

# 2018 CDC EHDI Hearing Screening and Follow-up Survey (HSFS): Explanations\*

All requested data <u>only refer to infants born in year 2018</u> (*i.e., January 1, 2018 – December 31, 2018*) and the EHDI services they received. Please contact Suhana Ema (SEma1@cdc.gov) with any questions. Thank you for completing this survey.

# Instructions\*

- Only documented, non-estimated data are to be reported on this survey.
- Include information about any services that infants born in the calendar year 2018 received in 2019 (e.g., include infant born in December 2018 who did not receive a diagnostic evaluation until March 2019).
- All jurisdictions should report severity data using the ASHA classification system.
- Please use chronological age when reporting data related to age of screening, diagnosis, and intervention.
- Fields highlighted in green are totals that will be automatically calculated by the survey. These totals are based on data entered into fields highlighted in yellow.
- Directions for submitting the survey will appear on the Final tab page once all the errors have been corrected.

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# Part 1: Hearing Screening Data

# **Total Occurrent Births**

- This field is the total number of <u>live, occurrent</u> births (within the reporting jurisdiction) born in the 2018 calendar year.
  - o "Live, occurrent births" refers to infants who were born alive.
  - o If an infant was born deceased, this case is not to be reported in this field.
  - If the infant was initially born alive and became deceased later, this case is to be reported in this field.
- This number 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 According to Vital Records**

- This field is the total number of <u>live, occurrent</u> births in the 2018 calendar year according to the Vital Records program in the reporting jurisdiction.
  - o "Live, occurrent births" refers to infants who were born alive.
  - If an infant was born deceased, this case is not to be reported in this field.
  - If the infant was initially born alive and became deceased later, this case is to be reported in this field.
- This number can include births that occurred in military facilities.
- This number should be similar to the number reported for "Total Occurrent Births." This field is intended as a quality assurance indicator for data completeness. This number does <u>not</u> affect any of the automatically calculated values in the survey.

# Optional: Total Occurrent Births at Military Facilities According to Vital Records

- This field is the total number of live, occurrent births at military facilities according to the Vital Records program in the reporting jurisdiction.
  - o "Live, occurrent births" refers to infants who were born alive.
  - If an infant was born deceased, this case is not to be reported in this field.
  - If the infant was initially born alive and became deceased later, this case is to be reported in this field.
- 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.

### **Optional:** Total Occurrent Homebirths

- This field is the total number of live, occurrent births that took place in a residence/home.
  - "Live, occurrent births" refers to infants who were born <u>alive</u>.
  - $\circ$   $\;$  If an infant was born deceased, this case is not to be reported in this field.
  - If the infant was initially born alive and became deceased later, this case is to be reported in this field.
- The screening status for births reported in this field must be reported in the appropriate "Overall Documented Screening Results," "Detailed Screening Results," or "No Documented Screening/Undetermined" fields.

# **Overall Documented Screening Results (Most Recent/Final Screen)**

• 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.
- Please note that infants who cannot be tested in both ears due to obvious conductive malformations should be reported in the appropriate "Not Passed" fields, instead of the "No Documented Screening/Undetermined" section.

# **Total Documented as Screened**

- This field is the total number of infants screened for hearing loss.
  - This number will be <u>automatically</u> calculated based on the following fields: • Total Passed + Total Not Passed

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

- This field is the total number of infants screened for hearing loss who passed their most recent/final hearing screening.
- Both ears should be screened **at the same time** (but not required) in order to be reported in the "Total Passed" category.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Passed: Before 1 Month of Age + Passed: After 1 Month of Age + Passed: Age Unknown

# Passed: Before 1 Month of Age

- This field is the total number of infants screened for hearing loss before one month of age who passed their most recent/final hearing screening.
- One month is equal to 30 days.
- Passed before one month of age = 30 days or less.

# Passed: After 1 Month of Age

- This field is the total number of infants screened for hearing loss after one month of age who passed their most recent/final hearing screening.
- One month is equal to 30 days.
- Passed after one month of age = 31 days or more.

### Passed: Age Unknown

• This field is the total number of infants screened for hearing loss who passed their most recent/final hearing screening at unknown age.

### Total Not Passed (most recent/final screen)

- This field is the total number of infants screened for hearing loss who did not pass their most recent/final hearing 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.
- This number includes infants who could not be screened in both ears due to obvious conductive malformations.
- This number includes infants who did not receive a hearing screening because they were referred directly for diagnostic testing by an approved medical provider.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Not Passed: Before 1 Month of Age + Not Passed: After 1 Month of Age + Not Passed: Age Unknown

### Not Passed Before 1 Month of Age

- This field is the total number of infants screened for hearing loss before one month of age who did not pass their most recent/final hearing screening.
- One month is equal to 30 days.
- Not passed before one month of age = 30 days or less.

## Not Passed: After 1 Month of Age

- This field is the total number of infants screened for hearing loss after one month of age who did not pass their most recent/final hearing screening.
- One month is equal to 30 days.
- Not passed after one month of age = 31 days or more.

## Not Passed: Age Unknown

• This field is the total number of infants screened for hearing loss who did not pass their most recent/final hearing screening at an unknown age.

# **Detailed Screening Results (if applicable)**

- Please only report detailed screening results, if applicable.
- Jurisdictions that conduct and report two-stage screening results (inpatient & outpatient screen) should complete these fields.

Passed (most recent/final screen):

- <u>Passed initial / No outpatient</u>: Infants who passed the initial screening and, did not receive an outpatient screening, missed an outpatient screening or refused an outpatient screening.
- <u>No initial / Passed outpatient</u>: Infants who did not receive an initial screening, missed an initial screening, or refused an initial screening, and passed the outpatient screening.
- <u>Passed initial / Passed outpatient</u>: Infants who passed the initial screening and passed the outpatient screening.
- <u>Referred initial / Passed outpatient</u>: Infants who did not pass the initial screening and passed the outpatient screening.

