# Early Hearing Detection and Intervention Hearing Screening and Follow-up Survey

## Reinstatement with Change

## INFORMATION COLLECTION 0920-0733

## Supporting Statement A

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# A. Justification

## A.1. Circumstances Making the Collection of Information Necessary

This Information Collection Request is submitted under the classification "reinstatement with change." The length of data collection extension requested for OMB-PRA approval is three years. The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) is making this request as authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241; **Attachment 1**).

Background

NCBDDD promotes the health of babies, children, and adults, with a focus on preventing birth defects and developmental disabilities and optimizing the health outcomes of those with disabilities. As part of these efforts the Center is actively involved in addressing the early identification of hearing loss among newborns and infants. Congenital hearing loss is a common birth defect that affects 1 to 3 per 1,000 live births, or approximately 12,000 children across the United States annually.[1, 2] Studies have shown that children with a delayed diagnosis of hearing loss can experience preventable delays in speech, language, and cognitive development.[3 - 5] To ensure children with hearing loss are identified as soon as possible, many states and United States (U.S.) territories have implemented Early Hearing Detection and Intervention (EHDI) programs and enacted laws related to infant hearing screening. The majority of these EHDI programs have adopted the "1-3-6" plan, which consists of three core goals: 1) screening all infants for hearing loss before 1 month of age, 2) ensuring diagnostic audiologic evaluation before 3 months of age for those who do not pass the screening, and 3) enrollment in early intervention services before 6 months of age for those identified with hearing loss.

Federal support for identifying children with hearing loss began with the Children's Health Act of 2000, which authorized federal programs to support EHDI activities at the state level. Since then, funds have been distributed to states via cooperative agreements from the CDC and grants from the Health Resources and Services Administration (HRSA). States are using these federal monies to enhance EHDI

programs and develop corresponding tracking and surveillance systems. These systems are intended to help EHDI programs ensure infants and children are receiving recommended hearing screening, follow-up, and intervention services.

The mission of the CDC-EHDI team is for every state and U.S. territory to have a complete EHDI tracking and surveillance system that will help ensure infants and children with hearing loss achieve communication and social skills commensurate with their cognitive abilities. As part of this mission the CDC-EHDI team, in collaboration with representatives of state and U.S. territorial EHDI programs, developed seven National EHDI Goals that reflect the "1-3-6 plan" and address integration with the medical home (coordinated care by a medical provider) and development of tracking and surveillance systems to minimize loss to follow-up (**Attachment 3**). Many of the defined performance indicators for these goals involve obtaining data related to the number of children screened for hearing loss, referred for and receiving follow-up testing (e.g., diagnostic audiologic evaluation) and enrolled in early intervention services. The purpose of the revised survey (**Attachment 4B**) is to obtain annual state data on the performance indicators in a consistent manner, which is needed to assess progress towards meeting the National EHDI Goals. In addition, the availability of these data will better enable the CDC-EHDI team to provide technical assistance to states and respond to questions by the general public, policy makers, and Healthy People 2010 officials.

The Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA) previously distributed a survey annually (for calendar years 1999 – 2004) to EHDI programs (**Attachment 5**). At DSHPSHWA's request, CDC-EHDI provided assistance with the analysis of this data. This survey requested aggregate data about the number of infants screened for hearing loss, referred for and receiving follow-up testing, and who were enrolled in early intervention services. Although some of the EHDI benchmarks were included on the now retired DSHPSHWA survey, responses to the survey were not standardized due to some ambiguities in the phrasing of the questions. This was especially apparent in regards to data reported about the number of infants referred for and receiving recommended follow-up services (e.g., diagnostic testing and early intervention), as states have used different methods to calculate this information. The result of this was variability within the data reported by states and

territories, which has made it difficult to assess overall progress in meeting the National EHDI Goals. This prompted the need for a new survey that included clearly stated questions that require standardized responses. Specifically, standardized information related to when and how many infants receive follow-up services at different stages of the EHDI process was needed to help assess progress related to the National EHDI Goals and answer questions asked by policymakers and the public.

Following discussions with DSHPSHWA about the need for standardized data, it was agreed that CDC-EHDI would be better equipped to develop a new survey tool to replace the DSHPSHWA survey. When this original CDC EHDI information collection was approved by the Office of Management and Budget (OMB) in October 2006 (Control #: 0920-0733), DSHPSHWA was no longer surveying states. Additionally, DSHPSHWA and states, such as Colorado, supported the original information collection (**Attachments 6 and 7**). As with the original OMB approved EHDI information collection and the reinstatement with change (2010), representatives of state and U.S. territorial EHDI programs will be requested to complete this survey (**Attachments 4B and 4C**). No educational efforts are anticipated to be needed for respondents to be able to complete this mildly revised survey, as states and U.S. territorial EHDI programs already collect and maintain such data for their own internal uses.

