

2015 CDC EHDI Hearing Screening and Follow-up Survey (HSFS): Explanations*

All requested data only refer to infants born in year 2015 (i.e., January 1, 2015 – December 31, 2015) and the EHDI services they received. Please contact Suhana Alam (SAlam1@cdc.gov) and Kris Subbiah (KSubbiah@cdc.gov) with any questions. Thank you for completing this survey.

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 the calendar year 2015 received in 2016 (e.g., include infant born in December 2015 who did not receive a diagnostic evaluation until March 2016).
- 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</u>, <u>occurrent</u> births (within the reporting jurisdiction) born in the 2015 calendar year.
- 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</u>, <u>occurrent</u> births in the 2015 calendar year according to the Vital Records program in the reporting jurisdiction.
- 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.
- 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 take place in a residence/home.
- 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 number will be automatically 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 the most recent/final hearing screening.

- This number should include all infants who were documented to have passed a hearing screening, regardless of the age it was completed.
- Both ears should be screened at the same time (but not required) in order to be reported in the "Total Passed" category.

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 most recent/final hearing screening.
- One month is equal to 30 days.
- Passed before one month of age = up to 30 days.
- This number should not be greater than the number reported for "Total Passed (most recent/final screen)."

Total Not Passed (most recent/final screen)

- This field is the total number of infants screened for hearing loss who did not pass the 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 are referred directly for diagnostic testing by an approved medical provider.

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 the most recent/final hearing screening.
- One month is equal to 30 days.
- Not passed before one month of age = up to 30 days.
- This number should not be greater than the number reported for "Total Not Passed (most recent/final screen)."

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.
- Referred initial / Passed outpatient: 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

Not Passed (most recent/final screen):

- Referred initial / No outpatient: 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.
- Referred initial / Referred outpatient: Infants who did not pass the initial screening and did not pass the outpatient screening.
- Referred initial / straight to diagnostic evaluation: Infants who did not pass the initial screening and was 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

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

Total Documented as Not Screened

- This number will be <u>automatically</u> calculated based on the following fields:
 - Infant Died + Non-resident + 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

- 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 jurisdiction 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 2015 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 three 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 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 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.
 - o 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 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.
 - 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.

Unknown

- 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 **not** be reported in this category.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

Other

• 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"
- Scenario 2: Infant is born in a hospital but the hospital does not have any record of the infant having a
 hearing screening administered before discharge. The hospital did not report any information to the
 state or territory about any screenings being administered before or after discharge.
 - o 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 <u>any</u> difference between these values you will receive an 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 <u>initial diagnosis</u> of either permanent hearing loss or no 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 automatically 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 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 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.

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 = up to 90 days.
- This number should not be greater than the number reported for "Total with No Hearing Loss."

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.

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 = up to 90 days.
- This number should not be greater than the number reported for "Total Permanent Hearing Loss."

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.
- This number should not be greater than the number reported for "Total Permanent Hearing Loss."

Sample Scenarios

- Scenario 3: 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"
- Scenario 4: Infant first seen by audiologist at 45 days, diagnostic ABR administered at 150 days (5 months) indicates permanent hearing loss
 - o 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 automatically 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 + Unable to Receive Diagnostic Testing Due to Medical Reasons + Parents / Family Declined Services + Moved Out of Jurisdiction + 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

- 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 nonresidents of the reporting jurisdiction.
 - o If information is available about diagnostic testing that a nonresident (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 cases where it is not possible to separate if an infant did not receive a diagnosis because they were a non-resident versus if an infant did not receive a diagnosis because they moved out of the 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 two reasons.
- 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" 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.

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 having moved out of jurisdiction (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 "Diagnosed with No Hearing Loss" or "Diagnosed with Permanent Hearing Loss" category, instead of in this field.
- For cases where it is not possible to separate whether an infant did not receive a diagnosis because they
 were a non-resident versus if an infant did not receive a diagnosis because they moved out of the
 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 two reasons.
- 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 "Moved Out of Jurisdiction," 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 2015 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 three 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 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 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.
 - o 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 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.
- This number is used to calculate the number of infants lost to follow-up / lost to documentation.

Unknown

- 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.

Other

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

Total Diagnosed and Not Diagnosed (automatically calculated)

- This number will be automatically 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 an 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 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 automatically populated.
- It is the same number as the "Total with Permanent Hearing Loss" field in the "Diagnostic Data" section.

Total Documented Referral Status

- This number will be automatically calculated based on the following fields:
 - o Referred to Part C EI + Not Referred to Part C EI + Unknown
 - o The "Referred to Part C El Before Six Months of Age" field is not included in this calculation.

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 El services (regardless of eligibility).

Referred to Part C El Before Six 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 = up to 180 days.
- This number should not be greater than the number reported for "Referred 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).

Unknown

 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.

Documented Intervention Services

Total Enrolled in Part C El

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

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.

Total Receiving Part C El Services

- This number will be automatically calculated based on the following fields:
 - Received Services Before 6 Months of Age + Received Services After 6 Months of Age
 - The "Received Services After 6 Months of Age Due to Family Initially Declining Services" field is not included in this calculation.

Received 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 El 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 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 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 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 El services after 6 months of age due to parents / family initially declining services.
- This number should not be greater than the number reported for "Received Services After 6 Months of Age."
- One month is equal to 30 days.
- Received services after 6 months of age = 181 days or more

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** El 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 automatically calculated based on the following fields:
 - Received Services Before 6 Months of Age + Received Services After 6 Months of Age

Received 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 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

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 Intervention 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 + Unable to Receive El Due to Medical Reasons + Parents / Family Declined Services + Moved Out of Jurisdiction + Infant Adopted + Homebirths + 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 EI 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 El services due to death.

