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Restructuring Data Reported from Jurisdictional Early Hearing Detection and Intervention (EHDI) Programs: A Pilot Study

Suhana Alam, MPH[1], **Winnie Chung, AuD**[1], **Xidong Deng, PhD**[1], **Tammy O'Hollearn, LBSW**[2], **Jim Beavers, BGS**[3], **Rebekah F. Cunningham, PhD**[4], **Alyssa K. Rex, AuD**[4], **ThuyQuynh N. Do, PhD, MPH**[1]

[1]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

[2]Iowa Department of Public Health, Des Moines, Iowa

[3]Nebraska Department of Health and Human Services, Lincoln, Nebraska

[4]Indiana State Department of Health, Indianapolis, Indiana

Abstract

Objective.—To assess the feasibility, benefits, and challenges surrounding individual-level versus aggregate data reporting by jurisdictional EHDI programs to the Centers for Disease Control and Prevention (CDC).

Method.—Using data reported to CDC by three jurisdictions in 2011, descriptive statistics were used to assess the feasibility of collecting and reporting individual-level data. Comparisons were made on what can be learned from individual-level data as opposed to CDC's aggregate survey data.

Results.—Individual-level data provided a detailed overview of the population served, services received, and variations across jurisdictions in data collection, reporting, and quality monitoring practices. Several challenges and areas needing improvement were identified: variations in (1) data standardization; (2) data collection and reporting procedures; and (3) protocols for recommended follow-up services.

Conclusions.—Using individual-level data, CDC was able to perform in-depth statistical analyses and learn more about each jurisdiction's population, their EHDI process, and challenges to data collection, tracking, and surveillance efforts. As a result, CDC was able to provide more targeted technical assistance. All of the above would not be feasible using aggregate survey data. The pilot study demonstrated that individual-level data reporting to CDC is feasible and offers many opportunities for both CDC and jurisdictional EHDI programs.

Keywords

Early hearing detection and intervention; newborn hearing screen; surveillance and tracking

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Correspondence concerning this article should be addressed to: Suhana Alam, MPH, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 4770 Buford Highway, MS-E88, Atlanta, GA 30341. Phone: 404-498-0984; Fax: 770-488-0270; SAlam1@cdc.gov.

Introduction

Newborn hearing screening (NBHS) is one of the 31 primary conditions included on the Recommended Universal Screening Panel (Health Research & Services Administration, 2017). However, NBHS alone does not ensure that a child with hearing loss (HL) is identified (Winston-Gerson & Hoffman, 2017). Early diagnosis of HL involves a series of steps and services through multiple providers. If an infant does not pass NBHS, it is crucial to determine if the infant received appropriate and timely follow-up diagnostic services. If HL is present, the infant needs to receive recommended intervention services as early as possible to reduce the likelihood for developmental delays (Vohr, 2003). Most U.S. states and territories have an EHDI program with goals to screen infants for HL no later than 1 month of age, diagnose HL no later than 3 months of age for infants who did not pass the hearing screening, and enroll infants identified with permanent HL into early intervention (EI) no later than 6 months of age. EHDI programs accomplish these 1–3-6 goals through active tracking, surveillance, and coordination with clinical service providers and families (Williams, Alam, & Gaffney, 2015).

CDC supports jurisdictional EHDI programs by providing programs with funding and assistance to develop, maintain, and enhance the collection of hearing screening, diagnosis, and EI data. Through the Hearing Screening and Follow-up Survey (HSFS), CDC collects aggregate data based on individually identifiable records from jurisdictional EHDI programs about NBHS, which allows for evaluation of the timeliness of receipt of hearing screening, diagnosis, and enrollment in EI services. This survey tool helps assess and monitor EHDI progress nationally and assists states and territories in strengthening their programs by identifying data gaps and areas of need (Alam, Gaffney, & Eichwald, 2014; CDC, 2017). The voluntary survey is sent annually to each EHDI program.

Although the HSFS allows CDC to generate national reports about the number of infants screened, diagnosed, and enrolled in EI and to assess progress toward the 1–3-6 goals, several limitations and questions cannot be addressed by the survey's data. The use of aggregate data can lead to an ecological fallacy where inferences are incorrectly generalized to the whole jurisdictional population (i.e., using aggregate data to infer individual-level relationships; King, 2013; Stewart & Tierney, 2002). Detailed data quality checks are not possible using aggregate data. Although CDC provides definitions for each HSFS data item, some respondents may quantify and aggregate their data differently when they participate in the survey (Alam, Satterfield, Mason, & Deng, 2016). Improving data standardization is not possible without seeing individual-level data. It is difficult to provide a descriptive summary of the individual services when data are aggregated.

Aggregate data do not allow for in-depth analyses of infant and family sociodemographic characteristics and the receipt of EHDI-related services. Aggregate data do not allow for answering key questions, such as the average age when an infant is diagnosed with HL. As a result, it is often not possible for CDC to use HSFS to identify potential program gaps and needs that would help provide more targeted technical assistance. To address these limitations, CDC implemented a pilot study in September 2010 known as individual EHDI (iEHDI), in which the participating jurisdictions assembled and transmitted limited sets of de-identified, individual-level data to CDC. The objective of this article is to describe the feasibility, benefits, and challenges surrounding the reporting and use of individual-level data compared to HSFS data for EHDI.