# Total Passed (most recent/final screen)

- This number will be <u>automatically</u> calculated based on the following fields:
  - Passed initial/No outpatient + No initial/Passed outpatient + Passed initial/Passed outpatient
     + Referred initial/Passed outpatient
- If there is any difference between the value calculated for "Total Passed" in the "Detailed Screening Results" section and the value calculated for "Total Passed" in the "Overall Documented Screening Results" section, you will receive an orange caution message. Because this section only applies to certain jurisdictions, you will not receive a red error message and can still proceed with submitting the survey.

Not Passed (most recent/final screen):

- <u>Referred initial / No outpatient</u>: Infants who did not pass the initial screening and did not receive an outpatient screening, missed an outpatient screening or refused an outpatient screening.
- <u>No initial / Referred outpatient</u>: Infants who did not receive an initial screening, missed an initial screening, or refused an initial screening, and did not pass the outpatient screening.
- <u>Passed initial / Referred outpatient</u>: Infants who passed the initial screening and did not pass the outpatient screening.
- <u>Referred initial / Referred outpatient</u>: Infants who did not pass the initial screening and did not pass the outpatient screening.
- <u>Referred initial / straight to diagnostic evaluation</u>: Infants who did not pass the initial screening and were referred directly for diagnostic evaluation.

# Total Not Passed (most recent/final screen)

- This number will be <u>automatically</u> calculated based on the following fields:
  - Referred initial/No outpatient + No initial/Referred outpatient + Passed initial/Referred outpatient + Referred initial/Referred outpatient + Referred initial/straight to diagnostic evaluation
- If there is any difference between the value calculated for "Total Not Passed" in the "Detailed Screening Results" section and the value calculated for "Total Not Passed" in the "Overall Documented Screening Results" section, you will receive an orange caution message. Because this section only applies to certain jurisdictions, you will not receive a red error message and can still proceed with submitting the survey.

# No Documented Screening / Undetermined (Most Recent/Final Screen)

## **Total Documented as Not Screened**

- This field is the total number of infants not screened for hearing loss.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Infant Died + Non-resident / Moved Out of Jurisdiction + Unable to be Screened Due to Medical Reasons + Parents / Family Declined Services + Infant Transferred and No Documentation of Screening + Infant Adopted + Homebirths + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown + Other

### Infant Died

• This field is the total number of infants who were not documented as screened due to death.

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

- This field is the total number of infants who were not documented as screened or the results are unknown because these infants were documented to be non-residents of the reporting jurisdiction or have moved out of the reporting jurisdiction (e.g., to another state) where they were born.
  - This number should be kept to a minimum. Reporting jurisdictions should collaborate in tracking infants in need of services.

#### Unable to be Screened Due to Medical Reasons

- This field is the total number of infants who were unable to be screened due to a medical reason(s) that 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 (most recent/final screen)" category instead of the "Unable to be Screened due to Medical Reasons" field.

### Parents / Family Declined Services

• This field is the total number of infants who were not documented as screened due to documented parental or family's refusal of the hearing screening.

### Infant Transferred and No Documentation of Screening

• This field is the total number of infants who were born in one facility and then transferred to a different medical facility **and** who do not have documentation of the completion of at least one hearing screening in the facility where the infant was born or the facility to where the infant was transferred.

#### Infant Adopted

• This field is the total number of infants who were not documented as screened due to adoption.

#### **Homebirths**

• This field is the total number of infants who were not documented as screened because they were born in a residence/home.

### Parents / Family Contacted but Unresponsive

Note:

- The number reported in this field is used to calculate the number of infants lost to follow-up / lost to documentation.
- Please select which definition was used for the 2018 data, either the revised or old definition (see explanations below).

### **Revised Unresponsive Definition:**

• For a case to be identified and reported as "Unresponsive," the following is required:

A documented two-way conversation or written communication with the child's legal parent or guardian in which they have acknowledged awareness of the corresponding 1:3:6 recommendation (e.g., screen, outpatient re-screen, diagnostic evaluation, or early intervention services) and have nevertheless not obtained the recommended service. To accomplish this, the following two criteria addressing adequate documentation and communication are required.

(1) To satisfy the verbal or written two-way conversation requirement, the conversation must be between the parent/guardian and the EHDI program, the child's PCP, hospital staff, or other similar healthcare representative(s) designated by the EHDI program. Individual child-level documentation must be made for each family.

- For example, it would be acceptable to classify a family as unresponsive if a PCP reported that she has talked with the specific family about needing a hearing screen, but the family has not gone on to receive one.
- It would <u>not</u> be acceptable to classify a family as unresponsive if the PCP simply reported that she recommends follow-up for "all" of their patients.

(2) To satisfy the documentation requirement, documentation must occur in one of the following <u>three</u> ways:

(a) There must be documentation that an actual response was received from the parent (e.g., note of a verbal communication or copy of an email response from the parent).

#### OR

(b) There must be an official documented record that a written correspondence was sent from the EHDI program and was received by a member of the family (e.g., a return receipt for USPS mail).

#### OR

(c) There is documentation that the parents or family responded that they would bring the infant in for recommended screen/re-screen/diagnostic evaluation/early intervention services AND they did not show up for at least one confirmed appointment.

• If the parent is unresponsive but you know you have the right family (e.g., voicemail message has right name, mail is not returned), but you do not have the two criteria required, the infant should be included in the "Unable to Contact" field.

### **Old Unresponsive Definition:**

- Parents or family of an infant who did not receive a hearing screen 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 <u>not</u> 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 receive a hearing screen 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 hearing screen 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 hearing screen before they can be reported in this category.

