



2009 CDC EHD Hearing Screening and Follow-up Survey (HSFS): 2009 Explanations*

This document provides explanations of the fields in the 2009 HSFS, which is a voluntary survey. All requested data only refers to infants born in calendar year **2009** (i.e., January 1, 2009 – December 31, 2009). If you have questions, please contact Marcus Gaffney at: MGaffney@cdc.gov / (404) 498 3031

Please Note*

- Only documented data is to be reported on this survey. No estimated data should be reported.
- Please use chronological age when reporting data related to age of screening, diagnosis, and intervention
- Parts 1 and 2 are grouped together and are accessed using the same link. Part 3 is accessed using a separate link and can only be completed after Parts 1 and 2 have been submitted.
- Fields highlighted in **yellow** are Totals that will be automatically calculated by the survey.
- To help avoid error messages select Calculate Totals (+) near the top of each page before going to the next section. This will check that the status of all infants in each section has been accounted for.
- Do not use the *Enter* key or include any commas with the data you report on the survey.
- **0** will sometimes appear in blank fields in the survey. You can delete this 0 before entering data or simply enter the data after the 0 without any spaces (e.g., 0100).

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Part 1: 2009 Documented Hearing Screening Data

Total Occurrent Births

- The number entered here should represent the total number of live, occurrent births (within the reporting jurisdiction) born in calendar year 2009.
- This should include any infants born in the reporting jurisdiction, including those born in military facilities, even if they are residents of another jurisdiction.

Total Occurrent Births Reported by Vital Records

- The total number of live, occurrent births according to the jurisdictional Vital Records program. This can include births that occurred in military facilities.
- This should be the same or very similar to the value reported for “Total Occurrent Births.”
- Intended as a quality assurance indicator.
- This number does not affect any of the automatically calculated values in the survey.

Optional: Total Occurrent Births at Military Facilities

- This is an *optional* field and a response is not required.
- The number of live, occurrent births at military facilities according to the jurisdictional Vital Records program.
- This number should not include any births that occurred outside of military facilities (e.g., births in civilian hospitals).
- Any births reported in this field must also be included in the above “Total Occurrent Births” field.
- Any data entered in this field will not be included in the automatically calculated “Total Occurrent Births” values in the Screening section.
- If there are no *military hospitals* in the jurisdiction please enter the word “none”

Optional: Total Occurrent Births at Military Facilities with Hearing Screening Results Reported to the EHDI Program

- This is an *optional* field and a response is not required.
- Any births reported in this field must also be included in the appropriate “Passed” and “Not Passed” fields.
- Any data entered in this field will not be included in any of the automatically calculated “Total Occurrent Births,” “Total Pass” and Total Not Pass” values in the Screening section.
- If there are no *military hospitals* in the jurisdiction please enter the word “none”

Hearing Screening

- Please report only the results of the final hearing screen on record, which is defined as the **last or most recent** hearing screening an infant received.
 - For example, if an infant was screened before hospital discharge and then again at two weeks, please report only the results for the screen performed at two weeks.
- Infants who cannot be tested in both ears due to obvious conductive malformations should be reported in the appropriate “Not Pass” category instead of the “Missed” category.

Total Documented as Screened

- This value will be automatically calculated based on the fields:
 - Total Pass + Total Not Pass

Total Documented as Not Screened

- This value will be automatically calculated based on the fields:
 - [Infants Died + Parents/Family Declined Services + Missed + Unknown](#)

Infant Died

- Infants who were not screened due to death.

Parents / Family Declined Services

- Infants who were not screened due to documented parental or family refusal of the hearing screening.

Missed

- Includes cases where an infant was documented to have **not** received a hearing screening for reasons other than parental refusal or death.
- Infants who were only successfully screened in one ear, with no documentation of both ears being screened at the same time during a future visit, should be reported in this category.
 - Infants who cannot be tested in both ears due to obvious conductive malformations should be reported in the appropriate "Not Pass" category instead of the "Missed" category.
 - Infants not screened due to either death or parental refusal should **not** be reported in this category.

Unknown

- Includes cases where it cannot be documented whether an infant was screened for hearing loss or not. This includes cases where no hearing screening results are reported to the jurisdiction.
 - Infants not screened due to either death or parental refusal should **not** be reported in this category.

Sample Scenarios (*Unknown and Missed*)

- **Scenario 1:** Infant is born in a hospital but the hospital does not have any record of the infant having a hearing screening administered before discharged. The hospital reported to the state or territory that the infant was not screened for hearing loss before or after discharge

Report data – "Missed"

- **Scenario 2:** Infant is born in a hospital but the hospital does not have any record of the infant having a hearing screening administered before discharge. The hospital did not report any information to the state or territory about any screenings being administered before or after discharge.

- Report data – "Unknown"

Passed (*final screen*)

- A final screen is defined as the last or most recent, documented hearing screening an infant received.
- Both ears should be screened **at the same time** in order to be reported in a "Passed" category.
- This includes all infants who were documented to have passed a hearing screening, regardless of the age it was completed.

Total Pass

- This value will be automatically calculated based on the fields:
 - [Pass Before 1 Month of Age + Pass After 1 Month of Age but Before Three Months of Age + Pass After 3 Months of Age + Pass: Age Unknown](#)

Pass Before 1 Month of Age

- The total number of infants screened for hearing loss before one month of age who passed (the most recent completed screen).
- A month is equal to *30 days*.
- Pass before one month of age = 0 - 30 days

Pass After 1 Month of Age but Before Three Months of Age

- The total number of infants screened for hearing loss after 1 month of age but before three months of age who passed (the most recent screen).
- Pass after one month, but before three months = 31 - 90 days

Pass After 3 Months of Age

- The total number of infants screened for hearing loss after 3 months of age who passed (the most recent screen).
- Pass after three months = 91+ days

Pass: Age Unknown

- All infants who passed a hearing screening but where the age at the time of the (most recent) screen is unknown.

