

# 2012 CDC EHDI Hearing Screening and Follow-up Survey (HSFS): Explanations\*

Thank you for completing this survey. All requested data <u>only</u> refer to infants born in year **2012** (*i.e.*, *January 1*, *2012* – *December 31*, *2012*) and the EHDI services they received. Please contact Tonya Williams with any questions at: <u>TWilliams10@cdc.gov</u> / (404) 498-3026

# Instructions\*

- Only <u>documented</u>, <u>non-estimated</u> data are to be reported on this survey.
- Include information about any services that infants born in calendar year 2012 received in 2013 (*e.g., an infant born in December 2012 but did not receive a diagnostic evaluation until March 2013*).
- Severity data can be reported using either the DSHPSHWA or ASHA classification system. The option to select the system is located on the online Survey introduction page.
- Please use chronological age when reporting data related to age of screening, diagnosis, and intervention.
- Part 3 (Demographics) 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 <u>avoid</u> error messages select "<u>Calculate Totals (+)</u>" 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.
- <u>Do not</u> use the "*Enter*" key or include any commas with the data you report on the survey.
- A "**0**" will sometimes appear in blank fields. This can be deleted *or* simply enter data after the "0" (e.g., 0100).
- A summary of reported data will be displayed <u>after</u> the survey is submitted, which can then be printed and/or exported into Microsoft Excel and saved.

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# Part 1: 2012 Documented Hearing Screening Data

# **Total Occurrent Births**

- The number entered here should represent the total number of <u>live, occurrent</u> births (within the reporting jurisdiction) born in calendar year 2012.
- 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 <u>live, occurrent</u> births in calendar year 2012 according to the jurisdictional Vital Records program. This can include births that occurred in military facilities.
- This should be the same or very close 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: Number of infants in the NICU >30 days

- This is an *optional* field and a response is not required.
- The number of live, occurrent births born in calendar year 2012 that were in a Neonatal Intensive Care Unit (NICU) or other specialized care unit (i.e., non-well baby nursery) for more than 30 continuous days.
- This number should <u>not</u> include any live births not in a NICU or other specialized care unit for more than 30 continuous days.
- Any data entered in this field will <u>not</u> be included in the automatically calculated "Total Occurrent Births" values in the Screening section.
- New: Determining appropriate documentation of a stay in a NICU or other specialized care unit for more than 30 continuous days is the responsibility of each jurisdiction.

# **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 <u>not</u> include any live 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.
- If there are no military hospitals in the jurisdiction please enter the word "none."

# <u>Optional</u>: 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 in this field must also be included in the appropriate "Passed" and "Not Passed" fields.
- 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 <u>automatically</u> calculated based on the fields:
  - o Total Pass + Total Not Pass

### **Passed** (most recent/final screen)

- A final screen is defined as the last or most recently 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 <u>automatically</u> 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 one 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 three 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 the age at the time of the (most recent) screen is unknown.

# Optional NICU Infants (>30days): Pass

- All infants in a NICU or other specialized care unit (i.e., non-well baby nursery) for more than 30 days who passed a hearing screening performed at >30 days.
- Any infants reported in this field must *also* be reported in the appropriate Age field for Pass
  - *Example:* If an infant in the NICU passed their final/most recent hearing screening at 35 days of age they should be reported in *both* the fields "Pass after 1 Month but before 3 Months of Age" and "NICU Infants (>30days): Pass"
- Any data entered in this field will <u>not</u> be included in the automatically calculated "Total Pass" in the Passed section.

# Not Passed (final screen)

- A final screen is defined as the last or most recently 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 <u>not</u> passed a hearing screening, including (*if applicable*) infants that did not pass an inpatient screening and were not documented to have received an outpatient 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 Passed" section.

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

# Optional NICU Infants (>30days): Not Pass

- All infants in a NICU or other specialized care unit (i.e., non-well baby nursery) for more than 30 days who did not pass a hearing screening performed at >30 days.
- Any infants reported in this field must **also** be reported in the appropriate age field for Not Pass
  - *Example:* If an infant in the NICU did not pass their final/most recent hearing screening at 95 days of age they should be reported in *both* the fields "Not Pass After 3 Months of Age" and "NICU Infants (>30days): Not Pass"
- Any data entered in this field will <u>not</u> be included in the automatically calculated "Total Pass" in the Passed section.