Non-resident

- 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 nonresidents of the reporting jurisdiction.
- For cases where it is not possible to separate if an infant did not receive intervention because they were
 a non-resident versus if an infant did not receive intervention because they moved out of the 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 two reasons.

Unable to Receive El 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.

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 having moved out of jurisdiction (e.g., to another state).
- For cases where it is not possible to separate if an infant did not receive intervention because they were
 a non-resident versus if an infant did not receive intervention because they moved out of the 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.

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 2015 data, either the revised or old definition (see explanations below).

Revised 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 three 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 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."
- o 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 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.
 - o 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 El.

Unknown

- 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.

Other

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

Total Enrolled in Intervention & No Intervention Services (automatically calculated)

- This value will be automatically 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 Enrolled in Intervention & No Intervention Services" at the bottom of the "Intervention Data" section must be the <u>same</u> as the value calculated for "Total Cases of Permanent Hearing Loss" at the top of the "Intervention Data" section.
- If there is <u>any</u> difference between these values you will receive an 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.
- This value will be automatically calculated based on the following fields:
 - Additional Cases of Non-permanent, transient hearing loss ID + Additional Cases of Permanent Hearing Loss (e.g., late onset)
- 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" categories in the "Diagnostic Data" section, it should <u>not</u> be included in this section.
- **Note:** Please **do not** report any information about these cases of hearing loss in Part 2 or Part 3 of this survey.

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 Enrolled in Intervention & No Intervention Services" field in the "Intervention Data" section. Only children born in the reporting jurisdiction (i.e., occurrent births) are to be included.
- 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
- If a case of hearing loss was already reported in the "Total Enrolled in EI," "Total from Non-Part C EI Services Only," or "Total with No Documented EI Services" categories, in the "Intervention Data" section, it should not 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.

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 Enrolled in Intervention & No Intervention Services" field in the "Intervention Data" section, it should not 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 do not report any information about these cases of hearing loss in Part 3 of this survey.

Part 2: Type and Severity of Hearing Losses

- 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 2015.
- 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 any difference between these values you will receive an
 error message and will not be able to submit the survey until you correct the error.
- The value for "Overall Total" will be automatically calculated based on the following fields in this section:
 - Totals by Child (Bilateral / right and left ear) + Totals by Child (Bilateral / Unknown ear) + Totals by Child (Unilateral / right ear) + Totals by Child (Unilateral / left ear) + Totals by Child (Unilateral / Unknown ear) + Totals by Child (Laterality Unknown) + Total Cases Resolved (i.e., change from hearing loss to no hearing loss)

Part 2: Organization

- The table in Part 2 is organized into different 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).

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

- 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.
- Bilateral Hearing Losses (i.e., hearing loss in both ears)
 - o The type and severity of hearing loss in each ear (i.e., right and left) should be reported.
 - If the type of the loss in the right and/or left ear is unknown use the appropriate "Unknown Ear" field(s).
- Laterality Unknown
 - o If the laterality of hearing loss is unknown, please use the appropriate "Laterality Unknown" field.
 - o 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 2015 survey are listed below.

ASHA Categories	Hearing loss range (dB HL)				
Normal	-10 to 15				
Slight	16 to 25 26 to 40 41 to 55				
Mild					
Moderate					
Moderately severe	56 to 70 71 to 90				
Severe					
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").
- Scenario 9: 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")

E				LATERAL		UNILATERAL			LATERALITY UNKNOWN (for cases where
		RIGHT EAR	LEFT EAR	(Note degree	OWN EAR e: record of loss for ch ear)	RIGHT EAR	LEFT EAR	UNKNOW N EAR	it is unknown if the loss is unilateral or bilateral)
	Slight								
	Mild		Α						
ıral	Moderate			В					
Sensorineural	Moderately Severe								
ารด	Severe	A, E							
Ser	Profound								
	Unknown Severity		E		В				
	Slight								
a)	Mild								
tive	Moderate								
Conductive	Moderately								
ouc	Severe								
Ö	Severe	С	С						
	Unknown Severity								D
	Totals by Ear	3	3	1	1				1
	Totals by Child	3			1				1

Part 3: Demographics

- Parts 1 and 2 of this survey should be completed <u>before</u> completing Part 3.
- Aggregate, demographic information is requested related to 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.
 - o Diagnostics Demographics: Total with No Hearing Loss, Total with Permanent Hearing Loss.
 - o Intervention Demographics: Total Enrolled in Part C El.
- Note: Please use the "Other" category to report any mothers classified as "multiple race."
- The selected data from Part 1 (e.g., Total Occurrent Births) will automatically 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.
 - o 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 totals in each section do not match you will get an error message indicating the values do not match the number(s) from Part 1. Additional error messages may also be displayed depending on the type of error.
- You will need to correct all errors before submitting the survey to CDC EHDI.

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. Note on Printing to PDF: In Microsoft Office 2013, select "File", "Export", "Create PDF/XPS Document" and press the button "Create PDF/XPS." Once the Publish dialog box appears, press the "Options..." button, and select the option to publish the "Entire Workbook." When you close the Options dialog, you will be prompted for a location to save the file. Microsoft Office 2007 and 2010 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.
- Directions for submitting the survey to CDC will appear once all the errors have been corrected.