

Centers for Disease Control and Prevention
MMWR Morbidity and Mortality Weekly Report

Identifying Infants with Hearing Loss — United States, 1999–2007

Weekly

March 5, 2010 / 59(08);220-223

Original Version: www.cdc.gov/mmwr/preview/mmwrhtml/mm5908a2.htm?s_cid=mm5908a2_e

Note: This version includes updates from the April 23, 2010 Errata

Congenital hearing loss affects two to three infants per 1,000 live births (1). Undetected hearing loss can delay speech and language development. A total of 41 states, Guam, and the District of Columbia have statutes or regulatory guidance to identify infants with hearing loss. All states and U.S. territories also have established Early Hearing Detection and Intervention (EHDI) programs, which embody evidence-based public health policy for addressing infant hearing loss (2,3). EHDI programs help ensure that newborns and infants are screened and receive recommended follow-up through data collection and outreach to hospitals, providers, and families. To determine the status of efforts to identify newborns and infants with hearing loss, CDC analyzed EHDI surveillance data from 1999–2007. Differences in how data were reported and collected limit comparability between 1999–2004 and 2005–2007 data; however, available data indicated an increase in infants screened from 46.5% in 1999 to 97.0% in 2007. In addition, the number of infants documented with hearing loss in 2007 increased by nearly 500 infants among the same 21 states reporting data in 2001 (1,736 identified in 2001 versus 2,212 in 2007). These findings demonstrate progress toward achieving benchmarks for screening, evaluation, and intervention and document the continued need to ensure infants receive recommended services in a timely manner. Early identification of infants with hearing loss is endorsed by the Joint Committee on Infant Hearing, whose members include national professional and advocacy organizations (4). Recommended national EHDI benchmarks include the following: hearing screening no later than age 1 month, diagnostic audiologic evaluation no later than age 3 months (for those infants not passing the screening), and enrollment in early intervention no later than age 6 months (for those identified with a hearing loss).

For 1999–2004, the Directors of Speech and Hearing Programs in State Health Welfare Agencies (DSHPSHWA), a national organization that promotes public health programs targeting the diagnosis and treatment of communication disorders, collected data from states and territories and shared them with CDC. Data for 2005–2007 were obtained directly by CDC through a detailed survey sent to the directors of state and territorial EHDI programs. Unlike the DSHPSHWA data, which included estimates by programs, the CDC survey for 2005–2007 (the most recent data available) required that data be recorded or documented within program tracking systems. Aggregate estimates from hospitals and providers that were included in the DSHPSHWA data could not be used in response to the CDC survey. CDC also asked that state and territorial respondents report aggregate data for 2005–2007 that reflected the screening, diagnostic, and intervention status of every birth during that period. For infants for whom the receipt of services could not be documented, respondents were asked to report the reason (e.g., infant death or parental refusal). Infants were considered lost to follow-up (LFU) if they did not receive recommended follow-up diagnostic or intervention services or lost to documentation (LTD) if they received services without the results being reported to the EHDI program. Although strategies used to target LFU and LTD differ, these two categories are grouped together because it is not possible for programs to differentiate between infants who did not receive services and those whose receipt of services were not reported (5).

Data for 1999–2007 were requested from all 50 states, the District of Columbia, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands. The number of respondents ranged from 22 in 1999 to 50 in 2007. Some respondents provided partial data or were unable to provide any data for one or more reporting years, so the actual number of states and territories reporting data for specific

indicators varied for each year. In 1999, a total of 22 states and territories estimated that 660,639 (46.5%) of infants among total births were screened for hearing loss. By 2007, 47 states and territories reported that 3,345,629 (97.0%) infants were screened; three states in 2007 reported incomplete screening and follow-up data and were not included in the analysis. In 1999, eight states and territories estimated that 3,924 (48.2%) infants who did not pass the screening failed to receive a diagnostic evaluation and were therefore LFU/LTD. In 2005, the first year CDC collected data, 44 states and territories reported that 64.0% (38,411) of infants not passing the final or most recent screening did not receive recommended follow-up services and were therefore LFU/LTD. In 2007, LFU/LTD was reported at 46.1% (28,112) by 44 states and territories, representing a decrease of more than 17 percentage points from 2005 (Figure). The number of infants identified with hearing loss increased from an estimated 282 (1.1 per 1,000 screened) reported by nine states and territories in 1999 to 3,430 (1.2 per 1,000 screened) documented cases reported by 44 states and territories in 2007 (six states and territories responding to the 2007 survey were unable to provide this information). The overall number of infants with hearing loss enrolled in early intervention in 1999 was not reported to DSHPSHWA. In 2007, a total of 43 states and territories documented that 60.8% of infants with hearing loss were enrolled in early intervention by age 6 months.