Not Passed (*final screen*)

- A final screen is defined as the last or most recent documented hearing screening an infant received.
- The total number of infants screened for hearing loss who did **not pass** the screening.
- This consists of all infants who were documented to have not passed a hearing screening, including (*if applicable*) infants that did not pass an in-patient screening and were not documented to have received an out-patient screening.
- Infants who cannot be tested in both ears due to obvious conductive malformations should be reported in the age appropriate field in this "Not Pass" section.

Total Not Pass

- This value will be automatically calculated based on the fields:
 - [Not Pass Before 1 Month of Age](#) + [Not Pass After 1 Month of Age but Before Three Months of Age](#) + [Not Pass After 3 Months of Age](#) + [Not Pass: Age Unknown](#)

Not Pass Before 1 Month of Age

- The total number of infants screened for hearing loss before one month of age that did not pass (the most recent screen).
- A month is equal to 30 days.
- Not pass before one month of age = 0 - 30 days

Not Pass After 1 Month of Age but Before Three Months of Age

- The total number of infants screened for hearing loss after 1 month of age but before three months of age that did not pass (the most recent screen).
- Not pass after one month, but before three months = 31 - 90 days

Not Pass After 3 Months of Age

- The total number of infants screened for hearing loss after 3 months of age that did not pass (the most recent screen).
- Not pass after three months = 91+ days

Not Pass: Age Unknown

- All infants who did not pass a hearing screening but for whom the age at the time of the (most recent) screen is unknown

Optional: Inpatient (IP) /Outpatient (OP) Screening Protocol

Inpatient (IP) /Outpatient (OP) Screening Protocol Only

- This is an *optional* field that is designed to help determine loss to follow-up / loss to documentation during the hearing screening stage. A response is not required.
- Infants screened by a one stage or two stage in-patient protocol should not be reported in this field.
- This field applies to infants screened by facilities that use a two stage IP/OP protocol and should **only** be used to report cases of infants that did not pass the IP screen and were not documented to have received an OP screen due to one of the following reasons: 1) Parents / Family contacted but unresponsive, 2) Unable to contact, or 3) Unknown.
 - These cases must also be reported in the appropriate “No Documented Diagnosis/Undetermined” fields in the Diagnosis section (*i.e.*, *Parents / Family contacted but unresponsive, Unable to contact, or Unknown*).
 - Infants that did not pass the IP screen and were not documented to have received an OP screen due to one of the following reasons 1) Died, 2) Non-resident or moved of jurisdiction, or 3) Parents/family declined services should **not** be reported in this field. Instead, these cases should **only** be reported in the appropriate “No Documented Diagnosis/Undetermined” fields in the Diagnosis section.
- If an infant that was supposed to receive an IP and OP screen did not pass the IP screen, then did not receive the OP screen but was documented as receiving a diagnosis (*i.e.*, *hearing loss or no hearing loss*) they should be considered as having only a one-stage only screening.
 - This means these infants should be reported in the appropriate Hearing Screening “Not Pass” field but **not** included in the optional IP/OP Screening Protocol question. These infants will also need to be reported in the appropriate “No Documented Hearing Loss” or Documented Permanent ID Hearing Loss” field.

Additional IP/OP Notes:

- Some of the infants reported in the preceding “Not Passed” section may be reported in this field.
- Any data entered in this field will not be included in the automatically calculated “Total Not Pass” and “Total Occurrent Births” values in the Screening section.

Sample Scenarios (*Pass/Not Pass*)

- Scenario 3: Infant does not pass any hearing screening administered before being discharged from the hospital *and* passes follow-up screen performed at 21 days post birth
 - Report data – “Pass Before 1 Month of Age”
- Scenario 4: Infant does not pass any hearing screening administered before being discharged from the hospital and passes follow-up screen performed at 45 days post birth
 - Report data – “Pass After 1 month but Before 3 Months of Age”
- Scenario 5: Infant does not pass any hearing screening administered before being discharged from the hospital, does not pass follow-up screen performed at 21 days post birth, and referred for audiology
 - Report data – “Not Pass Before 1 Month of Age”

- **Scenario 6:** Infant does not pass any hearing screening administered before being discharged from the hospital and no follow-up screening is documented
 - Report data – “Not Pass Before 1 Month of Age”
 - * If a two stage IP/OP protocol was being used this infant should also be reported in the “Inpatient (IP) /Outpatient (OP) Screening Protocol Only” field if the infant did not die, was not a non-resident or did not move out of jurisdiction, or the parents/family did not decline the follow-up screening.
- **Scenario 7:** Infant does not pass any hearing screening administered before being discharged from the hospital, does not pass follow-up screening performed at 45 days post birth, and referred for audiology
 - Report data – “Not Pass After 1 month but Before 3 Months of Age”
- **Scenario 8:** Infant born in a facility that uses an IP/OP protocol does not pass the IP hearing screening at 1 day of age and is not documented to have received an OP screen for an *unknown* reason
 - Report data (*in three separate fields*)
 1. Screening Section: “Not Pass Before 1 Month of Age”
 2. Screening Section: “Not Pass IP screen and did not Receive an OP Screen” and
 3. Diagnostic Section: “Unknown”
- **Scenario 9:** Infant born in a facility that uses an IP/OP protocol does not pass the IP hearing screening at 1 day of age and is not documented to have received an OP screen because they were a *non-resident or moved of jurisdiction*
 - Report data (*in two separate fields*)
 1. Screening Section: “Not Pass Before 1 Month of Age”
 2. Diagnostic Section: “Non-resident or Moved Out of Jurisdiction”