Method

iEHDI Pilot Study

To participate, jurisdictions were required to have a comprehensive EHDI tracking and surveillance system in place and to routinely collect and maintain non-aggregated, individual-level data on all infants born in the jurisdiction, as well as the hearing screening and follow-up services they received. Three jurisdictions—Indiana, Iowa, and Nebraska—were selected and awarded funds to provide de-identified sets of specified data items to CDC for infants born in 2010. Two jurisdictions (Iowa and Nebraska) voluntarily provided these data to CDC for infants born in 2012.

Quarterly data sets were transmitted to CDC via a Secure Data Network (SDN). Jurisdictional participants and CDC jointly reviewed and finalized the list and format of data items to be transmitted. The list was based on items included in the HSFS and additional information already collected by the jurisdictional programs. Prior to transmission, participants were required to perform a data validation and verification check to identify and correct data format and logic errors. Format errors refer to errors in the type, value, or range of a single data item (e.g., an infant’s residence zip code coded in character string instead of numeric format). Logic errors occur when an illogical relationship is discovered when the data item is validated with another data item. For example, crosschecking the infant’s date of birth shows that the NBHS occurred before birth.

To maintain the data integrity and privacy, jurisdictions assigned each infant record a new identifier consisting of a 2-digit jurisdictional ID followed by a 13-digit record ID. The 13-digit record ID could not contain any direct personal identifiers or information that may indirectly identify the infant. The infant’s pseudonym was used to link records across the study period. Participating jurisdictions transmitted the data through an SDN operated by CDC Public Health Informatics and Technology Program Office. The data were stored in a stand-alone Microsoft Access database maintained by CDC Information Technology Services Office. Access was restricted to approved CDC EHDI program staff who had signed a data user agreement. CDC EHDI program staff performed an additional data review, validation, and verification check. All identified data errors were listed in a data quality report and shared with the jurisdictions to correct before retransmission.

When the datasets were in acceptable format and clear of obvious format or logic errors (e.g., an infant’s date of hearing screening occurring before the infant’s date of birth), in-depth statistical analyses were conducted to demonstrate the value of having individual-level data as opposed to HSFS (aggregate) data. A summary of 2010 and 2012 EHDI tracking and surveillance efforts was assembled. This information included the number of newborns not passing the final hearing screening, the status and results of diagnostic evaluation, the EI enrollment status, and infant and maternal characteristics for those diagnosed with permanent HL.

Demographic, Clinical, and Sociodemographic Variables

Descriptive variables collected from vital records were reported for the infant and parents, such as infant gender (male/female), marital status (married: yes/no). Maternal Age was calculated as the difference in years between the mother's date of birth and the child's date of birth, and categorized as ≤ 19 years, 20–34 years, ≥ 35 years. Ethnicity for mother and father were each categorized as Hispanic (Mexican/Mexican American/Chicana, Puerto Rican, Cuban, unspecified Hispanic, or other Spanish/ Hispanic/Latina) or Non-Hispanic. Maternal and Paternal Race were each categorized as White, Black or African American, or Other.

Infant clinical measures from birth certificates from vital records, including birth weight, low Appearance, Pulse, Grimace response, Activity, and Respiration (APGAR) score (score < 6 at 5 minutes: Yes/No), neonatal intensive care > 5 days (Yes/No), number of prenatal visits, and family history of permanent HL (Yes/No) were reported. Birth weight was categorized as Low (< 2,500 grams), Normal (2,500–4,000 grams), and High (≥ 4,001 grams). A low APGAR score is a potential risk factor that can be used for identifying HL in infants (Biswas, Goswami, Baruah, & Tripathy, 2012; Lin & Oghalai, 2011).

Socioeconomic variables included maternal education, principal source of payment, and receipt of women, infants and children (WIC) food & nutrition services (Yes/No). Maternal Education was categorized as Less than High School or Unknown (8th grade or less, 9th to 12th grade without a diploma, or unknown), Completed High School or General Education Development (GED), Some College or Associate's Degree, and Bachelor's Degree and Above (i.e., Bachelor's, Master's, Doctorate or professional degree). Principal source of payment included Private Insurance, Medicaid, and Other.

EHDI Screening, Diagnostic, and EI Variables

Tracking and surveillance variables included: screening methods, results of initial hearing screen, rescreen results, dates and results of diagnostic evaluation, and EI enrollment status. Table 1 provides a detailed summary of the EHDI screening, diagnostic, and EI variables. Permanent HL was described by laterality (bilateral/ unilateral), type of HL (Sensorineural, Permanent Conductive, Mixed, Auditory Neuropathy, Unknown Type), and severity (degree of HL: Mild (26–40 decibels, dB), Moderate (41–55 dB), Moderately Severe (56–70 dB), Severe (71–90 dB), Profound (91+ dB), and Unknown or Missing) for each ear (American Speech-Language-Hearing, 2017a, 2017b).

Statistical Analysis

Descriptive statistics (frequency counts and percentages) were used to analyze infant and parental sociodemographic characteristics of the newborn hearing screening population and of the infants with permanent HL, and key indicators for EHDI tracking and surveillance efforts for infants born in 2010 and 2012. Median age and standard deviation were calculated for maternal age (years) and infant age at first diagnostic evaluation (days). All analyses were performed using SAS Version 9.3 (SAS Institute Inc., Cary, NC) and validated by two of the authors.