The percentage of infants who were documented to be screened before age 1 month increased from 80.1% in 2005 to 85.4% in 2007, based on data from 46 states and territories. The percentage of infants receiving recommended diagnostic follow-up before age 3 months increased from 51.5% in 2005 to 66.4% in 2007, based on data from 44 states and territories. The percentage of infants receiving early intervention who were enrolled before 6 months increased from 57.0% in 2005 to 60.8% in 2007, based on data from 44 states and territories in 2005 and 43 in 2007 (Table).

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Editorial Note

Since the organized collection of data started in 2000 (for year 1999), demonstrated progress has been made in identifying and providing early intervention services to infants with hearing loss. For example, the reported mean percentage of infants screened for hearing loss increased from 46.5% in 1999 to 97.0% in 2007. The increase in screening most likely is due to a combination of several factors: 1) implementation of new or revised requirements to screen infants for hearing loss (within some states), 2) improvements in screening and diagnostic technology, 3) increased reporting by hospitals and other providers of hearing screening results, 4) improvements in data collection and state and territorial EHDI tracking and surveillance systems, 5) increased awareness about the importance of screening infants for hearing loss, 6) increased follow-up efforts by state EHDI programs, and 7) support by national agencies and organizations.

Although some data reported for 1999--2004 were estimated, the 2005--2007 data reflect results states and territories could document, providing a more accurate summary of EHDI-related efforts. Now that >95% of U.S. infants can be documented as having their hearing screened, remaining challenges include ensuring timely diagnostic evaluation for those who do not pass the screening and enrollment in early intervention for those with diagnosed hearing loss. In 2005, >60% of infants who had not passed the final or most recent screening were LFU/LTD. Some of those infants might have received audiologic evaluations, but the results were not reported to the EHDI program (i.e., undocumented evaluation) and their status could not be determined from available data. By 2007, LFU/LTD among infants not passing the final or most recent screening had decreased to approximately 46%. EHDI programs such as those in Massachusetts and Colorado, which often actively follow up with families and providers and reported LFU/LTD in 2007 of 5.6% and 6.4%, respectively, are good examples for other programs trying to improve overall follow-up rates. (6,7).

The findings in this report are subject to at least three limitations. First, the methods and definitions used to collect data for 1999--2004 differed from those used to collect data for 2005--2007. For 2005--2007, a more standardized methodology was used that focused on collecting complete, documented data. This

limits comparability between the 1999--2004 and 2005--2007 data, especially of the diagnostic data. Second, some states and territories were able to provide only limited data in one or more reporting years. Third, EHDI programs are designed to detect hearing losses at a threshold of 30--40 dB. The prevalence of all forms of hearing loss among children, including mild degrees of loss that fall below the screening threshold of detection and those that are either progressive or late-onset, is higher than that detected through newborn hearing screening (8,9).

Recent data indicate progress has been made in screening infants for hearing loss, reducing LFU/LTD, and raising enrollment in early intervention. However, challenges remain in providing and documenting receipt of recommended EHDI services. To address these challenges, federal funds are being used to enhance EHDI surveillance systems to capture more complete data, increase education and outreach efforts, and, in some states and territories, employ follow-up coordinators to ensure infants receive services. At the federal level, CDC, the Healthcare Information Technology Standards Panel, and other agencies are exploring how electronic health records can facilitate EHDI data collection and reporting and working to develop data reporting standards.

Acknowledgments

This report is based, in part, on data reported by EHDI programs in U.S. states, the Commonwealth of the Northern Mariana Islands, the District of Columbia, Guam, Palau, and the U.S. Virgin Islands.