Total Occurrent Births (*automatically calculated*)

- This value is automatically calculated based on the fields:
 - Total Pass + Total Not Pass + Infants Died + Parents/Family Declined Services + Missed + Unknown
 - The Inpatient (IP) /Outpatient (OP) Screening Protocol Only field is not included in the totals for the auto calculated “Total Occurrent Births” field.
- The value calculated for “Total Occurrent Births (*automatically calculated*)” must be the **same** as the value listed for “Total Occurrent Births” at the top of the Screening section. If there is **any** difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
 - Use the “Calculate Totals (*yellow fields*)” button near the top of the page to see if there is a difference between these values.
 - Error(s) can be corrected by going back to the Screening section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

Part 1: 2009 Documented Diagnostic Data

- If an infant received a diagnosis and records of more than one diagnostic evaluation/testing appointment are available, only information from the appointment where an initial diagnosis was made should be used when reporting diagnostic data in this section.
 - Example: An infant was diagnosed with a mixed hearing loss during an initial appointment at two months of age. At an appointment at four months of age the diagnosis was updated to a mixed bilateral profound loss. Diagnostic data is to be reported based on the initial appointment at two months, meaning the infant would be reported as diagnosed with hearing loss before three months of age.

Total Not Pass Screening

- This value is from the Screening section and it is automatically entered into the Diagnostic section.
 - It is the same as the “Total Not Pass” value that was calculated in the Hearing Screening section.
-

No Documented Hearing Loss

- Refers to the number of infants born in calendar year 2009 who did not pass a hearing screening but were found to have no documented hearing loss (e.g., normal hearing) following an audiological diagnostic evaluation/testing that included appropriate audiometric test(s).
- Purely conductive transient losses should be reported under the appropriate “No Documented Hearing Loss” category.

Total with No Hearing Loss

- This value will be automatically calculated based on the fields:
 - [No Hearing Loss Before 3 Months of Age + No Hearing Loss After 3 Months but Before 6 Months of Age + No Hearing Loss After 6 Months of Age + No Hearing Loss: Age Unknown](#)

No Hearing Loss Before 3 Months of Age

- Infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) before 3 months of age.
- A month is equal to 30 days.
- Normal hearing before 3 months of Age = up to 90 days.

No Hearing Loss After 3 Months but Before 6 Months of Age

- Infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) after 3 months but before 6 months of age.
- Normal hearing after 3 months but before 6 months of age = 91 - 180 days.

No Hearing Loss After 6 Months of Age

- Infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) after 6 months of age.
- Normal hearing after 6 months of age = 181 + days.

No Hearing Loss Documented: Age Unknown

- Infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) at an unknown age.
-

Documented Permanent Identified (ID) Hearing Loss

- Refers to the number of infants born in calendar year 2009 who did not pass a hearing screening and were diagnosed with a permanent hearing loss following audiological diagnostic evaluation/testing that included appropriate audiometric test(s).

- Permanent hearing loss includes cases of unilateral and bilateral hearing loss, both sensorineural and non-transient conductive hearing loss (e.g., resulting from craniofacial anomalies, ossicular fixation, etc.) and cases of auditory neuropathy.

Total Hearing Loss

- This value will be automatically calculated based on the fields:
 - [Hearing Loss ID Before 3 Months of Age + Hearing Loss ID After 3 Months but Before 6 Months of Age + Hearing Loss ID After 6 Months of Age + Hearing Loss ID: Age Unknown](#)

Hearing Loss ID Before 3 Months of Age

- Infants who did not pass a hearing screening and were identified with a hearing loss (following diagnostic evaluation) before 3 months of age.
- Hearing loss identified before 3 months of age = up to 90 days

Hearing Loss ID After 3 Months but Before 6 Months of Age

- Infants who did not pass a hearing screening and were identified with a hearing loss (following diagnostic evaluation) after 3 months but before 6 months of age.
- Hearing loss identified after 3 months but before 6 months of age = 91 - 180 days

Hearing Loss ID After 6 Months of Age

- Infants who did not pass a hearing screening and were identified with a hearing loss (following diagnostic evaluation) after 6 months of age.
- Hearing loss identified after 6 months of age = 181 + days

Hearing Loss ID: Age Unknown

- Infants who did not pass a hearing screening and were identified with a hearing loss (following diagnostic evaluation) at an unknown age.

Sample Scenarios (*Identified*)

- Scenario 10: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 60 days (*2 months*) indicates permanent hearing loss
 - Report data – “Hearing Loss ID: Before 3 Months of Age”
- Scenario 11: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 150 days (*5 months*) indicates permanent hearing loss
 - Report data – “Hearing Loss ID After 3 Months but Before 6 Months of Age”
- Scenario 12: Infant first seen by audiologist at 45 days, audiological assessment at 240 days (*8 months*) indicates permanent hearing loss.
 - Report data – “Hearing Loss ID After 6 Months of Age”

No Documented Diagnosis / Undetermined

- Refers to the total number of infants born in 2009 that did not pass the most recent hearing screening who do not have a documented diagnosis (i.e., No Hearing Loss or Hearing Loss) or whose status is undetermined.