Unable to Contact

- This field is the total number of infants who did not receive a hearing screen, where
- (1) 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 OR
- (2) it is known to the EHDI program that the right family was contacted but unresponsive (e.g., voicemail message has right name, mail is not returned) and the two criteria required for "Parents/Family Contacted but Unresponsive" are not met, the infant should be included in the "Unable to Contact" field.
  - 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.
    - If using the revised "Unresponsive" definition: If the parent is unresponsive but you know you
      have the right family (e.g., voicemail message has right name, mail is not returned), but you do
      not have the two criteria required, the infant should be included in the "Unable to Contact" field.
  - Before classifying a case as "Unable to Contact" the EHDI program should attempt to obtain correct information on the family.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

<u>Unknown</u>

- This field is the total number of infants where it is not documented whether an infant received a hearing screening. This includes cases where no hearing screening results are reported to the jurisdiction.
- Infants not screened due to parental refusal, death, non-residence, medical reasons, transferred and no
  documentation of screening refusal, or other known reasons should <u>not</u> be reported in this category.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

<u>Other</u>

• This field is the total number of infants who did not receive a hearing screen for reasons not listed above.

# Sample Scenarios (Unknown and Other)

- <u>Scenario 1:</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 reported to the state or territory that the infant was not screened for hearing loss before or after discharge.
  - Report data "Other"
- <u>Scenario 2</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**

- This number will be <u>automatically</u> calculated based on the following fields:
  - o Total Documented as Screened + Total Documented as Not Screened
- The value calculated for "Total Occurrent Births" at the bottom of the "Screening Data" section must be the <u>same</u> as the value reported for "Total Occurrent Births" at the top of the "Screening Data" section.
- If there is **any** difference between these values you will receive a red error message. You will need to correct the error before submitting the survey.
  - Error(s) can be corrected by going back to the "Screening Data" section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

# Part 1: Diagnostic Data

- Diagnostic data are to be reported for all infants included in the "Total Not Passed (most recent / final screen)" field in the previous "Hearing Screening Data" section.
- If an infant received a diagnosis and records of more than one diagnostic evaluation/testing appointment is available, only information from the appointment where an **initial diagnosis** of either permanent hearing loss or no hearing loss 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 Passed (most recent/final screen)

- This number is <u>automatically</u> populated.
- It is the same number as the "Total Not Passed (most recent/final screen)" field in the "Hearing Screening Data" section.

# **Documented Diagnostics**

# **Total with Documented Diagnosis**

- This field is the total number of infants who did not pass a hearing screening and had a documented diagnosis following an audiological diagnostic evaluation/testing.
- This number will be <u>automatically</u> calculated based on the following fields:
   o Total with No Hearing Loss + Total with Permanent Hearing Loss

### Total with No Hearing Loss

- This field is the total number of infants who did not pass a hearing screening but were found to have no documented hearing loss (e.g., normal hearing) following an audiological diagnostic evaluation/testing that included appropriate audiometric test(s).
- Purely conductive transient losses should be reported under the appropriate "No Documented Hearing Loss" category.
- This number will be <u>automatically</u> calculated based on the following fields:
  - No Hearing Loss: Before 3 Months of Age + No Hearing Loss: After 3 Months of Age + No Hearing Loss: Age Unknown

### No Hearing Loss: Before 3 Months of Age

- This field is the total number of infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) before three months of age.
- One month is equal to 30 days.
- No hearing loss before 3 months of age = 90 days or less.

### No Hearing Loss: After 3 Months of Age

- This field is the total number of infants who did not pass a hearing screening but were found to have no hearing loss (following diagnostic evaluation) after three months of age.
- One month is equal to 30 days.
- No hearing loss after 3 months of age = 91 days or more.

### No Hearing Loss: Age Unknown

• This field is the total number of infants who did not pass a hearing screening and were found to have no hearing loss (following diagnostic evaluation) at an unknown age.

Total with Permanent Hearing Loss

- This field is the total number of infants who did not pass a hearing screening and were diagnosed with a
  permanent hearing loss following audiological diagnostic evaluation/testing that included appropriate
  audiometric test(s).
- Permanent hearing loss includes cases of <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.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Permanent Hearing Loss: Before 3 Months of Age + Permanent Hearing Loss: After 3 Months of Age but Before 6 Months of Age + Permanent Hearing Loss: After 6 Months of Age + Permanent Hearing Loss: Age Unknown

#### Permanent Hearing Loss: Before 3 Months of Age

- This field is the total number of infants who did not pass a hearing screening and were diagnosed with a hearing loss (following diagnostic evaluation) before 3 months of age.
- One month is equal to 30 days.
- Hearing loss diagnosed before 3 months of age = 90 days or less.

# Permanent Hearing Loss: After 3 Months but before 6 Months of Age

- This field is the total number of infants who did not pass a hearing screening and were diagnosed with a hearing loss (following diagnostic evaluation) after 3 months of age but before 6 months of age.
- One month is equal to 30 days.
- Hearing loss diagnosed after 3 months of age but before 6 months of age = more than 90 days and up to 180 days.

### Permanent Hearing Loss: After 6 Months of Age

- This field is the total number of infants who did not pass a hearing screening and were diagnosed with a hearing loss (following diagnostic evaluation) after 6 months of age.
- One month is equal to 30 days.
- Hearing loss diagnosed after 6 months of age = 181 days or more.

Permanent Hearing Loss: Age Unknown

• This field is the total number of infants who did not pass a hearing screening and were diagnosed with a hearing loss (following diagnostic evaluation) at an unknown age.