# **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 inpatient 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 <u>only</u> 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 <u>must also</u> 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 <u>not</u> be reported in this field. These cases should <u>only</u> 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 <u>not</u> receive the OP screen but was documented to have received 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 <u>not</u> 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 <u>not</u> be included in the automatically calculated "Total Not Pass" and "Total Occurrent Births" values in the Screening section.

# Sample Scenarios (Pass/Not Pass)

- <u>Scenario 1</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 2</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 3</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 4</u>: Infant does not pass any hearing screening administered before being discharged from the hospital and <u>no</u> 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.
- <u>Scenario 5</u>: 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

- o Report data "Not Pass After 1 month but Before 3 Months of Age"
- <u>Scenario 6</u>: 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"
- <u>Scenario 7</u>: 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 Documented as Not Screened**

- This value will be <u>automatically</u> calculated based on the fields:
  - Infants Died + Non-resident + Unable to be Screened due to Medical Reasons + Parents/Family Declined Services + Infant Transferred and No Documentation of Screening + Missed + Unknown

### Infant Died

• Infants who were not screened due to death.

### Non-resident

• Infants that were not screened for hearing loss or the results of the screening are unknown because these infants were documented to be non-residents of the jurisdiction where they were born.

### Unable to be Screened due to Medical Reasons

- Infants unable to be screened for hearing loss due to a medical reason(s) that either made the screening not possible or not recommended by an approved medical provider
- Infants who cannot be tested in both ears due to obvious conductive malformations should be reported in the appropriate "Not Passed" category instead of the "Unable to be Screened due to Medical Reasons" field.

### Parents / Family Declined Services

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

### Infant Transferred and No Documentation of Screening

- Infants that were born in one facility and then transferred to a different medical facility and
- There is no documentation of at least one hearing screening being completed in either the facility where the infant was born or the medical facility where they were transferred to.

### **Missed**

- Includes cases where an infant was documented to have <u>not</u> received a hearing screening for reasons other than parental refusal or death.
- Infants who were only successfully screened in one ear and have 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 Passed" category instead of the "Missed" category.
  - o Infants not screened due to either death or parental refusal should <u>not</u> be reported in this category.

<u>Unknown</u>

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

### Sample Scenarios (Unknown and Missed)

- <u>Scenario 8:</u> 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"
- <u>Scenario 9</u>: 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"

# Total Occurrent Births (automatically calculated)

- This value is <u>automatically</u> calculated based on the values for the fields:
  - o Total Pass + Total Not Pass + Total Documented as Not Screened
  - The Inpatient (IP) /Outpatient (OP) Screening Protocol Only field is <u>not</u> included in the totals for the automatically calculated "Total Occurrent Births" field.
- The value calculated for "*Total Occurrent Births* (*automatically calculated*)" must be the <u>same</u> as the value listed for "*Total Occurrent Births*" at the top of the Screening section. If there is <u>any</u> difference between these values you will receive an error message when using the online survey and will not be able to continue with the survey until you correct the error.
  - Use the "<u>Calculate Totals (*yellow fields*)"</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 Screening section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

# Part 1: 2012 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 **<u>initial diagnosis</u>** 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 2 months of age. At an appointment at 4 months of age the diagnosis was updated to a mixed bilateral profound loss. Diagnostic data are to be reported based on the initial appointment at 2 months, meaning the infant would be reported as diagnosed with hearing loss before 3 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 <u>born</u> in calendar year 2012 who did <u>not</u> 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.
- No hearing loss 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.
- No hearing loss 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.
- No hearing loss 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 <u>born</u> in calendar year 2012 who did <u>not</u> pass a hearing screening and were diagnosed with a permanent hearing loss following audiologic diagnostic evaluation/testing that included appropriate audiometric test(s). • Permanent hearing loss includes cases of <u>unilateral and bilateral</u> 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 <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 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)

- <u>Scenario 10</u>: 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"
- <u>Scenario 11</u>: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 150 days (5 *months*) indicates permanent hearing loss
  - o Report data "Hearing Loss ID After 3 Months but Before 6 Months of Age"
- <u>Scenario 12</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 Documented Diagnosis / Undetermined

• Refers to the total number of infants born in 2012 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 <u>automatically</u> calculated based on the fields:
  - Audiologic Diagnosis in Process (Awaiting Diagnosis) + Non-resident + Moved Out of Jurisdiction + Infant Died + Unable to Receive Diagnostic Testing due to Medical Reasons + PCP did not Refer Infant for Diagnostic Testing + Parents / Family Declined Services + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown

# Audiologic Diagnosis in Process (Awaiting Diagnosis)

- Refers <u>only</u> to infants who 1) did not pass a hearing screening, 2) have been seen by an audiologist or other approved provider and 3) do <u>not</u> 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 <u>not</u> 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.
  - If an infant has received a documented diagnosis of either hearing loss or no hearing loss they should <u>not</u> be reported as being "In Process"
  - 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 <u>not</u> 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 <u>only</u> 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 <u>and</u> 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

- 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
  - If information is available about diagnostic testing that a nonresident (*of the reporting jurisdiction*) received, that information should be reported in the appropriate "No Documented Hearing Loss,"
     "Documented Permanent Identified (ID) Hearing Loss," or "No Documented Diagnosis" category instead of this field.
- New: For cases where it is not possible to separate if an infant did not receive a diagnosis because they were a Non-Resident or Moved out of Jurisdiction please report all these cases in the below "Moved out of Jurisdiction" field and include a note in the Comments section that it was not possible to separate these reasons.
- 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 they were a non-resident must be reported in this "Non-resident" field.

# 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 have moved (e.g., to another state)
  - If information is available about diagnostic testing that an infant (*that moved out of the reporting jurisdiction*) received, that information should be reported in the appropriate "No Documented Hearing Loss," "Documented Permanent Identified (ID) Hearing Loss," or "No Documented Diagnosis" category instead of this field.
- New: For cases where it is not possible to separate if an infant did not receive a diagnosis because they were a Non-Resident or Moved out of Jurisdiction please report all these cases in this field and include a note in the Comments section that it was not possible to separate these reasons.
- 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 they moved out of the jurisdiction where they were born must be reported in this "Moved Out of Jurisdiction" 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.

### Unable to Receive Diagnostic Testing due to Medical Reasons

• Infants that did not pass the final or most recent hearing screening and are unable to receive the diagnostic audiologic testing needed to confirm a hearing loss due to a medical reason(s) that either made the testing not possible or not recommended by an approved medical provider.

### Primary Care Provider (PCP) did not Refer Infant for Diagnostic Testing

 Infants that did not pass the final or most recent hearing screening and did not receive diagnostic audiological testing needed to confirm a hearing loss because the infant's PCP did not provide the necessary referral for this testing.

### Parents / Family Declined Services

- Infants who did not pass a hearing screening and did not receive diagnostic testing due to <u>documented</u> 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 <u>at least one</u> 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 here is used to calculate 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.

### <u>Unknown</u>

- 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 "Total with No Hearing Loss," "Total Hearing Loss," and "Total with No Diagnosis"
- The value calculated for "*Total Not Pass Screening* (automatically calculated)" must be the <u>same</u> as 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 when using the online survey and will not be able to continue with the survey until you correct the error.
  - Please use the "<u>Calculate Totals (*yellow fields*)"</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).

# **Optional: Other Documented Cases of 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 are to be reported in this field.
- Cases can be reported for both infants reported as passing and not passing the hearing screening.
- Infants reported as not passing the final, most recent hearing screening and found to have a nonpermanent hearing loss <u>must</u> also be reported in the appropriate "Total with No Hearing Loss" field.
- Any data entered in this field will <u>not</u> be included in the automatically calculated "Total Hearing Loss" field.

Permanent cases of hearing loss among infants reported as non-residents

- This is an *optional* field and a response is not required.
- Only cases of permanent hearing loss among infants reported as non-residents are to be reported in this field.
- Note: If an infant was already reported in an above "Documented Permanent Identified (ID) Hearing Loss" field they must <u>not</u> be reported in this field (i.e., *a case of hearing loss can only be reported one time on the survey*)
- Data entered in this field will <u>not</u> be included in the automatically calculated "Total Hearing Loss" field.

Permanent cases of hearing loss among infants that are residents but were born in a different jurisdiction

- This is an *optional* field and a response is not required.
- Only cases of permanent hearing loss among infants that are residents but were born in a different jurisdiction
- Data entered in this field will <u>not</u> be included in the automatically calculated "Total Hearing Loss" field.