Total with No Diagnosis

- This value will be automatically calculated based on the fields:
 - [Audiologic Diagnosis in Process \(Awaiting Diagnosis\) + Non-resident or Moved Out of Jurisdiction + Infant Died + Parents / Family Declined Services + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown](#)

Audiologic Diagnosis in Process (Awaiting Diagnosis)

- Refers only to infants who 1) did not pass a hearing screening, 2) have been seen by an audiologist or other approved provider and 3) do not yet have a diagnosis.
- Infants reported in this field must have been seen by an audiologist or other approved provider for diagnostic testing **at least one time and have a follow-up appointment already scheduled**.
 - If an infant has not been seen by an audiologist or other approved provider within 6 months of the last appointment for diagnostic testing and still does not have a documented diagnosis they should be reported in the “Unknown” or other appropriate “No Documented Diagnosis / Undetermined” category.
 - The number of infants reported as being In Process ought to be small as this should be a relatively rare event.

Additional “In Process” Notes:

- Only scheduling an appointment for an initial diagnostic evaluation or making a referral to an audiologist or clinic is not considered “In Process” and should not be reported in this field.
- If a case is considered “Open” by the respondent that does not automatically mean that it should be reported as “In Process.” Cases considered as “Open” should only be reported as being “In Process” if they meet the above stated criteria for this field.
- If an infant has actually been seen by an audiologist and a permanent hearing loss has been established it should be reported in the appropriate “Total Hearing Loss” field.
- If a permanent hearing loss has been diagnosed but the degree is still undetermined it should also be reported in the appropriate “Total Hearing Loss” field.

Non-resident or Moved Out of Jurisdiction

- Refers to cases where infants did not pass a hearing screening and the results of any diagnostic tests are unknown because they were documented to be nonresidents **or** moved (e.g., to another state)
- In cases where information is available about diagnostic testing that a nonresident born in the reporting jurisdiction received, the information should be reported in the appropriate “No Documented Hearing Loss,” “Documented Permanent Identified (ID) Hearing Loss,” or “No Documented Diagnosis” category.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass the IP screen and were not documented to have received an OP screen because of the reason “Non-resident or Moved Out of Jurisdiction” must be reported in this field.

Infant Died

- Infants who did not pass a hearing screening and did not receive diagnostic testing due to death.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass an IP screen and were not documented to have received an OP screen because of the reason “Infant Died” must be reported in this field.

Parents / Family Declined Services

- Infants who did not pass a hearing screening and did not receive diagnostic testing due to documented parental or family refusal.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass an IP screen and were not documented to have received an OP screen because of the reason “Parents/Family Declined Services” must be reported in this field.

Parents / Family Contacted but Unresponsive*Includes cases where:*

- Parents or family of an infant who did not pass the screening were contacted (e.g., by sending letters, making phone calls) but there is no documentation of a response.
 - In this case the program needs to verify that the contact information is correct. If the program does not have correct contact information for the parents or family (e.g., current mailing address, valid phone number) and is unable to obtain correct information this case should be reported as “Unable to Contact.”

- Parents or family of an infant who did not pass the screening were contacted (e.g., by sending letters, making phone calls). The program documented that the parents or family responded that they would bring the infant in for recommended diagnostic testing but they did not show-up for the appointment.
 - In this case an infant must have missed at least one confirmed appointment for diagnostic testing before they can be reported in this category.
- The number reported in this field is used to calculate the number of infant's loss to follow-up / loss to documentation.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass the IP screen and were not documented to have received an OP screen because of the reason "Parents / Family Contacted but Unresponsive" must also be reported in this field.

Unable to Contact

- Infants who did not pass a hearing screening where it is documented that the parents or family were not able to be contacted because the EHDI program/ hospital/provider did not have any current/correct contact information.
 - Examples of reasons for unable to contact include returned letters, a disconnected phone, and returned email messages indicating that the email address does not exist or is not valid.
 - Before classifying a case as "Unable to Contact" the EHDI program should attempt to obtain correct information for the family.
- The number reported in this field is used to calculate the number of infant's loss to follow-up / loss to documentation.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass the IP screen and were not documented to have received an OP screen because of the reason "Unable to Contact" must also be reported in this field.

Unknown

- Infants who did not pass a hearing screening where 1) there is no documentation that they received any follow-up audiologic diagnostic testing and 2) there has been no documented contact with the parents / family (e.g., there is no record that the parents/family declined diagnostic testing).
- The number reported in this field is used to calculate the number of infant's loss to follow-up / loss to documentation.
- *For jurisdictions with an IP/OP screening protocol:* Those infants that did not pass the IP screen and were not documented to have received an OP screen because of the reason "Unknown" must also be reported in this field.

Total Not Pass Screening (*automatically calculated*)

- This value is automatically calculated based on the sum of the values for "Normal Hearing," "Cases of Permanent ID Hearing Loss," and "No Diagnosis/Undetermined."
- The value calculated for "*Total Not Pass Screening* (automatically calculated)" must be the **same** as the value for "*Total Not Pass Screening*" at the top of the Diagnostic section. If there is **any** difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
 - Please use the "Calculate Totals (yellow fields)" button near the top of the page to see if there is a difference between these values.
 - Error(s) can be corrected by going back to the Diagnostic section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

Optional: Documented Cases of Non-Permanent ID Hearing Loss

Cases of non-permanent, transient hearing loss ID

- This is an *optional* field and a response is not required.
- Only cases of transient hearing loss that are not permanent should be reported in this field..
- Infants reported as not passing the final most/recent hearing screening and found to have a non-permanent hearing loss must also be reported in the appropriate “Total with No Hearing Loss” field.
- Any data entered in this field will not be included in the automatically calculated “Total Hearing Loss” field.