# Sample Scenarios

- <u>Scenario 3</u>: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 60 days (2 *months*) indicates permanent hearing loss
  - Report data "Permanent Hearing Loss: Before 3 Months of Age"
- <u>Scenario 4</u>: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 150 days (5 *months*) indicates permanent hearing loss
  - Report data "Permanent Hearing Loss: After 3 Months but Before 6 Months of Age"

# **No Documented Diagnostics / Undetermined**

# **Total with No Documented Diagnosis**

- This field is the total number of infants who did not pass the most recent hearing screening, and who do not have a documented diagnosis (i.e., No Hearing Loss or Permanent Hearing Loss) or whose status is undetermined.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Audiological Diagnosis in Process (Awaiting Diagnosis) + PCP/ENT did not Refer Infant for Diagnostic Testing + Infant Died + Non-resident / Moved Out of Jurisdiction + Unable to Receive Diagnostic Testing Due to Medical Reasons + Parents / Family Declined Services + Infant Adopted + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown + Other

# Audiological Diagnosis in Process (Awaiting Diagnosis)

- This field is the total number of infants who (1) did not pass a hearing screening, (2) have been seen by an audiologist or other approved provider, and (3) do not yet have a diagnosis.
- Infants reported in this field must have been seen by an audiologist or other approved provider for diagnostic testing at least one time and have a follow-up appointment already scheduled.
  - If an infant has not been seen by an audiologist or other approved provider within 6 months of the last appointment for diagnostic testing, and still does not have a documented diagnosis, the infant 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, the infant should not be reported in this "In Process" field.
  - The number of infants reported in this "In Process" field should be relatively small, as this should be a rare event.

# Additional "In Process" Notes

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

### PCP/ENT Did Not Refer Infant for Diagnostic Testing

• This field is the total number of infants who did not pass a hearing screening, and did not receive the diagnostic audiological testing needed in order to confirm a hearing loss due to the infant's Primary Care Provider (PCP) or Ear, Nose Throat doctor (ENT) not providing the necessary referral for this testing.

### Infant Died

- This field is the total number of infants who did not pass a hearing screening and did not receive the diagnostic audiological testing needed in order to confirm a hearing loss due to the death.
- For jurisdictions with an IP/OP screening protocol, infants who did not pass an IP screen and were not documented to have received an OP screen because the reason "Infant Died" must be reported in this field.

### Non-resident / Moved Out of Jurisdiction

- This field is the total number of infants who did not pass a hearing screening and the results of any diagnostic tests are unknown due to being documented as non-resident of the reporting jurisdiction or having moved out of the reporting jurisdiction (e.g., to another state)..
  - If information is available about diagnostic testing that a non-resident of the reporting jurisdiction or infant that moved out of the reporting jurisdiction received, that information should be reported in the

appropriate "Diagnosed with No Hearing Loss" or "Diagnosed with Permanent Hearing Loss" category, instead of in this field.

For jurisdictions with an IP/OP screening protocol, infants who did not pass an IP screen and were not
documented to have received an OP screen because of the reason being non-resident or moved out of
jurisdiction must be reported in this field.

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

• This field is the total number of infants who did not pass a hearing screening and are unable to receive the diagnostic audiological 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.

#### Parents / Family Declined Services

- This field is the total number of infants who did not pass a hearing screening and did not receive diagnostic audiological testing due to <u>documented</u> parental or family refusal.
- For jurisdictions with an IP/OP screening protocol, infants who did not pass an IP screen and were not documented to have received an OP screen because "Parents/Family Declined Services" must be reported in this field.

#### Infant Adopted

 This field is the total number of infants who did not pass a hearing screening and did not receive diagnostic audiological testing due to being adopted and the EHDI program/provider did not have the contact information for the adopting family.

#### Parents / Family Contacted but Unresponsive

Note:

- This number is used to calculate the number of infants lost to follow-up / lost to documentation.
- Please select which definition was used for the 2018 data, either the revised or old definition (see explanations below).

#### **Revised Unresponsive Definition:**

For a case to be identified and reported as "Unresponsive," the following is required: A documented two-way conversation or written communication with the child's legal parent or guardian in which they have acknowledged awareness of the corresponding 1:3:6 recommendation (e.g., screen, outpatient re-screen, diagnostic evaluation, or early intervention services) and have nevertheless not obtained the recommended service. To accomplish this, the following two criteria addressing adequate documentation and communication are required.

(1) To satisfy the verbal or written two-way conversation requirement, the conversation must be between the parent/guardian and the EHDI program, the child's PCP, hospital staff, or other similar healthcare representative(s) designated by the EHDI program. Individual child-level documentation must be made for each family.

- For example, it would be acceptable to classify a family as unresponsive if a PCP reported that she has talked with the specific family about needing a hearing screen, but the family has not gone on to receive one.
- It would <u>not</u> be acceptable to classify a family as unresponsive if the PCP simply reported that she recommends follow-up for "all" of their patients.

(2) To satisfy the documentation requirement, documentation must occur in one of the following <u>three</u> ways:

(a) There must be documentation that an actual response was received from the parent (e.g., note of a verbal communication or copy of an email response from the parent).

### OR

(b) There must be an official documented record that a written correspondence was sent from

the EHDI program and was received by a member of the family (e.g., a return receipt for USPS mail).

OR

(c) There is documentation that the parents or family responded that they would bring the infant in for recommended screen/re-screen/diagnostic evaluation/early intervention services AND they did not show up for at least one confirmed appointment.

 If the parent is unresponsive but you know you have the right family (e.g., voicemail message has right name, mail is not returned), but you do not have the two criteria required, the infant should be included in the "Unable to Contact" field.

### **Old Unresponsive Definition:**

- Parents or family of an infant who did not receive a hearing screen 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 <u>not</u> 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 receive a hearing screen 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 hearing screen 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 hearing screen before they can be reported in this category.

### Unable to Contact

• This field is the total number of infants who did not pass a hearing screening, where (1) 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 **OR**(2) it is known to the EHDI program that the right family was contacted but unresponsive (e.g., voicemail message has right name, mail is not returned) and the two criteria required for "Parents/Family Contacted but Unresponsive" are not met, the infant should be included in the "Unable to Contact" field.