As with the information collection reinstatement with change approved in 2010 (0920-0733), evaluation for the mildly revised survey will consist of two components. The first component is the overall survey response rate and item-specific completion rates. In addition, the number of questions asked by respondents about how to complete the revised survey will serve as another indicator of user acceptability. The second component for evaluation will involve the use of the data reported by states and U.S. territories. This will include standard indicators such as whether the information is made available to the public, referenced in presentations, and used in published EHDI-related articles. Additional indicators include determining through discussions within the CDC-EHDI Team whether the reported data is being used effectively to identify systematic areas of loss to follow-up. Data from the original and reinstated surveys have been used for a variety of activities, including, online posting of data for public and professional access, presentations and projects, serving as a source of information for technical

assistance to CDC-funded states, publications, and a tool to assess progress and identify challenges. It is anticipated that the data collected through the mildly updated survey would be used in the same way and because of further increased completeness and data quality, would be of even greater utility to the government and the public.

**1.1 Privacy Impact Assessment**

**i. Overview of the Data Collection System**

This data collection is intended to target only state and territorial EHDI program directors. CDC will utilize a revised survey (**Attachments 4B and 4C**) to obtain standardized annual state data related to the number of children screened for hearing loss, referred for and receiving follow-up testing (e.g., diagnostic audiologic evaluation). The survey will be administered via a secure website. The request to complete this survey is planned to be disseminated to a total of 59 respondents via an email, which will include a summary of the request and other relevant information.

**ii. Items of Information to be Collected**

The survey will be administered to state and territorial EHDI program directors. While the names of respondents in each jurisdiction will be known, these respondents will not provide personal information about themselves or any information in identifiable form (IIF) about infants screened for hearing loss. Each survey respondent will provide aggregate-level data about the screening and follow-up status of infants born in the jurisdiction represented by the respondent. Participation in the survey will continue to be voluntary and respondents will be advised that CDC plans to post jurisdictional-specific aggregate data on the CDC-EHDI website, which is accessible to the public, and in publications (for a representative publication). Survey responses will be evaluated in order to assess the states and territories overall progress in meeting the National EHDI Goals. The first component is the overall survey response rate and item-specific completion rates. The second component for evaluation will involve the use of the data reported by states and U.S. territories. This will include standard indicators such as whether the information is made available to the public, referenced in presentations, and used in published EHDI-related articles. Additional indicators include

determining through discussions within the CDC-EHDI Team whether the reported data is being used effectively to identify systematic areas of loss to follow-up.

**iii. Identification of Website(s) and Website Content Directed at Children Under 13 Years of Age**

This research will not involve Web-based data collection methods; will not refer respondents to a website; and will not involve children under 13 years of age.

## A.2. Purpose and Use of the Information

The CDC's NCBDDD will fund this research to obtain standardized annual state data related to the number of children screened for hearing loss, referred for and receiving follow-up testing (e.g., diagnostic audiologic evaluation).

### 2.1 Privacy Impact Assessment

**(1) Why the information is being collected**

As with the original and reinstated information collection the overall purpose of this updated survey is to consistently gather the aggregate data required to assess progress toward the National EHDI Goals.

**(2) Intended use of the information**

The collected data will continue to be used in four key ways. First, it will be used to determine annual rates of hearing screening, referral for further diagnostic testing, loss to follow-up, incidence of hearing loss in infants, and enrollment in early intervention. These data will assist in determining if infants and children are receiving recommended EHDI related services in a timely fashion. The information is intended to be made available through presentations, articles related to EHDI programs and infant hearing loss, and online at: www.cdc.gov/ncbddd/ehdi. Second, the data will be used to determine rates of loss to follow-up within different stages of the EHDI process. Aggregate information about maternal race, ethnicity, education, and age will be used to help determine whether rates of loss to follow-up are correlated with any of these demographic variables. This information is anticipated to continue to be important in developing methods to help minimize loss to follow-up so all children receive recommended

hearing-related services in a timely manner. Third, the data will be helpful in determining to what extent jurisdictional tracking and surveillance systems are capturing essential information related to follow-up services, identification, and enrollment in early intervention. It will also be used by CDC-EHDI to identify areas in jurisdictional EHDI systems that may require additional modification. This is anticipated to be helpful in providing technical support to funded jurisdictions as well as for assessing the impact of federal initiatives related to hearing loss in infants and children. Fourth, the requested data will aid in efforts to determine the prevalence of differing degrees of hearing loss (e.g., mild, severe, profound, etc.) among infants and children.

Information provided by this updated survey also has the potential to be used for other purposes. These include quality improvement activities by jurisdictional EHDI programs (e.g., identifying areas within the EHDI processes that could benefit from further development) and providing requested data for Healthy People 2020, Objective ENT-VSL-1 on newborn hearing screening, evaluation, and intervention (**Attachment 8**). In addition, the aggregate data will continue to be made available online to other state and federal agencies, organizations, and the general public.

The accuracy of these data are regarded as suitable for the stated purpose and intended uses. Although some jurisdictions may not be able to answer every question on the survey, the information will nonetheless be important in determining overall progress toward the National EHDI Goals, including the development and status of EHDI tracking and surveillance systems.

If these data are not consistently available on an annual basis it will be difficult, if not impossible, to determine whether infants and children are receiving recommended services and how EHDI programs are progressing towards achievement of the National EHDI Goals. This situation is anticipated to severely limit the ability of CDC and other state, federal, and private agencies to assist jurisdictions and ensure infants and children with hearing loss are identified and enrolled in intervention services as early as possible.