Results

Compared to HSFS data, it was feasible to receive more data items through the iEHDI pilot. Additional infant and family information not currently collected by the HSFS, such as maternal and paternal sociodemographic variables, infant birth characteristics, and risk factors for HL, were available through the pilot study. Table 2 compares the data items collected by the HSFS and iEHDI. With an increase in the range and depth of individual-level data, a comparison of individual infant characteristics at each benchmark was feasible (e.g., maternal characteristics of infants screened or diagnosed with HL).

Table 3 provides a summary of the infant and parental characteristics of each jurisdiction's infant population by year. Compared to HSFS data, Table 3 provides a more comprehensive description of the infant population in each jurisdiction and examples of the iEHDI information collected (e.g., birth weight of infant, family history of permanent childhood HL, and low APGAR score). As reflected in Table 3, birth cohort size varied across the three jurisdictions, however the infants had similar characteristics. There were more male than female births and the average birth weight was in the normal range. Across all three jurisdictions, more mothers were aged between 20–34 years, White, non-Hispanic, and had private insurance. Approximately 40% of the mothers received WIC food and nutrition services. Maternal education level varied by jurisdiction and birth year. A higher percentage of the fathers were White and non-Hispanic.

Table 4 provides summary statistics of key EHDI tracking and surveillance efforts by jurisdiction and birth year. The results of hearing screen, diagnostic evaluation for those not passing the screen, and the status of EI enrollment for those diagnosed with permanent HL revealed variations across the jurisdictions by cohort size and screening method. For example, Indiana had the largest birth cohort (*n* = 84,866) and the lowest rate of not passing the final hearing screen (3.0%) in 2010. The percentage of infants diagnosed with permanent HL varied across jurisdictions in 2010. Of those infants documented with permanent HL, 23.2% of Indiana and 28.2% of Iowa infants were not documented as receiving EI services in 2010. EI data were unavailable from Nebraska (Table 4).

Furthermore, iEHDI allows for comparing trends of key tracking and surveillance indicators within a jurisdiction (Table 4). Between 2010 and 2012, the percentage of infants who did not pass the final hearing screen decreased from 1.7% to 1.2% for Iowa, and from 1.0% to 0.4% for Nebraska. This may be a direct result of an increase in the percentage of infants passing the initial hearing screen. The decrease in the percentage of infants who did not pass the final hearing screening subsequently yielded a smaller cohort of infants in need of a diagnostic evaluation in 2012. Between 2010 and 2012, infants in Iowa who were not documented as receiving a diagnostic evaluation decreased from 56.7% to 44.4%. Likewise, a decrease from 28.2% to 17.0% was also seen for infants in Iowa who were not documented as receiving EI. For Nebraska, there was a decrease from 46.4% to 37.5% for infants who were not documented as receiving a diagnostic evaluation. EI enrollment data were not available for Nebraska in 2010. Altogether, Table 4 shows that it is feasible to track each infant's EHDI process and to perform subset analyses (e.g., assess EI enrollment status among infants diagnosed with permanent HL, using individual-level data). In addition, individual-level data allow for detailed understanding of each jurisdiction's EHD process, which was otherwise not possible using HSFS data.

As shown in Table 4, it was feasible to calculate the median age of infants who did not pass the hearing screen and received a diagnostic evaluation. The median age varied across years for each jurisdiction. Between 2010 and 2012, the median age when infants received a diagnostic evaluation decreased for Iowa (74 days vs. 48 days) and increased for Nebraska (49 days vs. 65 days). For Indiana, the median age was younger (48 days) in 2010. Currently, the HSFS does not gather this information.

Table 5 shows the summary of infant and maternal characteristics for infants who were a diagnosed with permanent HL in 2010 and 2012. Across all jurisdictions, regardless of the birth cohort size, 2.0 per 1,000 live born infants had permanent HL, reflecting combined data for 2010 and 2012 for Iowa and Nebraska and only 2010 data for Indiana. This prevalence rate of HL is higher than the national prevalence rate, which is 1.3 per 1,000 live born infants in 2010 and 1.4 per 1,000 live born infants for 2012 (CDC, 2017). Table 5 also shows that more than half of the infants diagnosed with permanent HL (≥ 70% in each jurisdiction) had bilateral HL, and most infants were born to married mothers and mothers who are White. Maternal education varied across jurisdictions. Regardless of laterality or jurisdiction, most infants had mild (≥ 48% in each jurisdiction), sensorineural (≥ 60% in each jurisdiction) HL. Although, it is feasible to estimate the prevalence of HL using the HSFS data, the ability to better understand both the infant and maternal characteristics of infants diagnosed with permanent HL is not feasible using current HSFS data.