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Suggested citation: Centers for Disease Control and Prevention. Identifying Infants with Hearing Loss — United States, 1999–2007. *MMWR* 2010;59:220-223.

What is already known on this topic?

During the past decade, screening and diagnosis of hearing loss in infants and the reporting of this information have expanded nationally.

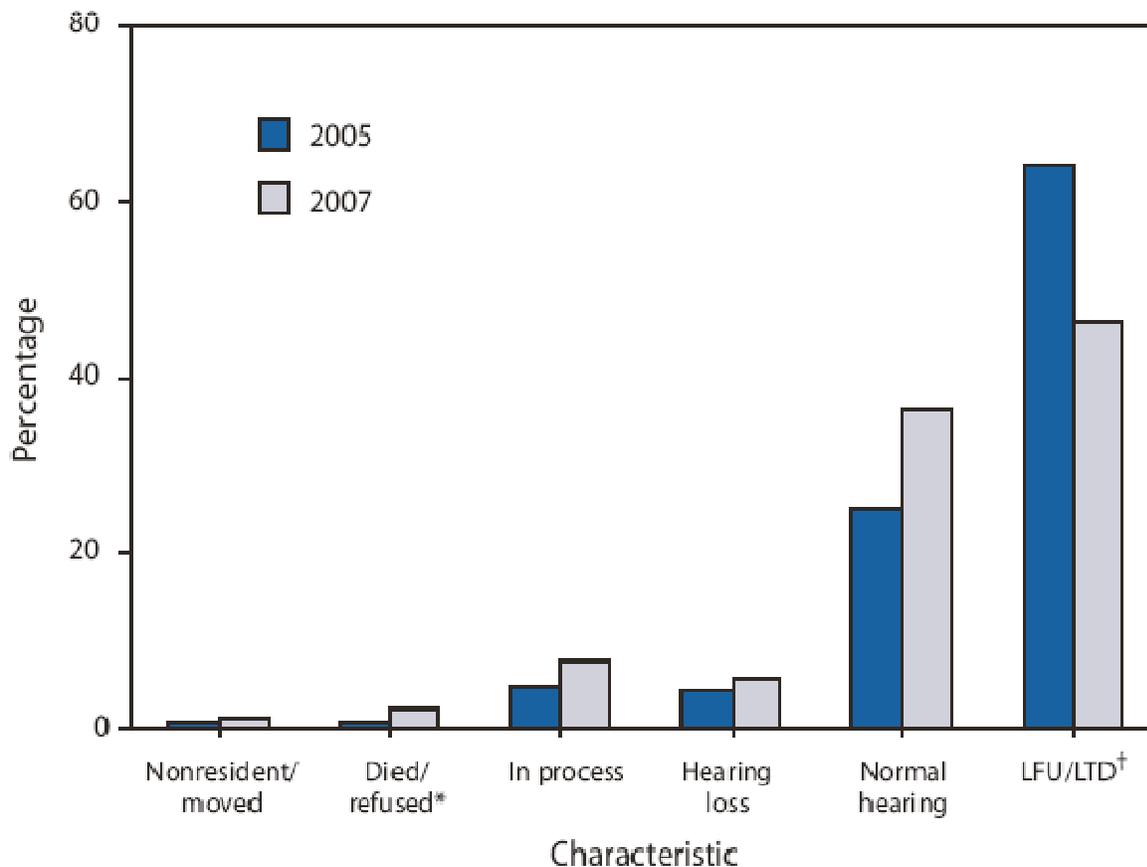
What is added by this report?

The requirement for state and territorial programs to report results based on documented data, rather than estimated, has led to more accurate data and assessment of efforts to identify infants with hearing loss; this documented data has shown a large increase in screening rates and indicated that challenges remain in ensuring infants receive recommended follow-up diagnostic and early intervention services.

What are the implications for public health practice?

Continued expansion of follow-up efforts by Early Hearing Detection and Intervention (EHDI) programs and data reporting by providers, data linkage and integration, and information sharing between providers and EHDI programs will be vital to further reduce loss to follow-up and to document program effectiveness in identifying infants with hearing loss and ensuring these infants receive appropriate early intervention services.

