

DSHPSHWA & Other Form Explanations (2001 Survey)

1. Hospital Reporting.

State will specify if hospitals are required to report hearing screening information.

1a) States will list what information (if any) hospitals are required to report.

2. Number of Live Births.

Each state is to report the number of live births reported by calendar year as determined by the state entity responsible for reporting vital statistics. Number of births may be reported by either residence or occurrence. Default is typically by occurrence.

3. Number Screened.

Each state is to report the number of infants receiving a physiological hearing screening test bilaterally. Two numbers will be reported: (3A) number screened prior to hospital discharge and (3B) number screened before 1 month of age.

- These numbers should be an unduplicated count of the number of infants screened. In other words, **infants included in 3A should not be included in 3B.**
- The numbers reported should reflect the number of infants screened, not the number of tests completed or number of ears screened.
- Collection of information on high risk indicators is not considered a physiological measure.
- At this time, the physiologic measures considered to provide valid screening results are EOAE and ABR (screening, automated, or conventional).
- The exact protocol, person who screens, pass/refer criteria, counting valid/invalid screening, and so forth are to be determined by each state.
- Children referred directly for diagnostic evaluation (e.g., because of high-risk factors) may be counted as screened after they receive the physiological hearing test.

EXAMPLES:

- For programs using a 2-stage hearing screening protocol, a child is considered screened if the first stage is completed before discharge. If the first stage is completed after discharge, the child should be counted in 2B.
 - Unilateral screening was considered, however, it was ruled out as a valid comparison to bilateral screening, which was determined as the basis for this data base.
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4. Number Referred for Audiologic Evaluation

Each state is to report the total number of infants from Number 3 (3A + 3B) that are referred from initial or multiple screenings for audiologic evaluation. An audiologic evaluation is defined as the use of a battery of audiometric procedures to determine type of hearing loss by obtaining frequency and intensity specific information for each ear.

EXAMPLES:

- An infant is considered referred for a audiologic evaluation only when a systematic active referral system can ensure the child is linked with appropriate diagnostic services. The number reported does not include children who have not completed the hearing screening process (e.g., those who do not ever have an actual screening test but are referred for diagnostic evaluation solely because they were missed).
 - These children would be counted as receiving a screening when the testing is performed according to time lines specified in #3).
 - A child is considered to be referred for diagnosis when he or she has completed the hospital-defined screening process.
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5. Number who Received Audiologic Evaluation by 3 months of age

Each state is to report the **total** number of infants from # 4 who were born in year 2001 and received an audiologic evaluation. This is the number of infants for whom hearing loss has been confirmed and infants for whom hearing loss has been ruled out.

5a) Each state is to report the number of infants from # 5 who were born in year 2001 and received an audiologic evaluation **by 3 months of age**. This is the number whom hearing loss has either been confirmed or ruled out.

Determining auditory status is a diagnostic process and usually will include more than one session. This item should reflect number of infants who have completed the process to sufficiently confirm or rule out hearing loss. The diagnostic process is expected to continue throughout early childhood.

The diagnostic process should include a combination of physiologic and behavioral measures and may include: ABR (click, frequency specific, bone conducted), EOAE (TEOAE and DPOAE), Immittance, and Behavioral measures. A diagnosis of hearing loss should not be based on the results of a single audiometric test.

EXAMPLES:

- After the initial screening, children referred for audiologic evaluations may initially receive only a screening that rules out a hearing loss. These children would be counted as referred and receiving the audiologic evaluation. In this case, the rescreening is considered part of the diagnostic evaluation and rules out a hearing loss.
- If a child is screened in the hospital and immediately an evaluation is performed before discharge, the child should be counted as screened, referred for audiologic evaluation, and having received the evaluation.

The time limit of 3 months of age was used in accordance with Joint Committee on Infant Hearing 1994 Position Statement goal to initiate audiologic diagnostic procedures as early as possible, in many cases within weeks of birth. Reporting the number of infants with diagnostic evaluations at 3 months of age should not be interpreted to mean that 3 months is the age at which the diagnostic evaluation is to be initiated or that evaluations performed past 3 months of age are not valid.