Discussion

As learned from the iEHDI pilot, individual-level data offered many opportunities for CDC. The pilot study allowed CDC and jurisdictional EHDI programs to collaborate and identify data quality issues (e.g., an infant's date of hearing screening occurring before the infant's date of birth and inconsistent screening and diagnostic results for a baby diagnosed with no HL) and implement procedures to correct them. It also highlighted inconsistencies in data standardization, which can adversely affect the quality and accuracy of data (King, 2013). For instance, the definition of passing the hearing screen varied from jurisdiction to jurisdiction, depending on the screening protocol used, which also differed between jurisdictions. According to Indiana's mandate, an infant is referred directly for a diagnostic evaluation after not passing two inpatient screenings. Alternatively, Iowa and Nebraska require an outpatient screen only if the infant did not pass the initial inpatient screen. In addition, the pilot study revealed that the data collection and reporting procedures vary from jurisdiction to jurisdiction. The processes by which infants receive recommended follow-up services vary in each jurisdiction. The data collection and process issues would not have been identified if the CDC EHDI program had relied only on HSFS data.

The study also allowed CDC to gain a better understanding of the challenges unique to each jurisdiction in terms of data collection and reporting. For example, EHDI data collected in one jurisdiction were captured from multiple sources and the relationship between discrete data items from the multiple sources were not always consistent. One data source might have documented a newborn passing the hearing screen for both ears while in another data source the same newborn was documented as failing hearing screen in one ear. Another challenge for jurisdictions was the time-consuming process of matching the newborn screening record report with the vital records report to create a final record with all variables for the iEHDI pilot. Due to the iEHDI partnership, a matching algorithm was used to automate this matching process. The algorithm enabled the jurisdictional EHDI program staff to match different iterations of the data or record by deterministic, probabilistic, or other types of similar measures and led to improvements in efficiency. This challenge would not have come to light without the pilot study. In terms of reporting data to CDC, one jurisdiction experienced the challenge of converting several data items in the jurisdictional database from text to numeric format to fulfill the iEHDI data requirements. They had to import certain data items from other sources (i.e., the Federal Information Processing Standard county code from the birth record into the jurisdictional database before transmitting the data to CDC). Another challenge noted in this pilot study was the increased costs for the participating jurisdictional EHDI programs to provide limited, de-identified datasets to CDC. The increased costs were due to the amount of personnel time and effort for the data management and collection required for this study, which were substantial for the jurisdictions. The increased costs were also due to upgrades made to the tracking and surveillance system, which in some cases, were necessary to make the pilot study feasible. The upgrades, while beneficial to the programs, are often times costly and the jurisdictions were challenged to find the financial means to make the upgrades feasible. This collaboration allowed for CDC to understand the challenges and the substantial efforts required from the participating jurisdictions to report individual-level data. Through this collaboration, CDC recognized that data standardization and more refined definitions are needed.

A major benefit seen in the pilot study is the availability of far more data items compared to HSFS (Table 2). Unlike HSFS, the iEHDI pilot gathered data on WIC enrollment status, paternal characteristics, infant birth characteristics, and risk factors for HL. Although these data items are already gathered at the jurisdictional level, the availability of these data items in the pilot study allowed for CDC to further understand each jurisdiction's infant population and their EHDI process. It also allowed for more research opportunities.

Individual-level data allow for in-depth statistical analyses, which is another benefit seen in the pilot study. In addition to learning more about each jurisdiction's infant population and their EHDI process, the individual-level data also allowed for more discussions between CDC and the jurisdictional EHDI programs. For instance, analyses revealed that Indiana had the largest birth cohort, yet a lower than expected proportion of newborns underwent initial newborn hearing screening. The analyses also revealed that even though the jurisdictions varied in birth cohort, the number and percentage of infants receiving newborn hearing screening and diagnostic evaluation were wide-ranging. This prompted questions about why the percentages seen are different and provided opportunity for discussions between CDC and jurisdictional EHDI programs, which is currently not feasible using HSFS data.

In addition, individual-level data allowed for identification and tracking of infants at different stages of the EHDI process and ability to assess the demographic and socioeconomic characteristics that may be associated with the receipt of recommended screening, diagnostic, and/ or intervention services. It was feasible to look at subsets of interests in further detail. For instance, we learned that for Indiana in 2010, 25.1% of the infants who did not pass the hearing screen as final result were not documented as having received a diagnostic evaluation (Table 4). Also for Indiana in 2010, we learned that 26.1% of the infants with permanent HL have family history of permanent childhood HL and 69.6% of the infants with permanent HL have bilateral HL (Table 5). The ability to assess subgroups in detail is not feasible using the current HSFS data. This pilot study demonstrated that key measures using individual-level data could be calculated at the national level which is not currently feasible using HSFS data (e.g., median age at first diagnostic visit, median age at referral, and median age when enrolled into early intervention). The ability to calculate these key measures allowed for assessing progress toward meeting the 1–3-6 goals which are measured by Healthy People 2020 Objective ENT-VSL-1 and three child health quality measures that were endorsed by the National Quality Forum (NQF) in August 2011 (NQF #1354: hearing screening before discharge from the hospital, NQF #1360: audiological evaluation no later than age 3 months [for those failing the screening], and NQF #1361: intervention no later than age 6 months [for those identified with a HL]; U.S. Department of Health and Human Services, 2018; National Quality Forum, 2018). The ability to calculate key measures allowed for more opportunities for improvement through targeted technical assistance from CDC.