- •
- 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.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

#### <u>Unknown</u>

- This field is the total number of infants who did not pass a hearing screening where 1) there is no documentation that they received any follow-up audiological 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).
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

#### <u>Other</u>

• This field is the total number of infants who did not receive a diagnosis for reasons not listed above.

# **Total Diagnosed and Not Diagnosed**

- This number will be <u>automatically</u> calculated based on the following fields:
  - Total with No Hearing Loss + Total with Permanent Hearing Loss + Total with No Documented Diagnosis
- The value calculated for "Total Diagnosed and Not Diagnosed" at the bottom of the "Diagnostic Data" section must be the <u>same</u> as the value calculated for "Total Not Passed (most recent/final screen)" at the top of the "Diagnostic Data" section.
- If there is <u>any</u> difference between these values you will receive a red error message. You will need to correct the error before submitting the survey.
  - Error(s) can be corrected by going back to the "Diagnostic Data" section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

# Part 1: Early Intervention (EI) Data

- Early Intervention (EI) data are to be reported for all infants included in the "Total with Permanent Hearing Loss" field in the previous "Diagnostic Data" section.
- Information about intervention services for infants with late onset and other types of cases should <u>not</u> be included in this section.

# **Total with Permanent Hearing Loss**

- This number is <u>automatically</u> populated.
- It is the same number as the "Total with Permanent Hearing Loss" field in the "Diagnostic Data" section.

### **Total with Referral Status**

- This number will be <u>automatically</u> calculated based on the following fields:
   Referred to Part C EI + Not Referred to Part C EI + Unknown Referral Status
- The following fields are not included in this calculation: Referred to Part C EI: Before Six Months of Age, Referred to Part C EI: After 6 Months of Age, Referred to Part C EI: Age Unknown.
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

•

### Referred to Part C EI

- This field is the total number of infants identified with a permanent hearing loss who were referred to Part C EI services (regardless of eligibility).
- This number will be <u>automatically</u> calculated based on the following fields:
  - Referred to Part C EI: Before 6 Months of Age + Referred to Part C EI: After 6 Months of Age + Referred to Part C EI: Age Unknown
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

### Referred to Part C EI: Before 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who were referred to Part C EI services before 6 months of age (regardless of eligibility).
- One month is equal to 30 days.
- Referred before 6 months of age = 180 days or less.
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

# Referred to Part C EI: After 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who were referred to Part C EI services after 6 months of age (regardless of eligibility).
- One month is equal to 30 days.
- Referred after 6 months of age = 181 days or more.
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

### Referred to Part C EI: Age Unknown

- This field is the total number of infants identified with a permanent hearing loss who were referred to Part C EI services at unknown age (regardless of eligibility).
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

# Not Referred to Part C EI

- This field is the total number of infants identified with a permanent hearing loss who were not referred to Part C EI services (regardless of eligibility).
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

Unknown Referral Status

- This field is the total number represents the number of infants identified with a permanent hearing loss whose referral status to Part C EI services is unknown.
- Due to variability, it is the responsibility of jurisdiction to define what constitutes a referral to Part C EI.

# **Documented El Services**

# Total Enrolled in Part C El Services

- This field is the total number of infants identified with a permanent hearing loss who were enrolled in Part C EI services.
- Enrollment in Part C EI is defined as documentation of an infant with hearing loss with a signed Individual Family Services Plan (IFSP).
- This number will be <u>automatically</u> calculated based on the following fields:
  - Signed IFSP: Before 6 Months of Age + Signed IFSP: After 6 Months of Age + Signed IFSP: Age Unknown

# Signed IFSP Before 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who were enrolled in Part C EI services before 6 months of age.
- One month is equal to 30 days.
- Enrolled before 6 months of age = 180 days or less.

# Signed IFSP After 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who were enrolled in Part C EI services after 6 months of age.
- One month is equal to 30 days.
- Enrolled after 6 months of age = 181 days or more.

# Signed IFSP: Age Unknown

• This field is the total number of infants identified with a permanent hearing loss who were enrolled in Part C EI services at unknown age.

# **Total Received Part C El Services**

- This number will be <u>automatically</u> calculated based on the following fields:
  - Received Part C El Services: Before 6 Months of Age + Received Part C El Services: After 6 Months of Age + Received Part C El Services: Age Unknown
  - The "Received Part C EI Services: After 6 Months of Age, Due to Family Initially Declining Services" field is not included in this calculation.

### Received Part C El Services: Before 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who began receiving Part C EI services before 6 months of age.
- One month is equal to 30 days.
- Received services before 6 months of age = 180 days or less.

### Received Part C El Services: After 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who began receiving Part C EI services after 6 months of age.
- One month is equal to 30 days.
- Received services after 6 months of age = 181 days or more.

### Received Part C EI Services: After 6 Months of Age, Due to Family Initially Declining Services

- This field is the total number of infants identified with a permanent hearing loss who began receiving Part C EI services after 6 months of age due to parents / family initially declining services.
- This number should not be greater than the number reported for "Total Received Part C El Services: After 6 Months of Age."
- One month is equal to 30 days.
- Received services after 6 months of age = 181 days or more.

Received Part C EI Services: Age Unknown

• This field is the total number of infants identified with a permanent hearing loss who began receiving Part C EI services at unknown age.

### Total from Non-Part C El Services Only

- This field is the total number of infants identified with a permanent hearing loss who were <u>only</u> enrolled in Non-Part C EI services.
- Due to variability about eligibility and availability, it is the responsibility of jurisdiction to define what constitutes enrollment in non-Part C intervention services.
- If an infant is receiving Part C EI, or both Part C and Non-Part C EI services, the infant should <u>not</u> be included in this section (i.e., they should be reported in the "Received Part C EI Services" section).
- This number will be <u>automatically</u> calculated based on the following fields:
  - Received Non-Part C El Services: Before 6 Months of Age + Received Non-Part C El Services: After 6 Months of Age + Received Non-Part Cl Services: Age Unknown

### Received Non-Part C El Services: Before 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who began receiving Non-Part C EI services before 6 months of age.
- One month is equal to 30 days.
- Received services before 6 months of age = 180 days or less.