FIGURE. Status of infants who did not pass initial hearing screening --- United States, 2005--2007



* Infant died or parents refused the screening.

† Lost to follow-up/lost to documentation.

TABLE. Number and percentage of infants screened for hearing loss, diagnosed, and enrolled in early intervention, United States, 1999–2007

Year	Screened				Diagnosed				Infants with Hearing Loss						
	Total		Before age 1 month		Total*		Before age 3 months [†]		LFU/LTD [§]		Total Identified	Enrolled in EI [¶]		Enrolled in EI before age 6 months	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	No.	(%)	No.	(%)
1999	660,639 (22)**	(46.5)	N/A ^{††}		N/A		4,221 (8)	(51.8)	3,924 (8)	(48.2)	282 (9)	N/A		N/A	
2000	1,496,014 (44)	(52.1)	N/A		10,124 (23)	(56.3)	3,931 (11)	(77.6)	7,859 (23)	(43.7)	855 (25)	590 (17)	(83.7)	446 (17)	(75.6)
2001	2,115,869 (48)	(65.4)	N/A		11,901 (27)	(55.7)	4,622 (14)	(78.2)	9,476 (27)	(44.3)	2,541 (35)	891 (27)	(65.0)	579 (24)	(69.7)
2002	2,941,115 (47)	(82.9)	N/A		17,254 (35)	(40.4)	7,899 (26)	(69.5)	25,469 (35)	(59.6)	2,553 (37)	1,137 (30)	(64.0)	531 (25)	(64.9)
2003	3,417,964 (50)	(88.1)	N/A		20,083 (37)	(55.2)	(10,671) (31)	(81.7)	16,309 (37)	(44.8)	2,899 (44)	1,702 (38)	(65.6)	1,064 (35)	(67.4)
2004	3,496,452 (49)	(91.8)	N/A		25,376 (41)	(48.7)	14,909 (36)	(75.7)	26,704 (41)	(51.3)	3,600 (47)	1,859 (40)	(65.3)	1,277 (38)	(69.9)
2005	3,231,594 (48)	(94.2)	2,471,554 (46)	(80.1)	17,691 (44)	(29.5)	9,106 (44)	(51.5)	38,411 (44)	(64.0)	2,634 (44)	1,522 (44)	(57.8)	868 (44)	(57.0)
2006	3,129,585 (49)	(95.2)	2,706,029 (49)	(86.5)	23,024 (47)	(34.1)	10,831 (47)	(47.0)	32,189 (47)	(47.7)	3,261 (47)	1,703 (45)	(55.4)	973 (45)	(57.1)
2007	3,345,629 (47)	(97.0)	2,709,244 (46)	(85.4)	25,696 (44)	(42.2)	17,052 (44)	(66.4)	28,112 (44)	(46.1)	3,430 (44)	2,046 (43)	(60.8)	1,243 (43)	(60.8)

Sources: 1999–2004: Directors of Speech and Hearing Programs in State Health and Welfare Agencies Annual Survey; data reported on this survey were often estimated. 2005–2007: CDC Early Hearing Detection and Intervention Annual Hearing Screening and Follow-up Survey.

* Diagnosis data for 1999–2004 refer to the number of infants not passing the hearing screening that were estimated to have received a diagnostic audiologic evaluation. Diagnosis data for 2005–2007 refer to the number of infants reported as not passing the final or most recent hearing screening that were documented to have been diagnosed with a hearing loss or found to have normal hearing (i.e., no hearing loss).

[†] During 1999–2004, the number of respondents reporting data about infants diagnosed before age 3 months was less than the number reporting overall diagnostic data.

[§] LFU/LTD: Loss to follow-up/loss to documentation.

[¶] Early Intervention (EI). In 1999, data only were requested about the number of infants receiving a diagnostic evaluation before age 3 months and the number of infants enrolled in EI before age 6 months. No data were requested about the overall number that received a diagnostic evaluation or enrolled in EI. Early intervention data for 2005 – 2007 includes children only receiving Part C services and those only receiving non-Part C services.

** Number of responding states (including the District of Columbia and Guam).

^{††} Data not available.