Conclusions

Because of the limitations of HSFS data, the iEHDI pilot study was implemented to explore the feasibility, benefits, and challenges surrounding reporting of individual-level data from the jurisdictional EHDI programs to CDC. Findings of the pilot study demonstrated that reporting of individual-level data to CDC is feasible and more in-depth analyses benefit both CDC and jurisdictional EHDI programs. More importantly, it offered an opportunity for CDC and jurisdictional EHDI programs to collaborate to identify, discuss, and implement procedures to improve the quality and usefulness of data in ensuring infants receive recommended screening, diagnostic, and EI services. In-depth analyses also increased CDC's understanding of each jurisdiction's EHDI process, making it possible to detail EHDI tracking and surveillance efforts and for CDC to better understand the gaps and needs of each jurisdictional EHDI program. This in turn allows for CDC to provide more targeted and relevant technical assistance to the jurisdictions. All of the above are not feasible using the currently reported HSFS data. Although there were challenges in reporting individual-level data, benefits seen in this pilot study outweighed the challenges. Lessons learned from this iEHDI pilot were used to inform and guide current activities and procedures for expanding EHDI data collection at CDC. This includes refining data definitions and incorporating activities from the pilot study into the ten jurisdictional EHDI programs currently funded to gather and report individual-level data.

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Acronyms:

CDC	Centers for Disease Control and Prevention
EHDI	Early Hearing Detection and Intervention
EI	early intervention
HL	hearing loss
HSFS	Hearing Screening and Follow-up Survey
iEHDI	individual EHDI
NBHS	Newborn hearing screening
NQF	National Quality Forum
SDN	Secure Data Network

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Table 1

Summary of the Definitions Used for Early Hearing Detection and Intervention Screening, Diagnostic, and Early Intervention Variables.

Variable	Definition
Initial Hearing Screen Results	
Pass	Infants who passed the initial hearing screening
Not Pass	Infants who did not pass the initial hearing screening
Not Screened	Inants who did not receive the initial hearing screening
Unknown Status	Infants whose initial hearing screening status was unknown
Infants Receiving Rescreen	
Pass	Infants who did not pass the initial hearing screen and passed the rescreen
Not Pass	Infants who did not pass the initial hearing screen and did not pass the rescreen
Not Screened	Infants who did not pass the initial hearing screen and did not receive the rescreen
Final Hearing Screen Results	
Pass	Infants who (1) Passed the initial screen and rescreen (2) Passed the initial screen and did not receive a rescreen; (3) Passed the initial screen and were not documented to have received a rescreen; (4) Did not pass the Initial screen and passed the rescreen; or (5) Did not receive the initial screen but passed the rescreen
Not Pass	Infants who (1) Passed the Initial screen but not the rescreen; (2) Did not pass both the initial and the rescreen; (3) Did not pass the Initial and did not receive a rescreen; (4) Did not pass the Initial and not documented as having received a rescreen; or (5) Did not receive the initial screen and did not pass the rescreen
Not Screened	Infants who were not screened or not documented as having received any hearing screening
Diagnostic Evaluation Status	
Diagnosed	Infants who did not pass the hearing screen as the final result and received a diagnostic evaluation, regardless of the diagnostic result being conclusive or inconclusive
Not Diagnosed	Infants who did not pass the hearing screen as the final result and did not receive a diagnostic evaluation
Died or Moved	Infants who did not pass the hearing screen as the final result and did not receive a diagnostic evaluation because the infant expired or the family moved
Refused	Infants who did not pass the hearing screen as the final result and did not recieve a diagnostic evauation because the family has refused the evaluation
Diagnostic Results	
No Hearing Loss	Infants diagnosed as having no hearing loss
Permanent Hearing Loss	Infants diagnosed with permanent hearing loss
Non-Permanent Hearing Loss	Infants diagnosed with non-permanent hearing loss

Variable	Definition
In Process	Infants who did not pass the hearing screening as the final result and are still In the evaluation process for a conclusive diagnosis
Unknown Status	Infants who did not pass the hearing screening as the final result and received a diagnostic evaluation but the diagnosis was not known to the EHDI program
Status of EI Service for those Diagnosed with Permanent Hearing Loss	
Receiving EI	Infants who did not pass the hearing screen as the final result, diagnosed as having a permanent hearing loss, and enrolled into early intervention services
Not Receiving EI or Unknown	Infants who did not pass the hearing screen as the final result, diagnosed as having a permanent hearing loss, and not enrolled into EI services or the enrollment status is unknown to the EHDI program
Died or Moved	Infants who did not pass the hearing screen as the final result, diagnosed with a permanent hearing loss, and not enrolled into EI services because the infant expired or the family moved
Refused	Infants who did not pass the hearing screen as the final result, diagnosed with a permanent hearing loss, and not enrolled into EI services due to family refusal

Table 2

Comparison of Data Collected Between Hearing Screening and Follow-up Survey (HSFS) and Individual Early Hearing Detection and Intervention (iEHDI)

Data Item	HSFS	iEHDI
Individual-level infant birth information (e.g., birth date, birth county, time, birth weight, birth order, birthing facility, transfer)		x
Gender of infant	x	x
Birth jurisdiction	x	x
Maternal race/ethnicity	x	x
Maternal education	x	x
Maternal residence (jurisdiction and/or zip code)		x
Maternal age	x	x
Marital status of mother		x
Plurality		x
Prenatal visits		x
WIC enrollment status		x
Paternal race/ethnicity		x
Paternal education		x
Principle source of payment		x
Number of hearing screening received		x
Initial hearing screening information		x
Initial screening results for each ear		x
Final initial hearing screening result		x
Reason for no initial screen		x
Rescreen result for each ear		x
Follow-up screening information (date and location)		x
Reason for no rescreen		x
Date and location of initial diagnostic visit		x
Date and location of most recent diagnostic visit		x
Result of most recent diagnostic visit		x
Diagnosis date	x	x
Number of documented visits during diagnostic process		x

