# CDC-EHDI Hearing Screening and Follow-up Survey (HSFS): 2008 Explanations



This document provides an explanation for the majority of fields in the 2008 CDC-EHDI HSFS, which is a voluntary response survey. All requested data <u>only</u> refers to infants and children born in calendar year **2008** (i.e., January 1, 2008 – December 31, 2008). If you have any questions, please contact Marcus Gaffney at (404) 498-3031 or <u>MGaffney@cdc.gov</u>

# **Please Note**

- Fields highlighted in yellow are "Totals" that will be automatically calculated by the survey.
- To help <u>avoid</u> <u>error messages</u> press the "<u>Calculate Totals (+)</u>" button near the top of each page before going to the next section. This will allow you to check that the calculated totals match (*e.g.*, # of births).
- **Do not use** the "Enter" key or include any commas with the data you enter in the survey.
- 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.
- "0" will sometimes appear in blank fields in the survey. You can delete this "0" before entering data <u>or</u> simply enter the data after the "0" without any spaces (e.g., 0100).

| • | art 1: 2008 Hearing Screening Data (Occurrent Births)   |                       |
|---|---|-----------------------|
|   | <ul> <li>Total Occurent Births</li> <li>Hearing Screening</li> <li>Sample Scenarios (Unknown / Missed)</li> <li>Passed (final screen)</li> <li>Not Passed (final screen)</li> <li>Sample Scenarios (Pass/Not Pass)</li> <li>Total Occurent Births (automatically calculated)</li> </ul>   | 1<br>2<br>2<br>2<br>3 |
| • | art 1: 2008 Diagnostic Data (Occurrent Births)  |                       |
|   | <ul> <li>Total Not Pass.</li> <li>Normal Hearing.</li> <li>Cases of Permanent Identified (ID) Hearing Loss.</li> <li>Sample Scenarios (Identified).</li> <li>No Diagnosis / Undetermined.</li> <li>Total Not Pass Screening (automatically calculated).</li> <li>Permanent Hearing Loss not included in "Total Not Pass"</li> </ul>   | 5<br>6<br>6<br>7      |
| • | art 1: 2008 Early Intervention Data (Occurent Births)   |                       |
|   | <ul> <li>Total Cases Hearing Loss</li> <li>Referrals to Part C Early Intervention (EI)</li> <li>Total Referred, Not Referred and Unknown (<i>automatically calculated</i>).</li> <li>Enrolled in Part C Early Intervention Services</li> <li>Receiving ONLY Intervention Services from Non Part C EI</li> <li>No Services</li> <li>Total Intervention &amp; No Services (<i>automatically calculated</i>).</li> </ul> | 9<br>9<br>10<br>10    |
| • | art 2: 2008 Hearing Loss Type and Severity  |                       |
|   | <ul> <li>Type</li> <li>Severity</li> <li>Laterality</li> <li>Hearing Loss Criteria</li> </ul>   | 12<br>12              |
| • | art 3: 2008 Demographics  Overview and Notes  | 15                    |

# Part 1: 2008 Hearing Screening Data (Occurrent Births)

#### **Total Occurrent Births**

- The number entered here should represent the total number of <u>live, occurrent births</u> (within the reporting state, territory, or district) born in calendar year 2008.
- This should include any infants born in the reporting state or territory, even if they are legal residents of another state or territory.

# **Total Occurrent Births Reported by Vital Records**

- The number of live, occurrent births according to the state or territorial Vital Records program.
- 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

# **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 done at two weeks.
- Infants that can not 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 Screened**

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

#### **Total Not Screened**

- This value will be automatically calculated based on the fields:
  - Infants Died/Parents Declined Services + Unknown/Missed

# Infant Died / Parents Declined Services

Infants that were not screened due to death or parental refusal of the screening.

#### Unknown / Missed

- Includes cases where either 1) an infant did not receive a hearing screening (i.e., missed) or 2) where it cannot be confirmed if an infant was screened for hearing loss (i.e., unknown)
  - o Includes cases where results of hearing screenings are not reported to the state or territory.
  - Infants not screened due to either death or parental refusal should <u>not</u> be reported in this category.
- Infants that 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 included in this category.
- Infants that can not be tested in both ears due to obvious conductive malformations should be reported in the appropriate "Not Pass" category instead of the "Unknown/Missed" category.