**Impact of Privacy on Respondents:** As noted in section A.1 above, no IIF will be collected. While the names of respondents in each jurisdiction will be known, these respondents will not provide personal information about themselves or any personally identifiable information about infants screened for hearing loss. Each survey respondent will provide aggregate-level data about the screening and follow-up status of infants born in the jurisdiction represented by the respondent. Participation in the survey will continue to be voluntary and respondents will be advised that CDC plans to post jurisdictional-specific aggregate data on the CDC-EHDI website, which is accessible to the public, and in publications (for a representative publication).

## A.3. Use of Information Technology and Burden Reduction

In order to reduce the burden on respondents and improve data quality this survey will continue to be made available for completion via a secure website. The continued inclusion of automatic checks to help minimize data errors and the convenience of being able to complete and submit the survey via the internet should continue to help ensure a minimal level of burden. Financial costs will continue to be minimized because no mailing fees will be associated with responding to this survey.

As with the original and reinstated information collection, data quality with the updated survey should remain high because it will continue to feature several error checks that have to be satisfied before the survey can be finalized and submitted. As before there will also be no need to reenter the data into a separate database at CDC, which will decrease the potential for data entry errors. This system has and should continue to help ensure a complete data set that will provide the information needed to generate the statistics (e.g., annual rates of hearing screening) required to ensure infants and children are receiving recommended services, assess progress related to the National EHDI Goals and address questions from the public and other stakeholders.

## A.4. Efforts to Identify Duplication and Use of Similar Information

No other federal agencies collect this type of information. In the past there have been other surveys conducted by non-governmental organizations attempting to collect some information from state EHDI

programs; however, these surveys did not provide the standardized, high-quality data needed to measure progress towards National EHDI Goals, Healthy People (particularly Objective ENT-VSL, **Attachment 8**), and NCBDDD and HHS performance measures. HRSA also relies on the EHDI related data collected by CDC to help assess progress of jurisdictions. In addition, DSHPSHWA no longer surveys state EHDI programs and instead solely relies on the EHDI related data collected by CDC.

### A.5. Impact on Small Businesses or Other Small Entities

Not applicable as small businesses are not part of the respondent universe.

### A.6. Consequences of Collecting the Information Less Frequently

As with other state health reporting to Federal agencies (e.g., Department of Education/Special Education, Title V MCH Block Grant, immunizations, etc), and the original information collection, jurisdictions will again be requested to complete this survey on an annual basis for several reasons. They report each year's birth and death data (i.e., Vital Statistics) annually. By using these established intervals, we will continue to minimize the burden to the respondent by employing a clear reporting schedule that states and territories already use to report data. Collecting data annually has and will continue to enable more expeditious tracking and analysis of trends over time.

There are no legal obstacles to reduce the burden.

### A.7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances. This request fully complies with the regulation.

1) Respondents will not be asked to make copies of any documents;

2) Respondents do not need to retain records;

3) This data collection is designed to produce valid and reliable results that can be generalized to the universe of study;

4) This data collection does not include the use of a statistical data classification that has not been reviewed and approved by OMB;

5) This data collection does not include a pledge of confidentiality that is not supported by appropriate authorities; and

6) This data collection does not involve requiring respondents to submit proprietary trade secrets or other confidential information.

**A.8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside Agency**

In addition to internal review, CDC-EHDI solicited input on data collection efforts from outside reviewers in two ways: (A) public comment in response to a *Federal Register Notice* and (B) experts in early newborn hearing screening. These opportunities for feedback are discussed below.

A. A copy of the agency's 60-day Federal Register Notice is attached (*60-day Federal Register Notice* **Attachment 2**). The notice, as required by 5 CFR 1320.8 (d), was published on March 28, 2013 (volume 78, number 60, pages 18986 - 18987). No public comments were received in response to this notice.

B. Consultations with Individuals Outside of the Organization: Several efforts were made during the development of the original information collection to consult with persons outside the agency to maximize the quality and utility of this collection and ensure that it provided essential information.

i. Regarding development of the original information collection a meeting was held in June 2004 with representatives from other federal agencies (e.g., HRSA, the National Institutes of Health,

and the Department of Education), DSHPSHWA and state EHDI programs to discuss data related issues, including the need, availability, method, and frequency of collection. Participants agreed that aggregate level data was required in order to determine progress towards the National EHDI Goals. HRSA, DSHPSHWA, and states again provided input related to the minor changes that are now being proposed for the revised survey.

ii. DSHPSHWA allowed the CDC EHDI team to use their retired 2004 survey as a model for the design of the original CDC EHDI information collection and provided significant input during the development of the original survey. DSHPSHWA also provided input for the minor changes that are being proposed for the revised survey.

iii. Representatives of four state EHDI programs (Alaska  Indiana, Iowa, and Maryland) provided input about updates for the survey and reviewed draft versions of the updated survey that included the proposed minor changes, and provided comments.

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iv. Key data items recommended by the CDC-EHDI Data Committee for collection continue to be included in the revised version of the survey.

## A.9. Explanation of Any Payment or Gift to Respondents

There are still no plans to provide any payment or gift to respondents.