# Part 1: 2012 Documented Intervention Data

- Information about intervention services is only requested for those infants and children with permanent hearing loss who were reported in the previous "Documented Permanent Identified (ID) Hearing Loss" section.
  - Information about intervention services for infants and children with late onset and other types of cases should <u>not</u> be included in the data reported in the "Documented Intervention Data" 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 <u>Part C</u> 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 <u>automatically</u> calculated based on the fields:
  - Referred and Eligible for Part C EI + Referred and Not Eligible for Part C EI + Referred but Eligibility Unknown

### Referred and Eligible for Part C El

- Infants identified with permanent 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 El

- Infants identified with permanent 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 permanent 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 identified with permanent hearing loss who were either:
  - o Not referred for Part C EI.
  - Where it is unknown whether they were referred for Part C EI.

### Optional: Referred to Part C El Before Six Months of Age

- Includes infants identified with permanent hearing loss who were referred for Part C intervention services before 6 months of age.
- Referred before 6 months of age = up to 180 days.
- This value is not included in the above calculation for "Total Referred for Part C EI."

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

- "Total Referred, Not Referred and Unknown" based on the sum of the values for "Total Referrals to Part C EI" and "Not Referred to Part C EI and Unknown".
- The value for the *optional* field "Referred to Part C EI Before Six Months of Age" is <u>not</u> included in the automatic calculation of this value.
- The value calculated for "*Total Referred, Not Referred and Unknown* (automatically calculated)" must be the <u>same</u> as the value 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 when using the online survey 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 identified with a permanent hearing loss who were enrolled in jurisdictional Part C early intervention services.
- New: Enrollment in Part C early intervention is defined as documentation of these infants with hearing loss having a signed Individual Family Services Plan (IFSP).

# Total Enrolled in Part C El

- This value will be <u>automatically</u> 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 loss who were enrolled in Part C 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 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 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 <u>not</u> be reported in this field.

# Receiving ONLY Intervention Services from Non-Part C EI

- Infants identified with a permanent hearing loss who were <u>only</u> 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 El services**

- This value will be <u>automatically</u> 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 loss 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 loss 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 loss 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 <u>automatically</u> calculated based on the fields:
  - Not Eligible for Services + Infant Died + Parents Declined Services + Non-resident + 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 <u>not</u> enrolled in early intervention due to death.

# 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

- Unknown whether infants with confirmed hearing loss are receiving early intervention services or not because they were documented to be non-residents.
- New: For cases where it is not possible to separate if an infant did not receive intervention because they were a Non-Resident or Moved out of Jurisdiction please report all these cases in the below "Moved out of Jurisdiction" field and include a note in the Comments section that it was not possible to separate these reasons.

### Moved Out of Jurisdiction

- Unknown whether infants with confirmed hearing loss are receiving early intervention services or not because they were documented to have moved (e.g., to another state).
- New: For cases where it is not possible to separate if an infant did not receive intervention because they were a Non-Resident or Moved out of Jurisdiction please report all these cases in this field and include a note in the Comments section that it was not possible to separate these reasons.

# 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.

### <u>Unknown</u>

- 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 <u>automatically</u> calculated based on the fields:
  - Total Enrolled in Part C EI + Monitoring Services + Total from Non-Part C EI Services Only + Total No Services

- The value calculated for "Total Intervention & No Services (*automatically calculated*)" must be the <u>same</u> 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 when using the online survey and will not be able to continue with the survey until you correct the error.
  - Use the "<u>Calculate Totals (*yellow fields*)"</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 1: 2012 Additional Cases Not Reported

# Hearing Loss not included in above "Permanent Identified (ID) Hearing Loss"

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

- Refers to cases of hearing loss that were <u>not included</u> in the "Total Not Pass" value from the Hearing Screening Section. Only children born in the reporting 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*).
  - o 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 <u>not</u> be included in the "Permanent Hearing Loss not included in Total Not Pass."
- Note: Please <u>do not</u> report any information about these cases of hearing loss in Part 2 or Part 3 of this survey.

### 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.

# Cases of Hearing Loss <u>not</u> 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

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

- Cases of hearing loss that were initially reported in the above "Hearing Loss not included in above Permanent Identified (ID) Hearing Loss (*e.g., Cases of permanent late onset hearing loss*)."
  - This consists of cases of confirmed hearing loss where infants initially passed the hearing screening (*e.g., late onset hearing loss*).
  - o It may also include children who were missed or whose parents refused the hearing 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" category it should <u>not</u> be included in the "Permanent Hearing Loss not included in Total Not Pass."