# Sample Scenarios (Unknown/Missed)

- <u>Scenario 1</u>: Infant does not have any hearing screening administered before being discharged from the hospital *and* does not have follow-up screens performed
  - Report data "Unknown/Missed"
- <u>Scenario 2</u>: Infant is born in a hospital but no information about if a hearing screening was done before discharge is reported to the state or territory *and* no information about any screenings being administered after discharge is reported.
  - o Report data "Unknown/Missed"

# Passed (final screen)

- A final screen is defined as the last or most recent hearing screening an infant received.
- Both ears must be screened in order to be reported in a "Passed" category.
- This should include all infants that 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 that passed (the most recent 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 that 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 that passed (the most recent screen).
- Pass after three months = 91+ days

# Pass: Age Unknown

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

# Not Passed (final screen)

- A final screen is defined as the last or most recent hearing screening an infant or child received.
- The total number of infants screened for hearing loss that did not pass the screening.
- This should include all infants that did **not** pass a hearing screening, regardless of the age it was completed.
- Infants that can not be tested in both ears due to obvious conductive malformations should be reported in the appropriate "Not Pass" category instead of the "Missed" category.

• This includes (for those states and territories with an inpatient/outpatient protocol) infants who did not pass their inpatient screen and then did <u>not</u> complete their outpatient screen (e.g., if the first screen was completed before one month please report this result in the "Not Pass Before 1 Month of Age" field).

#### **Total Not Pass**

- This value will be <u>automatically</u> 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 that did not pass a hearing screening but where the age at the time of the (most recent) completed screening is unknown

# Sample Scenarios (Pass/Not Pass)

- <u>Scenario 3</u>: 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"
- <u>Scenario 4</u>: 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"
- <u>Scenario 5</u>: 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"
- <u>Scenario 6</u>: Infant does not pass any hearing screening administered before being discharged from the hospital and no follow-up screening documented
  - Report data "Not Pass Before 1 Month of Age"

- <u>Scenario 7</u>: Infant does not pass any hearing screening administered before being discharged from the hospital, does not pass follow-up screen performed at 45 days post birth, and referred for audiology
  - Report data "Not Pass After 1 month but Before 3 Months of Age"

# Total Occurrent Births (automatically calculated)

- This value is automatically calculated based on the sum of the values reported for "Total Pass," "Total Not Pass," Infants Died/Parents Declined Services," and "Unknown/Missed."
- The value calculated for "Total Occurrent Births (automatically calculated)" should **match** the value that was entered for "Total Occurrent Births" at the top of this section.
- If there is <u>any</u> 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 Screening section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

# Part 1: 2008 Diagnostic Data (Occurrent Births)

- If there are records of more than one diagnostic evaluation available, information from only the <u>initial</u> comprehensive audiologic evaluation should be used to report data in the Diagnostic section.
  - o "Comprehensive" is used because it is the term listed in the National EHDI Goals. It will be up to the individual EHDI program to determine what constitutes the initial diagnosis.

## **Total Not Pass Screening**

- This value is taken from the Screening section and 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.

# **Normal Hearing**

- Includes infants that did not pass a hearing screening but were found to have normal hearing following an audiological diagnostic evaluation.
- Purely conductive transient losses should be reported under the appropriate "Normal Hearing" category.

## **Total Normal Hearing**

- This value will be automatically calculated based on the fields:
  - Normal Hearing Before 3 Months of Age + Normal Hearing After 3 Months but Before 6 Months of Age + Normal Hearing After 6 Months of Age + Normal Hearing: Age Unknown

## Normal Hearing Before 3 Months of Age

- Infants that did not pass a hearing screening but were found to have normal hearing (following audiological 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

## Normal Hearing After 3 Months but Before 6 Months of Age

- Infants that did not pass a hearing screening but were found to have normal hearing (following audiological 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

#### Normal Hearing After 6 Months of Age

- Infants that did not pass a hearing screening but were found to have normal hearing (following audiological diagnostic evaluation) after 6 months of age.
- Normal hearing after 6 months of age = 181 + days

## Normal Hearing: Age Unknown

• Infants that did not pass a hearing screening but were found to have normal hearing (following audiological diagnostic evaluation) at an unknown age.