## A.10. Assurance of Confidentiality to Respondents

The NCBDDD Privacy Officer reviewed the original information collection and determined that the Privacy Act was not applicable. Survey respondents will continue to provide information based on their roles as directors of jurisdictional EHDI programs. While the names of respondents in each jurisdiction will be known, these respondents will not provide personal information about themselves or any personally identifiable information about infants screened for hearing loss. Each survey respondent will provide aggregate-level data about the screening and follow-up status of infants born in the jurisdiction represented by the respondent. Participation in the survey will continue to be voluntary and respondents will be advised that CDC plans to post jurisdictional-specific aggregate data on the CDC-EHDI website, which is accessible to the public,

and in publications (for a representative publication, see the March 2010 MMWR article, Identifying Infants with Hearing Loss — United States, 1999–2007).

IRB approval is not required for this data collection. It was determined that this project is not considered to be research and that no further action is required by CDC for human subjects protections in accordance with federal regulation for the protection of human subjects in research (**Attachment 9**).

## A.11. Justification for Sensitive Questions

As with the original information collection this updated version will request aggregate, non-identifiable data, including demographic information, which has already been collected by jurisdictions for other purposes. Key demographic variables, including maternal race, ethnicity, and age, are needed to better describe and analyze the resulting data. As with the original the updated information collection does not include any sensitive questions.

## A.12. Estimates of Annualized Burden Hours and Costs

A total of 59 respondents will be asked to complete the updated survey each year during the 3-year requested data collection approval timeframe. Based on findings from the previous information collection it is estimated that the burden for individuals to read through the survey and decide whether or not to complete it is 10 minutes per person (**see Attachment 4A**). The 10 minute calculation was based on feedback received in pre-tests with 5 individuals and confirmed by the experience with the survey since the original OMB-PRA approval.

It is expected that 55 of the 59 potential respondents will complete the survey (**see Attachments 4B and 4C**) and therefore incur an additional burden of up to 4 hours per respondent (see table A.12-1). However, based on feedback from consulted experts about the length of time required to complete the original survey it is anticipated that it will only take some respondents a few minutes to complete the

revised survey. This is because jurisdictions often have already gathered and compiled the requested data for their own internal uses. Nevertheless, the more conservative time estimate of 4 hours per response from each of the 55 anticipated participants is shown in the Table below. This estimate is identical to the time estimate for the reinstated OMB-PRA approved estimate from 2010; the only change is the estimated number of respondents.

| | **A.12 – 1 Estimates of Annualized Burden Hours** | | | | |
|---|---|---|---|---|---|
| Respondents | Form Name | Number of Respondents | Number of Responses per Respondent | Average Burden per Response (in hours) | Total Burden Hours |
| EHDI Program State Program Coordinators Contacted | Survey Directions | 59 | 1 | 10/60 | 10 |
| EHDI Program State Program Coordinators who return the survey | Survey | 55 | 1 | 4 | 220 |
| **Totals** | | | | | 230 |

**12. B. Annualized Cost to Respondents**

The hourly wage for respondents was estimated using budget information provided in the annual reports for those jurisdictions with funding from the CDC-EHDI program. Based on this information the average annual salary for the director of a state EHDI program is estimated to be $65,000. This salary divided by 40 hours per week results in an estimated hourly wage of approximately $34.00 for an EHDI Program Director. The total estimated cost burden on all potential survey respondents is $7,820 (230 x 34.00). The average cost per respondent is estimated to be $132.54 ( 7,820 / 59).

| **A.12 – 2 Annualized Cost To Respondents** | | | |
|---|---|---|---|
| **Type of Respondents** | **Total Burden Hours** | **Hourly Wage Rate** | **Respondent Cost** |
| Contacted (n = 59) | 10 | 34.00* | $340 |

| | | | |
|---|---|---|---|
| Complete (n = 55) | 220 | 34.00* | $7,480 |
| **Total** | | | $7,820 |

*Based on an estimated yearly salary of $65,000

## A.13. Estimates of Other Total Annual Cost Burden to Respondents or Recordkeepers

There are no capital or maintenance costs to survey respondents.

## A.14. Annualized Costs to the Federal Government

As with the original information collection costs associated with this data collection are the result of the CDC-EHDI program personnel time involved in the design and distribution of the survey and the analysis of the collected data. The individual responsible for these tasks is a member of the CDC-EHDI team. Below costs for staff time dedicated to this survey are based on compensation at the GS 13 level (i.e., approximately $94,000). These costs are summarized in Table 1 below. Based on the reinstated version of the information collection, the time required by the designated CDC-EHDI team member to conduct this survey, which will consist of contacting jurisdictions primarily by email, is estimated to be 10 hours. Based on an average annual salary or $45.00 per hour, the cost of conducting this survey will be $450 annually. The time required to prepare the data for analysis, again based on experience from conducting the reinstated information collection, will be approximately 10 hours, resulting in a cost of $450 annually based on the current average salary. Data analysis is estimated to require 80 hours resulting in annualized analysis costs of approximately $3,600.

The time spent revising the reinstated information collection required an estimated 40 hours and was coordinated by a member of the CDC-EHDI team. The average annual salary of this individual was equivalent to a GS 13 (i.e., approximately $94,000). This resulted in an estimated development cost of $1,800. The costs associated with these updates are not anticipated to be incurred again during the requested three year life of this annual data collection because no changes to the survey are planned during this period. Also, no additional developmental costs related to this survey are anticipated during the next three years. Approximately 25 hours were spent preparing the renewal application for OMB, which resulted in a cost of $1,125 based on an average annual salary.