Hearing Loss not included in above “Permanent Identified (ID) Hearing Loss”

(e.g., Cases of late onset hearing loss)

- Refers to cases of hearing loss that were **not included** in the “Total Not Pass” value from the previous Hearing Screening Section. Only children born in the jurisdiction (i.e., occurrent births) are to be included.
 - This consists of cases of confirmed hearing loss where infants initially passed the hearing screening (e.g., late onset hearing loss).
 - It may also include children who were missed or whose parents refused a newborn screening.
 - If a case of hearing loss was already reported in the “Normal Hearing,” “Cases of Permanent Identified (ID) Hearing Loss”, or “No Diagnosis / Undetermined” categories it should **not** be included in the “Permanent Hearing Loss not included in Total Not Pass.”
- Intervention data for any cases reported in the previous “*Hearing Loss not included in the Permanent Identified (ID) Hearing Loss*”, should **only** be reported in the “*Cases of Hearing Loss not included in the above Intervention*” Section” that is located near the bottom of the Intervention section.
- Please **do not** report any information about these cases of hearing loss in Part 2 or Part 3 of this survey.

Cases of Hearing Loss Not included in the above “Total Hearing Loss”

- This value will be automatically calculated based on the fields:
 - [Hearing Loss ID: Before 3 Months of Age + Hearing Loss ID After 3 Months but Before 6 Months of Age + Hearing Loss ID After 6 Months of Age + Hearing Loss ID: Age Unknown](#)

Hearing Loss ID Before 3 Months of Age

- Infants identified with a hearing loss (following diagnostic evaluation) before 3 months of age.
- Hearing loss identified before 3 months of age = up to 90 days

Hearing Loss ID After 3 Months but Before 6 Months of Age

- Infants identified with a hearing loss (following diagnostic evaluation) after 3 months but before 6 months of age.
- Hearing loss identified after 3 months but before 6 months of age = 91 - 180 days

Hearing Loss ID After 6 Months of Age

- Infants identified with a hearing loss (following diagnostic evaluation) after 6 months of age.
- Hearing loss identified after 6 months of age = 181 + days

Hearing Loss ID: Age Unknown

- Infants identified with a hearing loss (following diagnostic evaluation) at an unknown age.

Part 1: 2009 Documented Intervention Data

- Information about intervention is only requested for those infants and children with permanent hearing loss who were reported in the “Cases of Permanent Identified (ID) Hearing Loss” section.
- Information about intervention for any cases reported in the “*Hearing Loss not included in above Permanent Identified (ID) Hearing Loss*” should only be reported in the “*Cases of Hearing Loss not included in the above Intervention section*” that is located near the bottom of the Intervention section.
 - Information about late onset and other types of cases should not be included in the data reported in the first part of the Intervention section.

Total Cases Hearing Loss

- This is the same as the “Total Hearing Loss” value that was automatically calculated in the Diagnostic section.

Referrals to Part C Early Intervention (EI)

- Infants identified with a hearing loss who were referred for Part C intervention services
- Includes referrals by the EHDI program or other entities approved to make referrals

Total Referred for Part C EI

- This value will be automatically calculated based on the fields:
 - Eligible for Part C EI + Not Eligible for part C EI + Eligibility Unknown

Referred and Eligible for Part C EI

- Infants identified with a hearing loss who were referred for and **eligible** for Part C intervention services.
- Eligibility is based on jurisdictional rules and/or guidelines for the provision of Part C services to infants and children with hearing loss.

Referred and Not Eligible for Part C EI

- Infants identified with a hearing loss who were referred for but determined to be **ineligible** for Part C intervention services.
- Eligibility is based on jurisdictional rules and/or guidelines for the provision of Part C services to infants and children with hearing loss.

Referred but Eligibility Unknown

- Infants identified with hearing loss who were referred for Part C intervention services where eligibility for services is unknown.

Not Referred to Part C and Unknown

- Includes infants with hearing loss who were either:
 - Not referred for Part C EI.
 - Where it is unknown whether they were referred for Part C or not.

Total Referred, Not Referred and Unknown *(automatically calculated)*

- “*Total Referred, Not Referred and Unknown (automatically calculated)*” is based on the sum of the values for “*Total Referrals to Part C EI*” and “*Total Not Referred to Part C EI and Unknown*”.

- The value calculated for “*Total Referred, Not Referred and Unknown* (automatically calculated)” must be the **same** as the value entered for “*Total Cases Hearing Loss*” listed at the top of the Intervention section. If there is any difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
 - Please use the “Calculate Totals (+)” button near the top of the page to see if there is a difference between these values.
 - Error(s) can be corrected by going back to the Intervention section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

Enrolled in Part C Early Intervention Services

- Infants identified with a permanent hearing loss who were enrolled in jurisdictional Part C early intervention services.
- Due to variability about eligibility and availability, it is the responsibility of each jurisdiction to define what constitutes enrollment in Part C intervention services.

Total Enrolled in Part C EI

- This value will be automatically calculated based on the fields:
 - [Enrolled Before 6 Months of Age + Enrolled After 6 Months but Before 12 Months of Age + Enrolled After 12 Months of Age + Enrolled: Age Unknown](#)

Enrolled Before 6 Months of Age

- Eligible infants identified with permanent hearing losses who were enrolled in Part C early intervention services before 6 months of age.
- Enrolled before 6 months of age = up to 180 days.