Data Item	HSFS	iEHDI
Laterality	x	x
Severity		x
Reason for no intervention	x	x
Referred to receive other services (i.e., genetic counseling, opthalmology, otolaryngology, other provider)		x
Early intervention enrollment information	x	x
Part C eligibility	x	x
Hearing aid, implant, or FM system		x
Risk factors and comorbidities (e.g., family history of hearing loss, birth defects, medical conditions)		x

Table 3

Summary of Infant and Parental Characteristics of the Newborn Hearing Screening Population, iEHDI 2010 and 2012.

Characteristic	Indiana[a]	Iowa		Nebraska	
	2010 *n* (%)	2010 *n* (%)	2012 *n* (%)	2010 *n* (%)	2012 *n* (%)
Total Number of Births	**84,866**	**38,572**	**38,427**	**26,247**	**26,284**
Gender of Infant					
Male	43,759 (51.6)	19,646 (50.9)	19,701 (51.3)	13,333 (50.8)	13,500 (51.4)
Female	41,106 (48.4)	18,926 (49.1)	18,726 (48.7)	12,914 (49.2)	12,777 (48.6)
Birth weight categories(g)					
Average infant birth weight ± SD	3,273.4 ±592.0	3,345.6 ±581.7	3,355.7 ± 577.0	N/A[d]	
Low (< 2500)	6,749 (8.0)	2,535 (6.6)	2,429 (6.3)		
Normal (2500–4000)	71,469 (84.2)	32,141 (83.3)	32,022 (83.3)		
High (≥ 4001)	6,569 (7.7)	3,879 (10.7)	3,965 (10.3)		
Unknown	79 (0.1)	17 (0.0)	11 (0.0)		
Family History of Permanent Childhood Hearing Loss	613 (0.7)	948 (2.5)	766 (2.0)		
Neonatal intensive care > 5 days	199 (0.2)	2,126 (5.5)	1,915 (5.0)		
Low APGAR score(<6) at 5 minutes	1,464 (1.7)	306 (0.8)	317 (0.8)		
Average number of prenatal visits	10.7 ±3.7	11.8 ±3.2	119 ±3.2		
Maternal Age (years)					
Median Age ± SD	27.0 ±5.9	27.7 ±5.6	28.1 ±5.5	28.0 ±5.0	28.4 ±5.5
≤ 19	8,716 (10.3)	3,139 (8.1)	2,5678(6.7)	1,943 (7.4)	1,678 (6.4)
20–34	66,994 (78.9)	31,334 (81.2)	31,629 (82.3)	21,305 (81.2)	21,435 (81.6)
≥ 35	9,115 (10.7)	4,097 (12.1)	4,230 (11.0)	2,999 (11.4)	3,171 (12.1)
Maternal Ethnicity					
Hispanic	6,739 (7.9)	3,309 (8.6)	3,373 (8.8)	3,776 (14.4)	3,648 (13.9)
Non-Hispanic	78,127 (92.1)	35,263 (91.4)	35,054 (91.2)	22,471 (85.6)	22,636 (86.1)
Maternal Race					
White	69,725 (82.2)	33,301 (86.3)	33,020 (85.9)	21,106 (80.4)	21,059 (80.1)
Black or African American	9,553 (11.3)	1,743 (4.5)	1,911 (5.0)	1,561 (6.0)	1,579 (6.0)

Characteristic	Indiana[a]	Iowa		Nebraska	
	2010 *n* (%)	2010 *n* (%)	2012 *n* (%)	2010 *n* (%)	2012 *n* (%)
Other race[b]	5,588 (6.6)	3,528 (9.1)	3,496 (9.1)	3,580 (13.6)	3,646 (16.4)
Maternal Education					
< High School or Unknown	17,651 (20.8)	5,271 (13.7)	4,890 (12.7)	3,763 (14.3)	3,308 (12.6)
Completed High School or GED	22,460 (26.5)	7,780 (20.2)	7,446 (19.4)	4,933 (18.8)	4,812 (18.3)
Some College or Associate’s Degree	24,038 (28.3)	8,373 (21.7)	13,549 (35.3)	9,048 (34.5)	6,336 (24.1)
≥ Bachelor’s Degree	20,717 (24.4)	11,987 (30.8)	12,542 (32.6)	8,503 (32.4)	11,828 (45.0)
Marital Status					
Married	48,720 (57.4)	25,154 (65.2)	24,875 (64.7)	17,558 (66.9)	17,664 (67.2)
Not Married/Unknown/Missing	36,146 (42.6)	13,418 (34.8)	13,552 (35.3)	8,689 (33.1)	8,620 (32.8)
Receipt of Women, Infants and Children (WIC)	39,746 (46.8)	14,879 (38.6)	14,380 (37.4)	N/A[d]	
Food & Nutrition Services					
Paternal Ethnicity					
Hispanic	36,629 (43.2)	8,726 (22.6)	8,807 (22.9)		
Non-Hispanic	48,237 (56.8)	29,846 (77.4)	29,620 (77.1)		
Paternal Race					
White	56,551 (66.6)	28,305 (73,4)	27,822 (72.4)		
Black or African American	7,080 (8.3)	1,511 (3.9)	1,776 (4.6)		
Other race[b]	21,235 (25.0)	8,576 (22.7)	8,829 (23.0)		
Principal Source of Payment					
Private Insurance	39,762 (46.8)	21,495 (55.7)	21,745 (56.6)	14,940 (56.9)	15,408 (58.6)
Medicaid	39,480 (46.5)	15,530 (40.3)	15,130 (39.4)	7,951 (30.3)	8,772 (33.4)
Other[c]	5,714 (6.7)	1,547 (4.0)	1,552 (4.0)	3,356 (12.8)	2,104 (8.0)

