months of Age" on CDC EHDI webpage.

Documented Enrollment in El (among those with permanent hearing loss; 51 jurisdictions)

Percent Enrolled in El (Part C and Non-Part C)

3,926 (# enrolled in Part C [3,753] + # in non-Part C EI [173]) / 6,518 (# with permanent hearing loss) x 100 = 60.2%

Percent Enrolled in El before 6 Months of Age (*Part C and Non-Part C*) 2,750 (# enrolled in Part C El before 6 months [2,694] + # in Non-Part C El before 6 Months [56]) / 6,518 (# with permanent hearing loss) x 100 = 42.2%

For source of numbers used in these calculations, see "2021 Summary of Early Intervention (EI) Among Infants Identified with Permanent Hearing Loss" and "2021 Summary of Infants Identified with Permanent Hearing Loss Enrolled in Early Intervention (EI) Before 6 Months of Age" on CDC EHDI webpage.

No Documented Enrollment in El (among those with permanent hearing loss; 51 jurisdictions)

Percent with No Documented El Services

2,592 (# not receiving any El services) / 6,518 (# w. permanent hearing loss) x 100 = 39.8%

Percent Infant Died

36 (# infant died) / 6,518 (# with permanent hearing loss) x 100 = 0.6%

Percent Parents / Family Declined

717 (# parents / family declined) / 6,518 (# with permanent hearing loss) x 100 = 11.0%

Percent Non-Resident / Moved

174 (# non-resident + # moved out of jurisdiction) / 6,518 (# with permanent hearing loss) x 100 = 2.7%

Percent Not Eligible for Part C Services

67 (# not eligible for Part C services) / 6,518 (# with permanent hearing loss) x 100 = 1.0%

Percent LFU / LTD for EI

1,275 (# unable to contact [362] + # unresponsive [203] + # unknown [710]) / 6,518 (# with permanent hearing loss) = $\times 100 = 19.6\%$

For source of numbers used in these calculations, see "2021 Summary of Reasons for No Documented Early Intervention (EI) Services Among Infants Identified with Permanent Hearing Loss" on CDC EHDI webpage.