Enrolled After 6 Months but Before 12 Months of Age

- Eligible infants identified with a permanent hearing loss who were enrolled in Part C early intervention services after 6 months but before 12 months of age.
- Enrolled after 6 months but before 12 months of age = 181 – 360 days.

Enrolled After 12 Months of Age

- Eligible infants and children identified with permanent hearing losses who were enrolled in Part C early intervention services after 12 months of age.
- Enrolled after 12 months of age = 361 + days.

Enrolled: Age Unknown

- Eligible infants and children identified with a permanent hearing loss who were enrolled in Part C early intervention services at an unknown age.

Monitoring Services

Receiving Only Monitoring Services

- Infants with a permanent hearing loss that were only receiving monitoring services.
- Infants receiving any type of intervention services (including Part C and non-Part C) should not be reported in this field.

Receiving **ONLY** Intervention Services from Non-Part C EI

- Infants identified with a permanent hearing loss who were only enrolled in **Non-Part C** early intervention services.
- If an infant is receiving both Part C and non-Part C services, they should not be included in this section.
- Due to variability about eligibility and availability, it is the responsibility of jurisdiction to define what constitutes enrollment in non-Part C intervention services.

Total Services from Non-Part C EI services

- This value will be automatically calculated based on the fields:
 - [Services Before 6 Months of Age + Services After 6 Months but Before 12 Months of Age + Services After 12 Months of Age + Services: Age unknown](#)

Services Before 6 Months of Age

- Infants identified with permanent hearing losses who were enrolled in only non-Part C early intervention services before 6 months of age.
- Services before 6 months of age = up to 180 days.

Services After 6 Months but Before 12 Months of Age

- Infants identified with a permanent hearing loss who were enrolled in only non-Part C early intervention services after 6 months but before 12 months of age.
- Services after 6 months but before 12 months of age = 181 – 360 days.

Services After 12 Months of Age

- Infants and children identified with permanent hearing losses who were enrolled in only non-Part C early intervention services after 12 months of age.
- Services after 12 months of age = 361 + days.

Services: Age unknown

- Infants and children identified with permanent hearing losses who were enrolled in only non-Part C early intervention services at an unknown age.

No Intervention Services

- Refers to cases of infants with permanent hearing loss where either 1) they are not receiving any intervention services (Part C or non-Part C services) or 2) it is unknown whether they are receiving any intervention services or not.

Total No Services

- This value will be automatically calculated based on the fields:
 - [Not Eligible for Services + Infant Died + Parents Declined Services + Non-resident or Moved Out of Jurisdiction + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown](#)

Not Eligible for Services

- Infants with a permanent hearing loss that were not eligible for Part C early intervention services
- This number should be the same as the number reported in “Referred and Not Eligible for Part C EI” field (located in the “Total Referred for Part C EI” section).

Infant Died

- Infants with a diagnosed hearing loss who were not enrolled in early intervention due to the death of the infant or child.

Parents / Family Declined Services

- Infants with a diagnosed hearing loss who were not enrolled in early intervention services due to documented parental or family refusal.

Non-resident or Moved Out of Jurisdiction

- Unknown whether infants with confirmed hearing loss are receiving early intervention services or not because either they were documented to be nonresidents **or** moved (e.g., to another state).

Parents / Family Contacted but Unresponsive*Includes cases where:*

- Parents or family of an infant with a permanent hearing loss were contacted (e.g., by sending letters, making phone calls) about enrollment in early intervention services but there is no documentation of a response.
 - In this case the program needs to verify that the contact information is correct. If the program does not have correct contact information for the parents or family (e.g., current mailing address, valid phone number) and is unable to obtain correct information this case should be reported as “Unable to Contact.”

Unable to Contact

- Infants with a permanent hearing loss where it is documented that the parents or family were not able to be contacted about enrollment in early intervention services because the EHDI program/provider did not have any current/correct contact information..
 - Examples of reasons for unable to contact include returned letters, a disconnected phone, and returned email messages indicating that the email address does not exist or is not valid.
 - Before classifying a case as “Unable to Contact” the EHDI program should attempt to obtain correct information for the family.
- The number reported in this field is used to calculate the number of infant’s loss to follow-up / loss to documentation for intervention.

Unknown

- Infants with a permanent hearing loss where 1) there is no documentation that they received any early intervention services and 2) there has been no documented contact with the parents / family (e.g., there is no record that the infant was not eligible for intervention services).
- The number reported in this field is used to calculate the number of infant’s loss to follow-up / loss to documentation for intervention.

Total Intervention & No Services *(automatically calculated)*

- This value will be automatically calculated based on the fields:
 - **Enrolled in Part C EI + Monitoring Services + Intervention from Only Non-Part C + No Intervention Services**
- The value calculated for “Total Intervention & No Services *(automatically calculated)*” must be the **same** as the value for “*Total Cases of Hearing Loss*” listed at the top of this section. If there is **any** difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
 - Use the “Calculate Totals (yellow fields)” button near the top of the page to see if there is a difference between these values.
 - Error(s) can be corrected by going back to the Intervention section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

Cases of Hearing Loss not included in the above “Intervention” Section (*e.g., Cases of late onset hearing loss*)

- Cases of hearing loss that were initially reported in the “Hearing Loss not included in above Permanent Identified (ID) Hearing Loss (*e.g., Cases of permanent late onset hearing loss*)” in the Diagnostics section.
 - This consists of cases of confirmed hearing loss where infants initially passed the hearing screening (*e.g., late onset hearing loss*).
 - It may also include children who were missed or whose parents refused a newborn screening.
 - If a case of hearing loss was already reported in the “Normal Hearing,” “Cases of Permanent Identified (ID) Hearing Loss”, or “No Diagnosis / Undetermined” categories it should **not** be included in the “Permanent Hearing Loss not included in Total Not Pass.”