### Received Non-Part C EI Services: After 6 Months of Age

- This field is the total number of infants identified with a permanent hearing loss who began receiving Non-Part C EI services after 6 months of age.
- One month is equal to 30 days.
- Received services after 6 months of age = 181 days or more.

#### Received Non-Part C El Services: Age Unknown

• This field is the total number of infants identified with a permanent hearing loss who began receiving Non-Part C EI services at unknown age.

# **Monitoring Services Only**

#### Received Only Monitoring Services

- This field is the total number of infants identified with a permanent hearing loss who were not enrolled in EI services (Part C or non-Part C), but are being monitored by a provider (e.g., audiologist) for any change in hearing status.
- Infants receiving any type of intervention (therapy) services (including Part C and non-Part C) should <u>not</u> be reported in this field.

# **No Documented El Services/Undetermined**

### **Total with No Documented El Services**

- This field is the total number of infants identified with a 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.
- This number will be <u>automatically</u> calculated based on the following fields:
  - Not Eligible for Part C Services + Infant Died + Non-resident / Moved Out of Jurisdiction + Unable to Receive El Due to Medical Reasons + Parents / Family Declined Services + Infant Adopted + Parents / Family Contacted but Unresponsive + Unable to Contact + Unknown + Other

### Not Eligible for Part C Services

• This field is the total number of infants identified with a permanent hearing loss who were not enrolled in El services due to not being eligible for Part C services.

#### Infant Died

• This field is the total number of infants identified with a permanent hearing loss who were not enrolled in EI services due to death.

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

 This field is the total number of infants identified with a permanent hearing loss who were not enrolled in El services due to being documented as non-resident of the reporting jurisdiction or having moved out of the reporting jurisdiction (e.g., to another state).

Unable to Receive EI Due to Medical Reasons

 This field is the total number of infants identified with a permanent hearing loss who were not enrolled in El services due to a medical reason(s) that either made the enrollment not possible or not recommended, by an approved medical provider

Parents / Family Declined Services

• This field is the total number of infants identified with a permanent hearing loss who were not enrolled in El services due to <u>documented</u> parental or family refusal.

#### Infant Adopted

 This field is the total number of infants identified with a permanent hearing loss who were not enrolled in El services due to being adopted and the EHDI program/provider did not have the contact information for the adopting family.

#### Parents / Family Contacted but Unresponsive

Note:

- This number is used to calculate the number of infants lost to follow-up / lost to documentation for EI.
- Please select which definition was used for the 2018 data, either the revised or old definition (see explanations below).

#### **Revised Unresponsive Definition:**

For a case to be identified and reported as "Unresponsive," the following is required: A documented two-way conversation or written communication with the child's legal parent or guardian in which they have acknowledged awareness of the corresponding 1:3:6 recommendation (e.g., outpatient re-screen, diagnostic evaluation, or early intervention services) and have nevertheless not obtained the recommended service. To accomplish this, the following two criteria addressing adequate documentation and communication are required.

(1) To satisfy the verbal or written two-way conversation requirement, the conversation must be between the parent/guardian and the EHDI program, the child's PCP, hospital staff, or other similar healthcare representative(s) designated by the EHDI program. Individual child-level documentation must be made for each family.

- For example, it would be acceptable to classify a family as unresponsive if a PCP reported that she has talked with the specific family about needing a diagnostic evaluation, but the family has not gone on to receive one.
- It would <u>not</u> be acceptable to classify a family as unresponsive if the PCP simply reported that she recommends follow-up for "all" of their patients.

(2) To satisfy the documentation requirement, documentation must occur in one of the following <u>three</u> ways:

(a) There must be documentation that an actual response was received from the parent (e.g., note of a verbal communication or copy of an email response from the parent).

OR

(b) There must be an official documented record that a written correspondence was sent from the EHDI program and was received by a member of the family (e.g., a return receipt for USPS mail).

OR

(c) There is documentation that the parents or family responded that they would bring the infant in for recommended re-screen/diagnostic evaluation/early intervention services AND they did not show up for at least one confirmed appointment.

 If the parent is unresponsive but you know you have the right family (e.g., voicemail message has right name, mail is not returned), but you do not have the two criteria required, the infant should be included in the "Unable to Contact" field.

# **Old Unresponsive Definition:**

- 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 <u>not</u> 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."
  - If using the revised "Unresponsive" definition: If the parent is unresponsive but you know you have the right family (e.g., voicemail message has right name, mail is not returned), but you do not have the two criteria required, the infant should be included in the "Unable to Contact" field.

## Unable to Contact

- This field is the total number of infants identified with a permanent hearing loss, where
- (1) 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 **OR**
- (2) it is known to the EHDI program that the right family was contacted but unresponsive (e.g., voicemail message has right name, mail is not returned) and the two criteria required for "Parents/Family Contacted but Unresponsive" are not met, the infant should be included in the "Unable to Contact" field.
- •
- 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 contact information for the family.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation for EI.

### <u>Unknown</u>

- This field is the total number of infants identified with a permanent hearing loss, where 1) there is no documentation that they received any EI 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 EI services).
- This number is used to calculate the number of infants lost to follow-up / lost to documentation for EI.

### <u>Other</u>

• This field is the total number of infants identified with a permanent hearing loss who were not enrolled in EI services for other reasons not listed above.