Note. iEHDI = Individual Early Hearing Detection and Intervention pilot study

[a] 2012 data for Indiana were not available

[b] Other race Includes American Indian/Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian. Native Hawaiian, Guamanian or Chamorro, Aamoan, other Pacific Islander, other race, multiracial (not specified), and unknown

[c] Other principal source of payment includes CHAMPUS/Trlcare, Indian Healthcare, self-pay, other, and missing.

[d] Data were not available.

Table 4

Summary of EHDI Tracking and Surveillance Efforts, iEHDI 2010 and 2012.

Characteristic	Indiana[b]	Iowa		Nebraska	
	2010 *n* (%)	2010 *n* (%)	2012 *n* (%)	2010 *n* (%)	2012 *n* (%)
Total	**84,866**	**38,572**	**38,427**	**26,247**	**26,284**
Screening Method					
Auditory Brainstem Response or Automated Auditory Brainstem Response	72,985 (86.0)	7,870 (20.4)	10,164 (26.4)	19,260 (73.4)	18,615 (71.5)
Otoacoustic Emissions, Transient-Evoked Otoacoustic Emissions or Distortion Project Otoacoustic Emissions Tests	11,881 (14.0)	29,935 (77.6)	27,657 (72.0)	3,127 (11.9)	2,760 (10.5)
Unknown		767 (2.0)	606 (1.6)	3,860 (14.7)	4,909 (18.7)
Initial Hearing Screen Results					
Pass	71,185 (83.9)	35,444 (91.9)	35,837 (93.3)	24,805 (94.5)	25,185 (95.8)
Not Pass	2,511 (3.0)	2,361 (6.1)	1,957 (5.0)	1,126 (4.3)	837 (3.2)
Not Screened	2,157 (2.5)	767 (2.0)	633 (1.7)	316 (1.2)	262 (1.0)
Unknown Status	9,013 (10.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Infants Receiving Rescreen (Total)	**N/A[a]**	**2,361**	**1,957**	**1,126**	**837**
Pass		1,735 (73.5)	1,504 (76.8)	873 (77.5)	722 (86.3)
Not Pass		303 (12.8)	219 (11.2)	48 (4.3)	58 (6.9)
Not Screened		323 (13.7)	234 (12.0)	205 (18.2)	57 (6.8)
Final Hearing Screen Results (Total)	**N/A[a]**	**38,572**	**38,427**	**26,247**	**26,284**
Pass		37,404 (97.0)	37,461 (97.5)	25,783 (98.2)	26,009 (99.0)
Not Pass		645 (1.7)	462 (1.2)	263 (1.0)	120 (0.4)
Not Screened		523 (1.4)	504 (1.3)	201 (0.8)	155 (0.6)
Diagnostic Evaluations Status (Total)	**2,511**	**645**	**462**	**263**	**120**
Diagnosed	1,726 (68.7)	265 (41.1)	237 (51.3)	129 (49.0)	55 (45.8)
Not Diagnosed	631 (25.1)	366 (56.7)	205 (44.4)	122 (46.4)	45 (37.5)
Died or Moved	73 (2.9)	11 (1.7)	15 (3.3)	4(1.5)	9 (7.5)
Refused	81 (3.2)	3 (0.5)	5 (01.1)	8 (3.0)	11 (9.2)

Characteristic	Indiana[b]	Iowa		Nebraska	
	2010 *n* (%)	**2010 *n* (%)**	**2012 *n* (%)**	**2010 *n* (%)**	**2012 *n* (%)**
Median Age Receiving First Diagnostic Evaluation ± *SD* (days)	48.0 ± 90.9	74.0 ± 130.8	48.0 ±126.1	49.0 ± 105.2	65.0 ± 119.7
Diagnostic Results (Total)	**1,726**	**265**	**237**	**129**	**55**
No Hearing Loss	1,441 (83.5)	142 (53.6)	181 (76.4)	70 (54.2)	17 (30.9)
Permanent Hearing Loss	138 (8.0)	78 (29.4)	53 (22.4)	49 (38.0)	38 (69.1)
Non-Permanent Hearing Loss	90 (5.2)	0 (0.0)	0 (0.0)	8 (6.2)	0 (0.0)
In Process	5 (0.3)	45 (17.0)	3(1.3)	0 (0.0)	0 (0.0)
Unknown Status	52 (3.0)	0 (0.0)	0 (0.0)	2(1.6)	0 (0.0)
Status of EI Service for those Diagnosed with Permanent Hearing Loss (Total)	**138**	**78**	**53**	**49**	**38**
Receiving EI	49 (62.8)	95 (68.8)	38 (71.7)	0 (0.0)	29 (76.3)
Not Receiving EI or Unknown	22 (28.2)	32 (23.2)	9 (17.0)	49 (100.0)[c]	3 (7.9)
Died or Moved	1 (1.3)	8 (7.4)	2 (3.8)	0 (0.0)	4 (10.5)
Refused	7 (9.0)	3 (2.8)	4 (7.6)	0 (0.0)	2 (5.3)

Note. EHDI = Early Hearing Detection and Intervention; EI = Early Intervention; IEHDI = Individual EHDI.