Hearing Loss Not included in above “Intervention” Section (*automatically calculated*)

- This value will be automatically calculated based on the following fields in this section:
 - **Total Enrolled in Part C EI + Total Services from Non-Part C EI services + No Intervention: Monitoring Only + No Intervention: Unknown**
- The value calculated for “*Hearing Loss Not included in above Intervention Section*” must be the **same** as the value for “*Total Cases of Hearing Loss (not included above)*” in the Diagnostics section. If there is **any** difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
 - Use the “Calculate Totals (yellow fields)” button near the top of the page to see if there is a difference between these values.
 - Error(s) can be corrected by going back to the Intervention section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

Total Enrolled in Part C EI

- Eligible infants identified with permanent hearing losses who were enrolled in Part C early intervention services

Total Services from Non-Part C EI services

- Infants identified with permanent hearing losses who were enrolled in only non-Part C early intervention services before 6 months of age.

No Intervention: Monitoring Only

- Infants with a permanent hearing loss who were only receiving monitoring services.
- Infants receiving any type of intervention services (including Part C and non-Part C) should **not** be reported in this field.

No Intervention: Unknown

- Infants with a permanent hearing loss where there is no documentation that they have received any early intervention services.

Part 2: Hearing Loss Type and Severity

- The type, laterality, and severity for every case of permanent hearing loss reported in Part 1 (“Total Hearing Loss”) must be reported in Part 2.
 - This information should only be for permanent cases of hearing loss identified in infants and children **born in calendar year 2009**.
 - Data should be reported from the **most recent/complete** diagnostic evaluation/testing if there are records of more than one evaluation available.
 - The most detailed diagnostic data for permanent cases of hearing loss reported in Part 1 (Diagnosis section) should be reported in this part of the survey.
 - For example if an infant was initially diagnosed with a sensorineural loss (*no severity data provided*) and during a later appointment the diagnosis is updated to be a sensorineural profound bilateral loss, only data from this most recent/complete appointment (*i.e., sensorineural profound bilateral*) is to be reported.
- If an infant that did not pass the final/most recent hearing screening initially had a diagnosis of hearing loss but was later diagnosed with no hearing loss report these cases in the field “Total Cases Resolved (*i.e., No permanent hearing loss*)” located near the bottom of the Type and Severity table.
- If an infant that did not pass the final/most recent hearing screening initially had a diagnosis of no hearing loss but was later diagnosed with a hearing loss do **not** report type and severity data for this case.
 - If this has occurred please report the total number of cases that changed from an initial diagnosis of no hearing loss to a later diagnosis of hearing loss in the “Comments” section at the end of Parts 1 and 2.
- To complete Part 2 the value for “Overall Total” (*located at the bottom of the table*) must be the **same** as the value for “Total Cases of Permanent Hearing Loss” that was reported in Diagnostics section of Part 1 (*and shown above the table*). If there is any difference between these values you will receive an error message and will not be able to continue with the survey until you correct the error.
- The value for “Overall Total” will be automatically calculated based on the following fields in this section:
 - **Totals by Child (Bilateral / right and left ear) + Totals by Child (Bilateral / Unknown ear) + Totals by Child (Unilateral / right ear) + Totals by Child (Unilateral / left ear) + Totals by Child (Unilateral / Unknown ear) + Totals by Child (Laterality Unknown) + “Total Cases Resolved (*i.e., change from hearing loss to no hearing loss*)”**

Part 2: Organization

- The table in Part 2 is organized into different sections so that the type, laterality and severity for each case of permanent hearing loss can be reported, even if one or more of these data components is unknown.
- Laterality is organized into three separate columns that include Bilateral, Unilateral, and Laterality Unknown (*fields for right ear, left ear, and unknown ear are included in the Bilateral and Unilateral columns*).
- Type is organized into three separate sections (organized by row) that include: Sensorineural, Conductive, Mixed, Type Unknown, and Auditory Neuropathy / Dyssynchrony (*fields for severity are included for each type of hearing loss section*).

Type of Hearing Loss

- Permanent types of hearing loss that can be reported include sensorineural, conductive, mixed, unknown, and auditory neuropathy/dyssynchrony.
 - Although there will be children with fluctuating conductive conditions, for the purpose of this survey **only** those with permanent hearing loss including unilateral and bilateral hearing loss and both sensorineural and non-transient conductive hearing loss (e.g., resulting from craniofacial anomalies, ossicular fixation, etc.) should be reported.
 - Jurisdictions may wish to maintain separate records for children identified with hearing loss of a non-congenital origin, such as fluctuating conductive losses.

Severity of Hearing Loss

- For cases of *sensorineural* and mixed hearing loss the severity can be reported as mild, moderate, severe, or profound. For cases of *conductive* hearing loss the severity can be reported as mild, moderate, or severe.
- If the severity is unknown please use the appropriate “Unknown Severity” field.

Laterality of Hearing Loss

Unilateral Hearing Losses (i.e., loss in one ear)

- The ear with the loss (i.e., right or left) and the type and severity of the loss should be reported.
- If it is unknown if the hearing loss is in the right or left ear use the appropriate “Unknown Ear” field.

Bilateral Hearing Losses (i.e., loss in both ears)

- The type and severity of hearing loss in each ear (i.e., right and left) should be reported.
- If the type of the loss in the right and/or left ear is unknown use the appropriate “Unknown Ear” field(s).