# **Total with El Services & No El Services**

- This value will be <u>automatically</u> calculated based on the fields:
  - Total Enrolled in Part C EI + Total from Non-Part C EI Services Only + Received Only Monitoring Services + Total with No Documented EI Services
- The value calculated for "Total with EI Services & No EI Services" at the bottom of the "Intervention Data" section must be the <u>same</u> as the value calculated for "Total with Permanent Hearing Loss" at the top of the "Intervention Data" section.
- If there is <u>any</u> difference between these values you will receive a red error message. You will need to correct the error before submitting the survey.
  - Error(s) can be corrected by going back to the "Intervention Data" section, reviewing the data, and entering the correct value(s) in the appropriate field(s).

# Part 1: Additional Cases Not Reported

# Cases of Hearing Loss not included in the "Diagnostic Data" section

# Total Additional Cases of Hearing Loss not included in Diagnostic Data

- This field is the total number of infants with hearing loss who were <u>not included</u> in the "Total with Permanent Hearing Loss" field in the "Diagnostic Data" section. Only children born in the reporting jurisdiction (i.e., occurrent births) are to be included.
- These cases should be reported in the appropriate "No Documented Screening/Undetermined (Most Recent/Final Screen)" category in the "Screening Data" section.
- If a case of hearing loss was already reported in the "Total with No Hearing Loss," "Total with Permanent Hearing Loss," or "Total with No Documented Diagnosis" category in the "Diagnostic Data" section, it should <u>not</u> be included in this section.
- Note: Please <u>do not</u> report any information about these cases of hearing loss in Part 2 or Part 3 of this survey.
- This value will be <u>automatically</u> calculated based on the following fields:
  - Additional Cases of Non-permanent, Transient Hearing Loss + Additional Cases of Permanent Hearing Loss (e.g., late onset)

# Additional Cases of Non-permanent, Transient Hearing Loss

• This field is the total number of additional infants identified with non-permanent, transient hearing loss.

# Additional Cases of Permanent Hearing Loss (e.g., late onset)

• This field is the total number of additional infants who initially passed the newborn hearing screening and were later identified with a permanent hearing loss (e.g., late onset).

# Cases of Hearing Loss not included in the "Intervention Data" section

### Total Additional Cases of Hearing Loss not included in Intervention Data

- This field is the total number of infants with hearing loss who were <u>not included</u> in the "Total with El Services & No El Services" field in the "Intervention Data" section. Only children born in the reporting jurisdiction (i.e., occurrent births) are to be included.
- If a case of hearing loss was already reported in the "Total Enrolled in Part C El Services," "Total from Non-Part C El Services Only," or "Total with No Documented El Services" category in the "Intervention Data" section, it should <u>not</u> be included in this section.
- Note: Please <u>do not</u> report any information about these cases of hearing loss in Part 2 or Part 3 of this survey.
- This value will be <u>automatically</u> calculated based on the following fields:
  - Additional Cases Enrolled in EI (Part C or non-Part C) + Additional Cases Not Receiving Intervention: Monitoring Only + Additional Cases Not Receiving Intervention: Unknown + Additional Cases Not Receiving Intervention: Other

### Additional Cases Enrolled in EI (Part C or non-Part C)

• This field is the total number of additional infants identified with a permanent hearing loss who were enrolled in EI services (Part C or non-Part C).

### Additional Cases Not Receiving Intervention: Monitoring Only

- This field is the total number of additional infants identified with a permanent hearing loss who were only receiving monitoring services.
- Infants receiving any type of EI services (including Part C and non-Part C) should <u>not</u> be reported in this field.

#### Additional Cases Not Receiving Intervention: Unknown

• This field is the total number of additional infants identified with a permanent hearing loss who were not receiving any EI services for unknown reasons.

## Additional Cases Not Receiving Intervention: Other

• This field is the total number of additional infants identified with a permanent hearing loss who were not receiving any EI services for other reasons.

# **Cases Enrolled in El without a Confirmed Diagnosis**

## Total Additional Cases Enrolled in El without Confirmed Diagnosis

- This field is the total number of infants who did not pass the newborn hearing screening but were enrolled in EI services without documentation of a hearing loss diagnosis.
- If a case enrolled in EI was already reported in the "Total with EI Services & No EI Services" field in the "Intervention Data" section, it should <u>not</u> be included in this section.
- Cases enrolled in EI that are reported in the "Audiological Diagnosis in Process (Awaiting Diagnosis)" field in the "Diagnostics Data" section should be reported in this field.
- These cases should be reported in the "Total Not Passed (most recent/final screen)" field in the "Screening Data" section, and in the appropriate "Total with No Documented Diagnosis" category in the "Diagnostic Data" section.
- Note: Please <u>do not</u> report any information about these cases of hearing loss in Part 3 of this survey.

# Part 2: Type and Severity of Hearing Losses

# Overview

- The type, laterality, and severity for <u>every case</u> of permanent hearing loss reported in Part 1 ("Total with Permanent 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 2018.
- Data should be reported from the <u>most recent/complete</u> 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 (Diagnostic Data 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 should be reported using the American Speech-Language-Hearing Association (ASHA). ASHA categories may be found on page 21.
- 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 "Additional Cases Not Reported" section of Part 1.
- 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 Data" section of Part 1 (and shown above the table). If there is <u>any</u> difference between these values you will receive a red error message and will not be able to submit 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)

### Organization

- The table in Part 2 is organized into different categories 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 categories 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 categories (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). Note: There is no "profound" severity for the Conductive hearing loss category.

# **Type of Hearing Loss**

- Permanent types of hearing loss that can be reported include Sensorineural, Conductive, Mixed, Type 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, mixed, type unknown, and auditory neuropathy hearing loss, the severity can be reported as slight, mild, moderate, moderately severe, severe, profound, or unknown severity. For cases of conductive hearing loss the severity can be reported as slight, mild, moderate, moderately severe, severe, or unknown severity.
- If the severity is unknown please use the appropriate "Unknown Severity" field.