Based on the calculations described above, the estimated annualized cost to the Government is $5,475.

**Table 1. Estimated Annual Cost to Conduct EHDI Surveys**

| Task | Cost |
|---|---|
| **Labor Costs** | |
| Survey Development (one time costs) | $1,800 |
| OMB Application (one time costs) | $1,125 |
| Survey Administration ($450 per year X 3 years) | $1,350 |
| Data Preparation ($450 per year X 3 years) | $1,350 |
| Data Analysis ($3,600 per year X 3 years) | $10,800 |
| **Total Costs for 3 Years** | **$16,425** |
| **Annual Estimated Costs** | **$5,475** |

*Labor Costs include Fringe and Benefits

## A.15. Explanations for Program Changes or Adjustments

Minor changes are proposed to the reinstated information collection that was approved by OMB in June 2010 (0920-0733). These proposed changes for the updated survey have been made in response to feedback from respondents and requests for additional information from state and national partners. These minor updates are intended to make the survey easier to complete and further improve the quality of the data that is collected. These changes include changing the order of some questions, splitting the previously combined question about the number of infants that were non-residents or moved out jurisdiction into two separate questions and adding new questions. These include questions asked about how many infants were in a neonatal intensive care unit (NICU) for more than 5 days, transferred without any documentation of a hearing screening, unable to be screened or receive diagnostic testing due to a medical reason, number of cases where a primary care physician did not refer an infant for diagnostic testing, and cases of permanent hearing loss among non-resident infants. The table for reporting type and severity of hearing loss data has also been updated so this data can be reported using either the classification system from the American Speech and Hearing Association (ASHA) or the current system from the DSHPSHWA. These proposed changes for the updated survey are explained in more detail below.

**SURVEY Part 1 (Screening, Diagnosis, and Intervention)**

- Hearing Screening Section:
  - Changed the order so that questions about infants that did not have a documented screen were moved from the beginning of the screening section to the end of this section. This was done to improve the structure of the survey and match the format of the Diagnostic and Intervention sections.
  - Added fields to report the overall number of infants that were in a NICU for more than 5 days, the number of these infants in the NICU that passed a hearing screening, and the number in the NICU that did not pass the screening. These fields were added in response to requests from respondents and partners to be able to determine screening rates among infants in the NICU for more than five days, which is a risk factor for hearing loss.
  - Added a field so respondents can report the number of infants that were not screened for hearing loss because they were a non-resident. This field was added in response to feedback from respondents that this was a reason why some infants were not screened.
  - Added a field to report infants that were “Unable to be Screened due to Medical Reasons.” This field was added in response to feedback that this was a reason why some infants were not screened.
  - Added a field to report “Infants Transferred and No Documentation of Screening.” This field was added in response to feedback that this was a reason why some infants were not screened.

- Diagnostic Section:
  - Separated the “Non-Resident or Moved Out of Jurisdiction” field into two separate fields (i.e., one data field for “Non-Resident” and one data field for “Moved Out of Jurisdiction”). This was done so

that it will be possible to report the number of infants not receiving diagnostic testing due to being a non-resident and the number that moved out of jurisdiction, which is information that has been requested by partners. This change will also enable more detailed analysis of the data that is reported.

- Added a field to report infants that were "Unable to Receive Diagnostic Testing due to Medical Reasons." This field was added in response to feedback from respondents that this was a reason why some infants were not screened.

- Added a field to report infants where an infant's "PCP did not Refer Infant for Diagnostic Testing." This field was added in response to feedback that this is a reason why some infants were not receiving diagnostic testing.

- Added two fields "Permanent cases of hearing loss among infants reported as Non-Residents" and "Permanent cases of hearing loss among infants that are residents but were born in a different jurisdiction." These fields were added in response to feedback from respondents that some cases of hearing loss were not being reported on the previous ICS because these infants were either non-residents or were born in another jurisdiction.

- Intervention Section:

  - Separated the "Non-Resident or Moved Out of Jurisdiction" field into two separate fields (i.e., one data field for "Non-Resident" and one data field for "Moved Out of Jurisdiction"). This was done so that it will be possible to report the number of infants not receiving intervention due to being a non-resident and the number that moved out of jurisdiction, which is information that has been requested by partners. This change will also enable more detailed analysis of the data that is reported.

**SURVEY Part 2 (Type and Severity)**

- The table for reporting type and severity of hearing loss data has been updated so this data can be reported using either the classification system from the American Speech and Hearing Association or the current system from the Directors of Speech and Language Programs in State Health and Welfare Agencies. This change has been made in response to a request from DSHPSHWA to start using the ASHA systems as it will provide more detailed and representative type and severity data. Respondents will have the option to use either the ASHA or DSHPSHWA systems to report data on the EHDI ICS. This is so that jurisdictions that have not yet switched to the ASHA system can continue to report type and severity data without any undue burdens.

  - In comparison to the DSHPSHWA classification system the ASHA system also includes two additional fields to classify the severity of a hearing loss (i.e., Mild and Moderately Severe)

## A.16. Plans for Tabulation and Publication and Project Time Schedule

The table below shows the anticipated project time schedule for Years 1, 2, and 3 of this revised survey.