[a] Indiana screening protocol does not require a hearing rescreen. Screening method numbers were estimated by average percent.

[b] 2012 data for Indiana were not available

[c] EI data for Nebraska were not available for 2010.

Table 5

Summary of Infant and Maternal Characteristics for Infants Diagnosed with Permanent Hearing Loss by Jurisdiction, Individual Early Hearing and Detection Intervention (iEHDI) Pilot Study 2010 and 2012

Characteristic	Indiana[a]	Iowa	Nebraska
	n (%)	*n* (%)	*n* (%)
Infants with Permanent Hearing Loss	**138 (0.2)**	**131 (0.2)**	**87 (0.2)**
Gender of Infant			
Male	75 (54.3)	70 (53.4)	45 (51.7)
Female	63 (45.7)	61 (46.6)	42 (48.3)
Laterality			
Bilateral Hearing Loss	96 (69.6)	97 (74.0)	38 (71.7)
Unilateral Hearing Loss	42 (30.4)	34 (26.0)	15 (28.3)
Type of hearing loss, right ear			
Sensorineural	93 (67.4)	100 (76.3)	53 (60.9)
Permanent Conductive	7(5.1)	1 (0.8)	7 (8.0)
Mixed	9 (6.5)	7 (5.3)	12 (13.8)
Auditory Neuropathy	6 (4.4)	1 (0.8)	3 (3.4)
Unknown Type	0 (0.0)	0 (0.0)	6 (6.9)
No Hearing Loss	23 (16.7)	22 (16.8)	6 (6.9)
Type of hearing loss, left ear			
Sensorineural	93 (67.4)	110 (84.0)	51 (58.6)
Permanent Conductive	7(5.1)	3 (0.2)	3 (3.4)
Mixed	12 (8.7)	5 (3.8)	10 (11.5)
Auditory Neuropathy	7(5.1)	1).8)	1 (1.1)
Unknown Type	0 (0.0)	0 (0.0)	9 (10.30)
No Hearing Loss	19 (13.8)	12 (9.2)	13 (14.9)
Severity of hearing loss, right ear			
Mild	77 (55.8)	64 (48.9)	44 (50.6)
Severe	14 (10.1)	17 (13.0)	15 (17.2)
Profound	16 (11.6)	12 (9.2)	20 (23.0)

Characteristic	Indiana[a]	Iowa	Nebraska
	***n* (%)**	***n* (%)**	***n* (%)**
Unknown or Missing	31 (22.5)	38 (29.0)	8 (9.2)
Severity of hearing loss, left ear			
Mild	78 (56.5)	65 (49.6)	42 (48.3)
Severe	16 (11.6)	22 (16.8)	9 (10.3)
Profound	16 (11.6)	13 (1.0)	23 (26.4)
Unknown or Missing	28 (20.3)	31 (23.7)	13 (14.9)
Birth weights (g)			
Low (< 2500)	25 (18.1)	13 (9.9)	N/A[c]
Normal (2500–4000)	103 (74.6)	109 (83.2)	
High (≥ 4001)	10 (7.3)	9 (6.9)	
Neonatal Intensive care > 5 days	35 (25.4)	28 (21.4)	
Low APGAR score (< 6) at 5 minutes	7(5.1)	10 (7.6)	
Family History of Permanent Child Hearing Loss	36 (26.1)	12 (9.2)	
Maternal Average Age ± *SE* (years)	28.5 ±6.7	27.6 ±5.5	28.3 ±6.8
Maternal Hispanic Ethnicity	18 (13.0)	4(3.1)	19 (21.8)
Maternal Race			
White	86 (62.3)	114 (87.0)	64 (73.6)
Black or African American	11 (8.0)	9 (6.9)	6 (6.9)
Other[b]	41 (29.7)	8(6.1)	17 (19.5)
Maternal Education			
< High School or Unknown	33 (23.9)	16 (12.2)	18 (20.7)
Completed High School	35 (25.4)	26 (19.8)	18 (20.7)
Some College or Associate's Degree	30 (21.7)	51 (38.9)	27 (31.0)
≥ Bachelor's Degree	40 (29.0)	38 (29.0)	24 (27.6)
Marital Status			
Married	80 (58.0)	79 (60.3)	59 (67.8)
Not Married/Unknown/Missing	58 (42.0)	52 (39.7)	28 (32.2)

[a] 2012 data for Indiana were not available

[b] Other race/ethnicity includes American indian/Alaska Native, Asian, Native Hawaiian/Pacific Islander, other, multiracial not specified, and unknown.

[c] Data were not available.