# **Laterality of Hearing Loss**

- Bilateral Hearing Losses (i.e., hearing 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).
  - The values calculated for "Totals by Ear Right Ear" and for "Totals by Ear Left Ear" must be the <u>same</u>. If there is <u>any</u> difference between these values you will receive a red error message. You will need to correct the error before submitting the survey.
- Unilateral Hearing Losses (i.e., hearing 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.
  - o If it is unknown if the hearing loss is in the right or left ear use the appropriate "Unknown Ear" field.
- Laterality Unknown
  - o If the laterality of hearing loss is unknown, please use the appropriate "Laterality Unknown" field.
  - $\circ$  The type and severity can be reported for cases with an unknown laterality.

# **Hearing Loss Criteria\***

- Severity or the degree of hearing loss provides information regarding the average/estimated hearing across the speech frequency range.
- Severity data should be reported using the American Speech-Language-Hearing Association (ASHA). The categories and their corresponding decibel (dB) ranges that are being used for this 2018 survey are listed below.

ASHA Categories	Hearing loss range (dB HL)				
Normal	-10 to 15				
Slight	16 to 25				
Mild	26 to 40				
Moderate	41 to 55				
Moderately severe	56 to 70				
Severe	71 to 90				
Profound	91+				

# Sample Scenarios (Type/Severity)

- <u>Scenario 5</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 6</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 7</u>: Infant diagnosed with a permanent conductive, bilateral hearing loss with a severe loss in both the right and left ears (noted by "C").
- Scenario 8: Infant diagnosed with a conductive permanent hearing loss (noted by "D").
- <u>Scenario 9</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	(Note degree	OWN EAR e: record e of loss for <u>ch</u> ear)	RIGHT EAR	LEFT EAR	UNKNOW N EAR	it is unknown if the loss is unilateral or bilateral)
	Slight								
	Mild		Α						
Iral	Moderate			В					
Sensorineural	Moderately Severe								
JSC	Severe	Α, Ε							
Sei	Profound								
	Unknown Severity		E		В				
	Slight								
0	Mild								
tive	Moderate								
Conductive	Moderately Severe								
ပိ	Severe	С	С						
	Unknown Severity								D
	Totals by Ear	3	3	1	1				1
	Totals by Child	3 1		1				1	

# **Part 3: Demographics**

- Parts 1 and 2 of this survey should be completed **before** completing Part 3.
- Aggregate, demographic information is requested for five demographic variables: infant sex, maternal age, maternal education, maternal ethnicity, and maternal race, for selected data items from Part 1. 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.
  - Diagnostics Demographics: Total with No Hearing Loss, Total with Permanent Hearing Loss.
  - o Intervention Demographics: Total Enrolled in Part C EI.
- The selected data from Part 1 (e.g., Total Occurrent Births) will <u>automatically</u> appear in Part 3 in the first row of green boxes called "Totals (from Part 1)" at the top of the table.
- Error checks are included to help ensure the consistency and accuracy of the demographic data.
  - For each demographic variable, the calculated total value in each column <u>must</u> match the automatically populated value for the Total from Part 1 for that column, at the top. If these two values do not match, you will receive a red error message indicating the values that do not match. All errors must be corrected before submitting the survey.
    - For example, if the "Total Occurrent Births" were reported as 100 in Part 1, the total of the numbers reported for "Total Occurrent Births-Male," "Total Occurrent Births-Female," and "Total Occurrent Births-Sex Unknown" must equal 100.
  - The value for "Total Occurrent Births" in each demographic category row should be greater than or equal to the sum of "Total Pass" and "Total Not Pass" for that demographic category. If it does not, you will receive an orange caution message indicating the values that do not match. This caution message indicates a potential data quality and the data entered must be reviewed. If the values are verified and the caution message remains, you can still proceed with submitting the survey.
    - For example, if the "Total Occurrent Births-Less than High School" were reported as 50, the total of the numbers reported for "Total Pass-Less than High School" and "Total Not Pass-Less than High School" must be less than or equal to 50.
  - The value for "Total Not Pass" in each demographic category row should be greater than or equal to the sum of "Total with No Hearing Loss" and "Total with Permanent Hearing Loss" for that demographic category. If it does not, you will receive an orange caution message indicating the values that do not match. This caution message indicates a potential data quality and the data entered must be reviewed. If the values are verified and the caution message remains, you can still proceed with submitting the survey.
    - For example, if the "Total Not Pass-Hispanic or Latino" were reported as 50, the total of the numbers reported for "Total with No Hearing Loss-Hispanic or Latino" and "Total with Permanent Hearing Loss-Hispanic or Latino" must be less than or equal to 50.
  - The value for "Total with Permanent Hearing Loss" in each demographic category row should be greater than or equal to the sum of "Total Enrolled in Part C EI." If it does not, you will receive an orange caution message indicating the values that do not match. This caution message indicates a potential data quality and the data entered must be reviewed. If the values are verified and the caution message remains, you can still proceed with submitting the survey.
    - For example, if the "Total with Permanent Hearing Loss-Other Maternal Race" were reported as 50, the number reported for "Total Enrolled in Part C EI-Other Maternal Race" must be less than or equal to 50.

# Submitting the HSFS

- After completing <u>all</u> sections please make sure all errors have been corrected. If a tab has errors, a message will display on the Final tab page indicating which page has errors. You can check the data you entered by clicking on the tab for the section(s) you want to review.
- All notes should be entered in the "Comments" field under the Final tab.
- At the end of the survey you will be able to create a PDF of the final data report for your records. In Microsoft Office 2018, select "File," "Export," "Create PDF/XPS Document." Once the Publish dialog appears, press the "Options..." button and select the option to publish the "Entire Workbook." Close the "Options" dialog, and choose a location to save the pdf file. Microsoft Office 2007, 2010 and 2013 have similar capabilities. If you do not have access to these programs, you can select from a variety of free or paid programs that allow you to create PDF documents from Excel files.
- Directions for submitting the survey to CDC will appear once all the red errors have been corrected.