**A.16-1 Project Time Schedule***

| Activity | Time Schedule |
|---|---|
| Distribute surveys to respondents | 2 - 3 months after OMB approval |
| Email Reminders (to increase response rate) | 3 - 4 months after OMB approval |
| Provide phone support for survey completion | 3 – 4 months after OMB approval |
| Download data from web application | 5 - 6 months after OMB approval |
| Data management and validation | 5 - 6 months after OMB approval |
| Initial Tabulation of Results | 5 - 6 months after OMB approval |
| Data validation with states (as needed) | 5 - 6 months after OMB approval |
| Final data analysis | 6 - 7 months after OMB approval |
| Dissemination of results | 6 – 7 months after OMB approval |
| REPEAT of all steps above | 13 - 24 months after OMB approval |

| | |
|---|---|
| for **Year Two** of Survey | |
| REPEAT of all steps above<br><br>for **Year Three** of Survey | 25 - 36 months after OMB approval |

**Note: This time schedule is dependent on if and when the information collection is approved by OMB and the amount of time for all respondents to return the survey.*

*Analyses Plan:* As with the original survey all information reported for the updated survey will be at the aggregate level. Therefore, annual national and regional calculations will continue to be performed on the jurisdictionally-based aggregate data to determine a number of relevant statistics, including overall rates of children screened for hearing loss, identified with hearing loss, enrolled in early intervention services, and loss to follow-up / loss to documentation. Prevalence rates of hearing loss per 1,000 infants screened and the frequency of differing types and severity of hearing loss will also be determined for all jurisdictions that provide data. All statistics will be calculated by CDC-EHDI personnel. A list of relevant statistics and an explanation of how they will be calculated is provided in the table below. Additional statistics may be generated as needed.

| **EHDI Aggregate Statistics (*state and national level*)** | **Explanation of Calculations** |
|---|---|
| Percent of infants in the NICU | (# in NICU / # of occurrent births)*100 |
| Percent screened for hearing loss | (# screened for hearing loss / # of occurrent births)*100 |
| Percent screened for hearing loss (*according to Vital Records*) | (# screened for hearing loss / # of occurrent births as reported by Vital Records)*100 |
| Percent screened for hearing loss (*excluding infant deaths and parents / family declining services*) | [(# screened for hearing loss / # occurrent births – *(# infant deaths + # parental & family refusals*) *100 |
| Percent screened for hearing loss (*excluding infants born in military facilities*) | (# screened for hearing loss / # of occurrent births – (# births in military facilities according to Vital Records)*100 |
| Percent not screened for hearing loss | (# not screened for hearing loss / # of occurrent births)*100 |
| Percent not screened due to infant deaths | (infant died / total # of occurrent births) *100 |
| Percent not screened due to being a non-resident | (# non-resident / total # of occurrent births) *100 |
| Percent unable to be screened due to a medical reason | (# unable to be screened due to medical reason / total # of occurrent births) *100 |

| | |
|---|---|
| Percent not screened due to parents / family declining services | (parents declined services / total # of occurrent births) *100 |
| Percent not screened due to being transferred | (# not screened due to being transferred / total # of occurrent births) *100 |
| Percent not screened due to infants being missed | (# missed / total # of occurrent births) *100 |
| Percent not screened due to being unknown | (# unknown / total # of occurrent births) *100 |
| Percent total pass | (total # pass / total # screened) *100 |
| Percent pass before one month of age | (pass before one month of age / total # pass) * 100 |
| Percent pass after one month but before 3 months of age | (pass after one month but before 3 months of age / total # pass) *100 |
| Percent pass after 3 months of age | (pass after 3 months of age / total # pass) * 100 |
| Percent pass among NICU infants | (pass among NICU infants / total # pass) * 100 |
| Percent total not pass | (total not # pass / total # not pass) *100 |
| Percent not pass before one month of age | (not pass before one month of age / total # not pass) * 100 |
| Percent not pass after one month but before 3 months of age | (not pass after one month but before 3 months of age / total # not pass) *100 |
| Percent not pass after 3 months of age | (not pass after 3 months of age / total # not pass) *100 |
| Percent not pass among NICU infants | (not pass among NICU infants / total # not pass) * 100 |
| Percent with normal hearing | (normal hearing / total not pass) *100 |
| Percent with normal hearing before 3 months of age | (normal hearing before 3 months of age / total not pass) *100 |
| Percent with normal hearing after 3 months but before 6 months of age | (normal hearing after 3 months before 6 months of age / total not pass) *100 |
| Percent with normal hearing after 6 months of age | (normal hearing after 6 months of age / total not pass) *100 |
| Percent with hearing loss | (hearing loss / total not pass) *100 |
| Percent with hearing loss before 3 months of age | (hearing loss before 3 months of age / total not pass) *100 |
| Percent with hearing loss after 3 months but before 6 months of age | (hearing loss after 3 months but before 6 months of age / total not pass) *100 |
| Percent hearing loss after 6 months of age | (hearing loss after 6 months of age / total not pass) *100 |
| Percent with no documented diagnosis due to audiologic diagnosis in process | (audiologic diagnosis in process / total not pass) *100 |
| Percent with no documented diagnosis due to non-resident | (non-resident / total not pass) *100 |
| Percent with no documented diagnosis due to moved out of jurisdiction | (moved out of jurisdiction / total not pass) *100 |
| Percent with no documented diagnosis due to infant death | (infant died / total not pass) *100 |
| Percent unable to receive testing due to medical reasons | (unable to receive testing due to medical reasons / total not pass) *100 |
| Percent where PCP did not refer infants for testing | (PCP did not refer / total not pass) *100 |
| Percent with no documented diagnosis due to parents / family declining services | (parents declined services / total not pass) *100 |
| Percent with no documented diagnosis due to parent / family unresponsive | (parents / family contacted but unresponsive / total not pass) *100 |
| Percent with no documented diagnosis due to parents / family unable to be contacted | (unable to contact / total not pass) *100 |
| Percent loss to follow-up / loss to documentation for diagnosis | (unknown / total not pass) *100 |