6. Number of Children with Permanent Childhood Hearing Loss (PCHL) Aged 0-7 Years

Each state is to report the **total** number of children born between **January 1, 2001 and December 31, 2001**, who are identified with Permanent Childhood Hearing Loss (PCHL), i.e. the number of children identified with hearing loss who were born in year 2001. This reported number should include any late identified cases of children identified with a PCHL who were born in 2001. This number will be updated each year as older children who were born in Year 2001 are identified with a hearing loss.

PCHL includes unilateral or bilateral permanent childhood hearing loss. Permanent hearing loss includes both sensorineural and non-transient conductive hearing loss (e.g., resulting from craniofacial anomalies, ossicular fixation, etc.). Hearing loss must be confirmed through a battery of audiometric tests that result in hearing loss detection at greater than 20 dB HL. A figure for each year will be given, and the number of children identified will be updated each year according to the birth year, as new children with hearing loss are identified. The number reported for previous years is cumulative and should be updated annually. The number will include the total number of children from the original cohort with hearing loss born in that year, regardless of when identified.

In addition to the total number of children with hearing loss, each child for whom hearing loss is detected will be classified by laterality, type, and degree of hearing loss according to 20 classifications.

6a) Each state is to report the number of children born in Year 2001, who are identified with a hearing loss, **that were screened through a Newborn Hearing Screening Program**. This is a subset of # 6 and includes only infants screened through the newborn screening programs. This number will remain the same, i.e. will not be updated in later years.

7. Average/Median Age in Months of Identification of Hearing Loss

Each state is to report the average and median age in months at which hearing loss was confirmed for the children in # 6. The average and median age and minimum and maximum ages will be calculated separately for each calendar year. The median age is the age at which 50% of the children are above and 50% of the children are below that age.

Age of confirmation of hearing loss is the age at which an audiologist has determined (confirmed) that a hearing loss is present. Obtaining complete, audiometric information is often an ongoing process with infants and this item should not be the age at which complete air and bone thresholds are obtained, but rather the age at which can be reasonably determined the presence or absence of a hearing loss.

For each year being reported, the average and median age will be calculated. Thus, the average and median age of diagnosis will be updated (and most likely change) on a yearly basis. The average and median age for each year will increase in subsequent years as children with congenital hearing loss are identified at later ages.

Examples for calculating average and median age of confirmation of hearing loss and updating average and median age annually:

Age of Audiologic Evaluation

Each state should obtain the age at which the infant/child received an audiologic evaluation of hearing loss in months rounded to the nearest week, expressed as:

5.00: 5 months
5.25: 5 months, 1 week
5.50: 5 months, 2 weeks
5.75: 5 months, 3, weeks

If the age of audiologic evaluation takes place in the first 4 days of the week, the age should be rounded down. If it occurs in the last 3 days of the week, it should be rounded up.

Example:

5 months, 2nd week, 4th day = 5.50 months
5 months, 2nd week, 5th day = 5.75 months

Average Age

If a state has 5 children born in 2001 identified with hearing loss with the following age of diagnosis: 1.00 month, 1.25 months, 3.75 months, 4.50 months, 6.25 months

The average for that state for 1998 would be reported as:

$1.00 + 1.25 + 3.75 + 4.50 + 6.25 = 16.75$ divided by 5 = 3.35 months

Median Age

Using the above ages, the median age for that state for 2001 would be reported as: 3.75 months (the age at which 50% of the children are above and 50% of the children are below).

Updating Each Year

Using the above ages, and supposing that in year 2001, 3 additional children born in year 2000 are identified with PCHL with the following ages of diagnosis:

3.50 months, 7.75 months, 13.00 months

The average age for 2001 would change to:

$1.00 + 1.25 + 3.75 + 4.50 + 6.25 + 3.50 + 7.75 + 13.00 = 41.00$ divided by 8 = 5.13 months

The median age would change to 5.4 months based on the following:

1.00, 1.25, 3.75, 4.50, 6.25, 3.50, 7.75, 13.00 (The midpoint is half of the difference between 4.5 and 6.25 = 5.4 months)

8. Number of Infants Receiving Intervention by 6 months of age

Each state is to report the **total** number of children identified in # 6 who are receiving appropriate intervention services as determined by each state. Because of the variability across states as to who qualifies for services, what services are available, it is the responsibility of each state to define what constitutes appropriate early intervention services, what the definition of enrolled is, etc. Intervention services must be specifically for children who are deaf or hard of hearing and may include, but are not limited to audiological services, educational services, medical or surgical treatment, etc.