# Cases of Permanent Identified (ID) Hearing Loss

- Infants that did <u>not</u> pass a hearing screening who were diagnosed with a permanent hearing loss following audiologic diagnostic evaluation.
- Refers to the number of infants <u>born</u> in calendar year 2008 who were identified with a permanent hearing loss (*i.e.* the number of children born in a state or territory in 2008 that were identified with hearing loss).
- Permanent hearing loss includes <u>unilateral and bilateral hearing loss</u>, both sensorineural and non-transient conductive hearing loss (e.g., resulting from craniofacial anomalies, ossicular fixation, etc.) and cases of auditory neuropathy.

Hearing loss should be confirmed through appropriate audiometric test(s).

# **Total Hearing Loss**

- This value will be <u>automatically</u> 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 that did not pass a hearing screening who were identified with a hearing loss (following audiological 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 that did not pass a hearing screening who were identified with a hearing loss (following audiological 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 that did not pass a hearing screening who were identified with a hearing loss (following audiological diagnostic evaluation) after 6 months of age.
- Hearing loss identified after 6 months of age = 181 + days

## Hearing Loss ID: Age Unknown

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

# Sample Scenarios (Identified)

- Scenario 8: 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 9: 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"
- <u>Scenario 10</u>: 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 Diagnosis / Undetermined

• Refers to the total number of infants and children (not passing a hearing screening) that do not have a diagnosis (i.e., Normal Hearing or Hearing Loss) or whose status is undetermined (i.e., diagnosis is still in process).

## **Total with No Diagnosis**

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

# **NEW:** Audiologic Diagnosis in Process (Awaiting Diagnosis)

- Refers to infants that did not pass a hearing screening where a diagnosis has not yet been made because audiological diagnostic evaluation is still ongoing.
- Infants reported in this category must have been seen by an audiologist for diagnostic testing <u>at least</u> one time.
- Scheduling an appointment for an initial diagnostic evaluation or making a referral to an audiologist or clinic is not considered "In Process".
- If an infant/child has actually been seen by an audiologist <u>and</u> a permanent hearing loss has been established it should be reported as a "confirmed hearing loss."
  - If a permanent hearing loss has been diagnosed but the degree is still undetermined it should also be reported as a "confirmed hearing loss."

## Infant Died / Parents Declined Services

• Refers to infants and children that did not pass a hearing screening but who did not complete audiologic diagnostic evaluation due to either 1) parental refusal of diagnostic testing or 2) death.

## 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 either the:
  - o Infants were nonresidents or
  - Infants moved to another state or territory
- In cases where information about diagnostic testing that a nonresident received (in the reporting state or territory) is available, the information should be reported in the appropriate "Normal Hearing," "Cases of Permanent Identified (ID) Hearing Loss," or "No Diagnosis" category.

# <u>Unable to contact / Unresponsive / Unk</u>nown

- Refers to those infants that did not pass a hearing screening where the parents/family were not able to be contacted or were unresponsive about the need for diagnostic testing.
- If it is unknown if an infant received audiologic diagnostic testing they should be reported in this category.
- This should include all remaining cases where it is not known if the child ever received any audiologic diagnostic services.

# **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)" should match the value for "Total Not Pass Screening" at the top of the Diagnostic section.
- If there is <u>any</u> 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 "<u>Calculate Totals(+)</u>" 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).

# Permanent Hearing Loss <u>not</u> included in "Total Not Pass" (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 state (i.e., occurrent births) are to be included.
  - This consists of cases of confirmed hearing loss where infants initially passed the screening (e.g., late onset hearing loss).

- It may also include children who were missed or who parents refused 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 <u>not</u> be included in the "Permanent Hearing Loss not included in Total Not Pass."
- For any cases reported in the "Permanent Hearing Loss not included in Total Not Pass", please do <u>not</u> include any information about intervention for these cases in the "Intervention" section.
- Also, please do not report any information about these cases 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 <u>automatically</u> 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 audiological 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 audiological 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 audiological 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 audiological diagnostic evaluation) at an unknown age.