| | |
|---|---|
| Percent with non-permanent, transient hearing loss | (non-permanent, transient hearing loss / total screened) * 100 |
| Percent cases of hearing loss among infants reported as Non-Residents | (hearing loss among infants reported as Non-Residents / total screened) * 100 |
| Percent cases of hearing loss among infants that are residents but born in a different jurisdiction | (hearing loss among infants that are residents but born in a different jurisdiction / total screened) * 100 |
| # Identified with hearing loss | Sum the reported # identified with hearing loss in each state & territory to yield a national level value |
| # Identified with hearing loss per 1,000 screened | (# identified with hearing loss / total # screened)* 1,000 |
| Percent total referred for Part C* early intervention | (total referred for Part C early intervention / # with hearing loss) *100 |
| Percent eligible for Part C early intervention | (eligible for Part C early intervention / # with hearing loss) *100 |
| Percent not eligible for Part C early intervention | (not eligible for Part C early intervention / # with hearing loss) *100 |
| Percent enrolled in Part C early intervention | (enrolled in Part C early intervention / # with hearing loss) *100 |
| Percent enrolled in Part C early intervention before 6 months of age | (enrolled in Part C early intervention before 6 months of age / # with hearing loss) *100 |
| Percent enrolled in Part C early intervention after 6 months but before 12 months of age | (enrolled in Part C early intervention after 6 months but before 12 months of age / # with hearing loss) *100 |
| Percent enrolled in Part C early intervention after 12 months of age | (enrolled in Part C early intervention after 12 months of age / # with hearing loss) *100 |
| Percent enrolled in non-Part C early intervention | (enrolled in non-Part C early intervention / # with hearing loss) *100 |
| Percent enrolled in non-Part C early intervention before 6 months of age | (enrolled in non-Part C early intervention before 6 months of age / # with hearing loss) *100 |
| Percent enrolled in non-Part C early intervention after 6 months but before 12 months of age | (enrolled in non-Part C early intervention after 6 months but before 12 months of age / # with hearing loss) *100 |
| Percent enrolled in non-Part C early intervention after 12 months of age | (enrolled in non-Part C early intervention after 12 months of age / # with hearing loss) *100 |
| Percent receiving no intervention services due to infant deaths | (infant died / # with hearing loss) *100 |
| Percent receiving no intervention services due to parents / family declining services | (parents declined services / # with hearing loss) *100 |
| Percent receiving no intervention services due to non-resident | (non-resident / # with hearing loss) *100 |
| Percent receiving no intervention services due to moving out of the jurisdiction | (moved out of jurisdiction / # with hearing loss) *100 |
| Percent receiving no intervention services due to receiving only monitoring services | (monitoring services / # with hearing loss) *100 |
| Percent receiving no intervention services due to parents / family contacted but unresponsive | (parents / family contacted but unresponsive / # with hearing loss) *100 |
| Percent receiving no intervention services due to parents / family unable to contact | (unable to contact / # with hearing loss) *100 |
| Percent loss to follow-up / loss to documentation for Intervention | (unknown / # with hearing loss) *100 |
| ***Type and Severity*** | |
| Cases of unilateral hearing loss (total) | Sum the # of cases unilateral hearing loss cases reported by states and territories to yield a national level value |