Laterality Unknown

- If the laterality of hearing loss is unknown use the appropriate “Laterality Unknown” field.
- The type and severity can be reported for cases with an unknown laterality.

Hearing Loss Criteria

- Severity or the degree of hearing loss provides information regarding the average/estimated hearing across the speech frequency range
- The categories below and their corresponding decibel (dB) ranges currently used for this survey are listed below. These categories and dB ranges will be used for the 2009 and 2010 surveys.

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

- If your jurisdiction uses different dB ranges, please select the “No” option in the “Hearing Loss Criteria” table and list the ranges that are used. If different categories are used to classify hearing loss, please list those categories and their corresponding dB ranges in the “Comments” field at the end of this survey.

Sample Scenarios (Type/Severity)

- Scenario 13: Infant diagnosed with a permanent sensorineural, bilateral hearing loss with a severe loss in the right ear and a mild loss in the left ear (noted by "A").
- Scenario 14: Infant diagnosed with a permanent sensorineural, bilateral hearing loss with a moderate loss in one ear and a loss of unknown severity in the other ear (noted by "B").
- Scenario 15: Infant diagnosed with a permanent conductive, bilateral hearing loss with a severe loss in both the right and left ears (noted by "C").
- Scenario 16: Infant diagnosed with a conductive permanent hearing loss (noted by "D").
- Scenario 17: Infant diagnosed with a bilateral sensorineural permanent hearing loss with a severe loss in the right ear and a loss of unknown severity in the left ear (noted by "E")

		BILATERAL			UNILATERAL			LATERALITY UNKNOWN <i>(for CASES where it is unknown if the loss is unilateral or bilateral)</i>
		RIGHT EAR	LEFT EAR	UNKNOWN EAR <i>(Note: record degree of loss for each ear)</i>	RIGHT EAR	LEFT EAR	UNKNOWN EAR	
Sensorineural	Mild		A					
	Moderate			B				
	Severe	A, E						
	Profound							
	Unknown Severity		E	B				
Conductive	Mild							
	Moderate							
	Severe	C	C					
	Unknown Severity							D
Totals by Ear		3	3	1	1			1
Totals by Child		3		1				1

Submitting Parts 1 and 2

- After completing all the sections you can check the data you entered by clicking on the section(s) you want to review by using the menu bar at the top of the screen (*this is not required*). Once you are sure the data is correct please proceed to the "Finalize" section listed in the menu bar.
- Once in the "Finalize" section you will be asked to enter your name, email address (*twice to ensure it is correct*), and the jurisdiction you are reporting data for.
 - Please note you need to enter this same email address in order to access Part 3 of this survey.
- Any notes can be entered in the "Comments" field at the end of the survey (*in the Finalize section*).
- Once you have entered this information please select the red "Submit Survey" button located under the "Comments" field. This will mark the completion of Parts 1 and 2.
 - **Please note:** Responses to Parts 1 and 2 can only be submitted once.

- If you have included commas with any of the numbers you entered you will **not** be able to submit the survey.
- Once the survey has been submitted a summary of all the data that has been entered will be displayed. This summary can be printed or exported into Microsoft Excel and then saved.

Part 3: Demographics

- Parts 1 and 2 of this survey must be completed **before** Part 3 can be accessed.
- Part 3 can only be accessed by using the **same** email address that was entered when submitting Parts 1 and 2.
- Aggregate, demographic information is requested related to gender, maternal age, education, ethnicity, and race for selected data items from Part 1. This part of the survey consists of separate three sections and requests the following data from Part 1:
 - Screening Demographics: Total Occurrent Births, Total Pass, Total Pass Before 1 Month, Total Not Pass, and Total Not Pass Before 1 Month.
 - Diagnostic Demographics: Normal Hearing, Normal Hearing Before 3 Months, Hearing Loss, and Hearing Loss Before 3 Months.
 - Intervention Demographics: Total Enrolled in Part C, Total Enrolled in Part C Before 6 Months, Total Services from *Non*-Part C EI, and Total Services from *Non*-Part C EI Before 6 Months.
- The selected data from Part 1 (e.g., Total Occurrent Births) will automatically appear in Part 3 in the **yellow** boxes at the top.
- Error checks are included to help ensure the consistency and accuracy of the demographic data.
 - For example, if the *Total Occurrent Births* was reported as **100** in Part 1, the total of the numbers reported for “Male,” “Female,” and “Unknown” **must equal 100**. If the numbers do not match respondents will receive an error message asking them to correct the data.
- Please click the "**Refresh Totals (+)**" button at the top of each section (i.e., Screening Diagnostics, and Intervention) to check that all the totals match the data from Part 1 before moving to a different section.
- If the totals in each section do not match you will see a **red asterisk (*)** by each automatically calculated total that does not match the number(s) from Part 1.
 - It is not possible to submit Part 3 until all errors have been corrected.
- **Note:** Please use the “Other” category to report any mothers classified as “**multiple race.**”

Submitting Part 3

- After entering all requested data please proceed to the “**Finalize**” section listed in the menu bar.
- Any notes about the demographic data can be entered in the “Comments” field.
- Once you have entered any notes (*if needed*) select the **red “Submit Survey”** button.
 - **Please note:** Responses to Part 3 can only be submitted once.
- If you included commas with any of the numbers you entered you will **not** be able to submit the survey.
- Once the survey has been submitted a summary of all the data that has been entered will be displayed. This summary can be printed or exported into Microsoft Excel and then saved.