# Part 1: 2008 Early Intervention Data (Occurent Births)

- Information about intervention is only requested for those infants with hearing loss that were reported in the "Cases of Permanent Identified (ID) Hearing Loss" section.
- Please do not report information about intervention for any cases reported in the "Permanent Hearing Loss not included in Total Not Pass" section

## **Total Cases Hearing Loss**

- This value is taken from the Diagnostic section and is automatically entered into the Intervention section.
- It is the same as the "Total Hearing Loss" value that was calculated in the Diagnostic section.

# Referrals to Part C Early Intervention (EI)

- Infants identified with a hearing loss that were referred for Part C intervention services
- Includes referrals by the state or territorial 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:
  - o Eligible for Part C EI + Not Eligible for part C EI + Eligibility Unknown

# Eligible for Part C EI

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

#### Not Eligible for part C El

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

#### Eligibility Unknown

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

## Total Not Referred to Part C and Unknown

- Includes infants with hearing loss that were either:
  - Not referred for Part C El or
  - o Where it is unknown if they were referred for Part C

# 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 El" and "Total Not Referred to Part C El and Unknown".
- The value calculated for "Total Referred, Not Referred and Unknown (automatically calculated)" should match the value entered for "Total Cases Hearing Loss" at the top of this page.
- 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 "<u>Calculate Totals (+)</u>" 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 and children identified with a permanent hearing loss who are enrolled in state or territorial Part C early intervention services.
- Due to variability about eligibility and availability, it is the responsibility of each state and territory to define what constitutes enrollment in Part C intervention services.

#### **Total Enrolled in Part C El**

- 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 that are 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 that are 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 that are 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 are enrolled in Part C early intervention services at an unknown age

# Receiving ONLY Intervention Services from Non-Part C El

- Infants and children identified with a permanent hearing loss who are <u>only</u> enrolled in <u>non-Part C</u> early intervention services.
- If a child 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 each state and territory to define what constitutes enrollment in non-Part C intervention services.

## **Total Services from Non-Part C El 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 that are enrolled in 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 that are enrolled in 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 that are enrolled in 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 that are enrolled in non-Part C early intervention services at an unknown age.

#### **No Services**

 Refers to cases of infants and children 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 if they are receiving any intervention services.

#### **Total No Services**

- This value will be automatically calculated based on the fields:
  - Infant Died / Parents Declined Services + Non-resident or Moved Out of Jurisdiction + Unable to Contact / Unresponsive / Unknown

# Infant Died / Parents Declined Services

• Refers to infants and children with a diagnosed hearing loss that were not enrolled in intervention due to either 1) parental refusal or 2) death of the infant or child.

#### Non-resident or Moved Out of Jurisdiction

- Refers to cases where it is unknown if infants and children with a confirmed hearing loss are receiving intervention because either the:
  - Infant or child were nonresidents or
  - o Infant or child moved to another state or territory

# Unable to contact / Unresponsive / Unknown

- Refers to infants and children with a confirmed hearing loss where the parents/family were not able to be contacted or were unresponsive about the need for intervention services.
- If it is unknown if an infant or child is receiving intervention services they should be reported in this
  category.

# **Total Intervention & No Services** (automatically calculated)

- The value for "Total Intervention & No Services (automatically calculated)" is based on the sum of the values for "Enrolled in Part C, "Receiving only non Part C," and "No Services."
- The value calculated for "Total Intervention & No Services (automatically calculated)" should be the **same** as the value for "Total Cases of Hearing Loss" listed at the top of this section.
- If there is <u>any</u> 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 "<u>Calculate Totals (+)</u>" 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).

# Part 2: 2008 Hearing Loss Type and Severity

- When reporting data about the type and severity of <u>permanent</u> hearing loss, please use information from the <u>most recent</u> audiologic evaluation if you have records of more than one evaluation.
- Information about the type, severity, and laterality for the total number of identified cases of hearing loss is requested to be reported in these tables.
  - o Information should only be reported for permanent cases of hearing loss identified in infants and children **born in calendar year 2008**.
- This section of the survey consists of four tables that each relate to a specific type of hearing loss.
  - Sensorineural
  - Conductive
  - Mixed
  - Auditory Neuropathy / Dyssynchrony

# **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 <u>unilateral and bilateral hearing loss</u> and both
     sensorineural and non-transient conductive hearing loss (e.g., resulting from craniofacial anomalies,
     ossicular fixation, etc.) should be reported.
  - States and territories 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.
- Cases where the type and laterality (i.e., unilateral or bilateral) of a hearing loss are known but the severity is unknown should be reported in the appropriate "Severity Unknown" field.
- **NEW:** Cases where the <u>type of hearing loss is unknown</u> should be reported in the "Permanent Type Unknown" table.