| | |
|---|---|
| Cases of unilateral sensorineural hearing loss (total) | Sum the # of cases unilateral sensorineural hearing loss cases reported by states and territories to yield a national level value |
| Cases of unilateral sensorineural hearing loss by severity (i.e., slight, mild, moderate, moderately severe, severe, and profound) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of unilateral conductive hearing loss (total) | Sum the # of cases unilateral conductive hearing loss cases reported by states and territories to yield a national level value |
| Cases of unilateral conductive hearing loss by severity (i.e., slight, mild, moderate, moderately severe, and severe) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of unilateral mixed hearing loss (total) | Sum the # of cases unilateral mixed hearing loss cases reported by states and territories to yield a national level value |
| Cases of unilateral mixed hearing loss by severity (i.e., slight, mild, moderate, moderately severe, severe, and profound) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of bilateral hearing loss (total) | Sum the # of cases bilateral hearing loss cases reported by states and territories to yield a national level value |
| Cases of bilateral sensorineural hearing loss (total) | Sum the # of cases bilateral sensorineural hearing loss cases reported by states and territories to yield a national level value |
| Cases of bilateral sensorineural hearing loss by severity (i.e., slight, mild, moderate, moderately severe, severe, and profound) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of bilateral conductive hearing loss | Sum the # of cases bilateral conductive hearing loss cases reported by states and territories to yield a national level value |
| Cases of bilateral conductive hearing loss by severity (i.e., slight, mild, moderate, moderately severe, and severe) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of bilateral mixed hearing loss (total) | Sum the # of cases bilateral mixed hearing loss cases reported by states and territories to yield a national level value |
| Cases of bilateral mixed hearing loss by severity (i.e., slight, mild, moderate, moderately severe, severe, and profound) | Sum the # of cases reported for each level of severity to yield national level data on type and severity of identified hearing loss |
| Cases of Type Unknown Hearing Loss (total) | Sum the # of cases type unknown hearing loss cases reported by states and territories to yield a national level value |
| Cases of Type Unknown Hearing Loss by severity | Sum the # of cases reported for each level of severity to yield national level data on the severity of identified cases of type unknown |
| Cases of Auditory Neuropathy/ Dyssynchrony (total) | Sum the # of Cases of Auditory Neuropathy/ Dyssynchrony cases reported by states and territories to yield a national level value |
| Cases of Auditory Neuropathy/ Dyssynchrony (i.e., slight, mild, moderate, severe, moderately severe, and profound) | Sum the # of cases reported for each level of severity to yield national level data on the severity of identified cases of Auditory Neuropathy/ Dyssynchrony |
| ***Demographics*** | |
| Hearing Screening by Maternal Age | Sum of the # of cases of Pass and Not Pass for each maternal age category (e.g., 15 – 19 years) / |

| | |
|---|---|
| | total # of occurrent births |
| Hearing Screening by Maternal Education | Sum of the # of cases of Pass and Not Pass for each maternal education category (e.g., less than high school) / total # of occurrent births |
| Hearing Screening by Maternal Ethnicity | Sum of the # of cases of Pass and Not Pass for each maternal ethnicity category (e.g., Hispanic or Latino) / total # of occurrent births |
| Hearing Screening by Maternal Race | Sum of the # of cases of Pass and Not Pass for each maternal ethnicity category (e.g., Hispanic or Latino) / total # of occurrent births |
| Diagnosis by Maternal Age | Sum of the # of normal hearing and hearing loss cases for each maternal age category / total # not passing the hearing screening |
| Diagnosis by Maternal Education | Sum of the # of normal hearing and hearing loss cases for each maternal education category / total # not passing the hearing screening |
| Diagnosis by Maternal Ethnicity | Sum of the # of normal hearing and hearing loss cases for each maternal ethnicity category / total # not passing the hearing screening |
| Diagnosis by Maternal Race | Sum of the # of normal hearing and hearing loss cases for each maternal race category / total # not passing the hearing screening |
| Intervention by Maternal Age | Sum of the # enrolled in Part C and non-Part C intervention for each maternal age category / total # identified with hearing loss |
| Intervention by Maternal Education | Sum of the # enrolled in Part C and non-Part C intervention for each maternal education category / total # identified with hearing loss |
| Intervention by Maternal Ethnicity | Sum of the # enrolled in Part C and non-Part C intervention for each maternal ethnicity category / total # identified with hearing loss |
| Intervention by Maternal Race | Sum of the # enrolled in Part C and non-Part C intervention for each maternal race category / total # identified with hearing loss |

Part C*: Refers to Part C of the Federal Individuals With Disability Act. This section of the law provides for early intervention services for children aged 0-3 with disabilities, including hearing loss.

Generated statistics will be compared to data previously reported to CDC to assess jurisdictional, regional, and national performance at different stages in the EHDI process (e.g., percent screened for hearing loss). Aggregate statistics will also be compared across jurisdictions. The titles of potential reports to be produced from the aforementioned analyses are listed in Attachment 10. Although the primary intent of this information collection is to generate aggregate jurisdictional and national-level statistics on hearing screening, referral, receipt of follow-up testing, identification, and intervention, within-state subgroups, analyses will be performed as the data allow.

*Data Management:* To ensure the accuracy of the information submitted, the data will be inspected for outliers and compared to data reported in previous years. Respondents will be contacted via email and/or phone in cases where any responses appear to be incomplete or do not correspond to other information reported. Please see **Attachment 11** for a copy of this email request.

### A.17. Reason(s) Display of OMB Expiration Date is Inappropriate

No such exemption is requested.

### A.18. Exceptions to Certification for Paperwork Reduction Act Submissions

No exceptions apply to this data collection.

**References**


1. Finitzo T, Albright K, O'Neal J. The newborn with hearing loss: detection in the nursery. Pediatrics. 1998 Dec; 102(6):1452-60.

2. Van Naarden K, Decoufle P, Caldwell K. Prevalence and characteristics of children with serious hearing impairment in metropolitan Atlanta, 1991–1993. Pediatrics. 1999 Mar; 103(3):570-5.

3. Yoshinaga-Itano C. Early intervention after universal neonatal hearing screening: impact on outcomes. Ment Retard Dev Disabil Res Rev. 2003; 9(4):252-66.

4. Yoshinaga-Itano C, Sedey AL, Coulter DK, Mehl AL. Language of early- and later-identified children with hearing loss. Pediatrics. 1998 Nov;102(5):1161-71.

5. Robinshaw HM. The pattern of development from non-communicative behavior to language by hearing impaired and hearing infants. Br J Audiol. 1996 Jun; 30(3):177-98.