8a) State should report the number of infants and / or children with a PCHL and born in year 2001 who are receiving appropriate early intervention services (as determined by each state) by 6 months of age.

The age of 6 months was selected in accordance with the recommendations of the Joint Committee on Infant Hearing 1994 Position Statement to encourage the enrollment of infants with identified hearing loss into appropriate early intervention as soon as possible. Appropriate intervention may include a range of services such as monitoring, speech-language therapy only or early intervention programming received on a regular basis by a parent-infant specialist, according to family choice.

To make comparisons between states, each state should indicate what types of services from the list below have been included in the number reported as receiving early intervention:

- A. Children with completed IFSPs.
- B. Children enrolled in Part C services.
- C. Children for whom intervention is received on a regular basis (at least 1 or 2 times per month).
- D. Children receiving speech/language therapy only.
- E. Children who are monitored periodically for changes in hearing level.
- F. Children whose families receive preventative counseling.
- G. Children whose families receive support services.
- H. All of the above.
- I. Other (describe):

9. Birthing Hospitals

Total number of birthing hospitals / facilities in the state.

10. UNHS Hospitals

State reports how many hospitals / facilities are classified as Universal Newborn Hearing Screening in the state.

11. UNHS Hospital Classification

States report if they classify Universal Newborn Hearing Screening birthing hospitals / facilities by the percent of infants they screen.

11a) If state does use a percent screened to classify Universal Newborn Hearing Screening hospitals / facilities, state selects one of the four listed choices. If the “other” option is selected, states are asked to provide the percent they use to classify Universal Newborn Hearing Screening hospitals / facilities.

12. Hospital Reporting of Hearing Screening Results

Select the type of method(s) or system(s) that birthing hospitals in the state use to report hearing screening information. All methods and/or systems used by birthing hospitals should be selected.

13. State Tracking of Hearing Screening Information

Select the type of tracking system that the state program uses to track hearing screening and follow-up information for infants and children. If the state does not currently use a system to track EHDl related information for infants and children, please indicate this by selecting the “None” option.

14. Degree of Hearing Loss

Categories of hearing loss are intended to provide information regarding that child's average/estimated hearing for the frequency range 500-2000 Hz. For children with certain types and degrees of losses (e.g. ski slope), data will be somewhat misleading. The data base is meant to be only a generalized way of categorizing type and degree of hearing loss and for simplicity's sake cannot incorporate all categories, type, and degree of hearing loss.

Mild Hearing Loss:	21 to 40
Moderate Hearing Loss:	41 to 70
Severe Hearing Loss:	71 to 90
Profound Hearing Loss:	91 +

The ages birth through 7 years were picked because the database should include all children with congenital hearing loss. It is assumed that by the end of the first year of school, all children with congenital hearing loss will be identified.

Although there will be children with fluctuating conductive conditions, for purposes of this database, only those with permanent conductive hearing loss are included. Conductive hearing loss associated with chronic or recurrent otitis media may be deleterious to child development in ways similar to that of permanent hearing loss, but this database does not track otitis media. The exclusion of other types of hearing loss in this database should not be interpreted to mean they are not important. States may also wish to maintain records for children identified with hearing loss of a

non-congenital origin, such as children with acquired hearing loss or progressive hearing loss. Determining whether a hearing loss is acquired vs congenital is difficult; however the purpose is to record only congenital hearing loss related to the identification through universal screening so children who develop hearing loss from diseases such as meningitis, and CMV, should not be included in this database.

15. Laterality and Type of Hearing Loss

Laterality of Hearing Loss

For each child, record the hearing loss according to laterality, with each child having either a unilateral or a bilateral hearing loss. Degree of unilateral hearing loss is to be reported according to the poorer ear. Degree of bilateral hearing loss is to be categorized according to the better ear.

Type of Hearing Loss

For each child, record the type of hearing loss identified, with each child having either a sensorineural, permanent conductive, or mixed hearing loss.