Total Cases of Hearing Loss (not included above)

- Value from the preceding Hearing Loss not included in above "Permanent Identified (ID) Hearing Loss" section
- Automatically populated

# Total Enrolled in Part C El

• Eligible infants identified with permanent hearing loss who were enrolled in Part C early intervention services

Total Services from Non-Part C El services

 Infants identified with permanent hearing loss who were enrolled in only non-Part C early intervention services

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 <u>not</u> 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.

# Hearing Loss not included in above "Intervention" Section (automatically calculated)

- This value will be <u>automatically</u> 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 <u>Not</u> included in above Intervention Section*" must be the <u>same</u> as the value for "*Total Cases of Hearing Loss (not included above*)" in the above Diagnostics fields. If there is <u>any</u> difference between these values you will receive an error message when using the online survey and will not be able to continue with the survey until you correct the error.
  - Use the "<u>Calculate Totals (*yellow fields*)"</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: 2012 Hearing Loss Type and Severity

- The type, laterality, and severity for <u>every case</u> 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 2012**.
  - 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*) are to be reported.
- Severity data can be reported either using the previous DSHPSHWA classification system <u>or</u> the system used by the American Speech-Language-Hearing Association (ASHA).
  - Do **not** attempt to report type and severity data using both of the classification systems
  - To choose either the DSHPSHWA or ASHA system you will need to select the option for the "ASHA system" or the "DSHPSHWA system" that is located on the Survey introduction page (*near the top*).
  - If you do not select an option you will receive an error message and will not be able to continue with the survey until you choose one of the options.
  - Note: Starting with the 2013 survey **only** the ASHA classification system is planned to be used.
- 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 <u>not</u> 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 <u>same</u> as the value for "Total Cases of Permanent Hearing Loss" that was reported in Diagnostic 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 <u>automatically</u> 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 elements is unknown.

- Laterality is organized into 3 separate sections 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 5 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 <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.
  - Jurisdictions may wish to maintain separate records for children identified with hearing loss of a noncongenital 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 <u>each</u> 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 data can be reported either using the previous DSHPSHWA classification system or the system used by the American Speech-Language-Hearing Association (ASHA).
  - The ASHA system includes additional categories and uses different decibel (dB) ranges compared to the DSHPSHWA system.
- Severity or the degree of hearing loss provides information regarding the average/estimated hearing across the speech frequency range
- The categories and their corresponding decibel (dB) ranges that are being used for this 2012 survey are listed below.
- 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 there corresponding dB ranges in the "Comments" field at the end of this survey.

# Sample Scenarios (Type/Severity)

- <u>Scenario 13</u>: 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"*).
- <u>Scenario 14</u>: 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"*).
- <u>Scenario 15</u>: Infant diagnosed with a permanent conductive, bilateral hearing loss with a severe loss in both the right and left ears (*noted by "C"*).
- <u>Scenario 16</u>: Infant diagnosed with a conductive permanent hearing loss (*noted by "D"*).
- <u>Scenario 17</u>: 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 (for CASES where
		RIGHT EAR	LEFT EAR	UNKNOWN EAR (Note: record degree of loss for <u>each</u> ear)		RIGHT EAR	LEFT EAR	UNKNOWN EAR	it is unknown if the loss is unilateral or bilateral)
a	Mild		Α						
enra	Moderate			В					
orin	Severe	A, E							
Sensorineural	Profound								
	Unknown Severity		Е		В				
ve	Mild								
Conductive	Moderate								
ndı	Severe	С	С						
ပိ	Unknown Severity								D
	Totals by Ear	3	3	1	1				1
	Totals by Child	3		1					1

# 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 of the screen (*this is not required*). Once you are sure
  the data are 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.
  - 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 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 <u>once</u>.
- If you included commas with any of the numbers you entered you will **<u>not</u>** be able to submit the survey.

- A summary of the reported data will be displayed <u>after</u> the survey is submitted, which can then be printed and/or exported into Microsoft Excel and saved.
  - Please note that you will be **unable** to retrieve the data you submitted after you close the online survey.

# Part 3: 2012 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 **<u>same</u>** email address 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 <u>Non</u>-Part C EI, and Total Services from <u>Non</u>-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* were 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 "<u>Refresh Totals (+)</u>" 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.
  - New: Additional error messages may also be displayed depending on the type of error.
  - $\circ$   $\;$  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.
- A summary of the reported data will be displayed <u>after</u> the survey is submitted, which can then be printed and/or exported into Microsoft Excel and saved.
  - Please note that you will be <u>unable</u> to retrieve the data you submitted after you close the online Survey.