# **Laterality of Hearing Loss**

- Unilateral refers to a hearing loss in one ear and bilateral refers to a hearing loss in both ears
- Cases where the type and severity of a hearing loss are known but the laterality is <u>unknown</u> should be reported in the appropriate "Laterality Unknown" field.
  - For example, if a child is reported with a sensorineural moderate hearing loss but it is unknown if the loss is unilateral or bilateral please use the "Laterality Unknown" field to report that case.
- The 2008 survey asks for the type and severity of hearing loss by the "better ear" (i.e. the ear with the least severe loss) and "worse ear" (i.e., the ear with the most severe loss) instead of by right and left ear.
  - Unilateral: respondents do not have to report if the loss is in the right or left ear.

 Bilateral: respondents are asked to report the degree of loss in both the "better" and "worse" ear (please see below "Note" for further explanation).

# Bilateral Hearing Losses

- Note: If it is not possible to report data by better ear / worse ear please report data by right ear / left ear instead. This can be done by:
  - o Reporting right ear hearing losses in the "worse" ear field.
  - o Reporting left ear hearing losses in the "better" ear field.
  - If data for right ear and left ear is being reported please note this in the comments field at the end of Parts 1 and 2 of the survey.
- If data is available about the type and severity of hearing loss in each ear please use the appropriate "better ear" and "worse ear" fields to report this information in the following way:
  - o For example, a sensorineural bilateral loss with mild in the left ear and moderate in the right ear: Please report this by noting the mild loss in the "better ear" sensorineural bilateral mild field and moderate loss in the "worse ear" sensorineural bilateral moderate field.
- In cases where the type is known but the <u>severity is unknown</u> please report this information in the following way:
  - o For example, conductive bilateral hearing loss with no information about severity. Please report this by noting a loss in the <u>unknown field</u> for conductive bilateral better ear and also the <u>unknown field</u> for conductive bilateral worse ear.

# **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 used for this survey are listed below.

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

- If your state or territory uses different dB ranges, please select the "No" option in this table and then list the ranges used in your state or territory in the appropriate fields.
- If your state or territory uses different categories to classify hearing loss, please list those categories and there corresponding dB ranges in the "Comments" field in the "Finalize" section of this survey

# Reviewing and Submitting Parts 1 and 2

- After completing <u>all</u> 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 (*this is not required*). Once you are sure the data is correct please proceed to the "Finalize" section by using 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 state or territory you are reporting data for.
  - Please note you will 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. This will be the end of Parts 1 and 2.
  - o Please note: Responses to Parts 1 and 2 can only be submitted one time.
- 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: 2008 Demographics

- Parts 1 and 2 of this survey must be completed <u>before</u> Part 3 can be accessed.
- Part 3 can only be accessed by using the same email address that was entered in Parts 1 and 2.
- The 2008 survey requests aggregate, demographic information related to gender, maternal age, education, ethnicity, and race for selected data from Part 1 of the survey. This part of the survey consists of three sections and requests the following data from Part 1:
  - Screening Demographics: Total Occurrent Births, Total Pass, and Total Not Pass
  - o Diagnostic Demographics: Normal Hearing and Hearing Loss
  - o Intervention Demographics: Total Enrolled in Part C and Total Services from *Non-Part C El*
- 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 have been added 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.
- **NEW:** The "Maternal Race" category for 2008 has been expanded to include the following choices: White (Not Hispanic), White (Hispanic), White (Ethnicity Unknown). Black or African American (Not Hispanic), Black or African American (Hispanic), and Black or African American (Ethnicity Unknown).
- 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.
  - o It is not possible to submit Part 3 until all errors have been corrected.

#### **Notes**

Please use the "Other" category to report any mothers classified as "multiple race."

# **Submitting Part 3**

- After entering data please proceed to the "Finalize" section.
- 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.
  - o Please note: Responses to Part 3 can only be submitted one time.
- If you included commas with any of the numbers you entered you will <u>not</u> 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.