Using Data to Improve Services for Infants with Hearing Loss: Linking Newborn Hearing Screening Records with Early Intervention Records

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Abstract: The purpose of this study was to match records of infants with permanent hearing loss from the New York Early Hearing Detection and Intervention Information System (NYEHDI-IS) to records of infants with permanent hearing loss receiving early intervention services from the New York State Early Intervention Program (NYSEIP) to identify areas in the state where hearing screening, diagnostic evaluations, and referrals to the NYSEIP were not being made or documented in a timely manner. Data from 2014–2016 NYEHDI-IS and New York Early Intervention System (NYEIS) information systems were matched using The Link King. There were 274 infants documented in NYEIS Information System as having received early intervention services, but not having documentation of failed hearing screening (*n* = 103) or a diagnostic evaluation confirming hearing loss (*n* = 171) in NYEHDI-IS. There were 40 infants with hearing loss in NYEHDI-IS who were not referred to NYSEIP, and 19 of these infants' providers documented in NYEHDI-IS that a referral to NYSEIP was made. The results from these analyses were used to direct targeted technical assistance to audiologists to educate them about the importance of early identification and referral and the reporting requirements to the New York State Department of Health with the goal of improving NYSEIP and the NYEHDI Program.

Key Words: data match, EHDI, early intervention, loss to follow-up, hearing loss

Acronyms: CDC = Centers for Disease Control and Prevention; EHDI = Early Hearing Detection and Intervention; MOU = Memorandum of Understanding; NYEHDI-IS = New York Early Hearing Detection and Intervention Information System; NYEIS = New York Early Intervention System; NYS = New York State; NYSEIP = New York State Early Intervention Program;

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Background

Hearing loss has been demonstrated to have a negative impact on a young child's speech and language development. Without early diagnosis and enrollment in early intervention services, a child may have persistent delays in social-emotional development and learning that could impact school readiness (Moeller, 2000; Yoshinaga-Itano & Gravel, 2001; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

State Early Hearing Detection and Intervention (EHDI) programs are tasked with ensuring the timely identification of young children and access to appropriate diagnostic and therapeutic supports and services. Each year the states' performance in achieving the Joint Committee on Infant Hearing guidelines is published on the Center for Disease Control and Prevention's (CDC, 2017) website. State performance in 2014 ranged greatly across these measures, with the greatest variation in documentation of diagnostic evaluation before three months of age (0 to 100%) and enrollment in early intervention services (0 to 100%; CDC, 2016a, 2016b).

Risk factors such as having a low socioeconomic status, missed newborn hearing screening, lack of parent and primary care provider education on the importance of early intervention, lack of family involvement, hearing

loss diagnosed at a late age, or living in a rural residential area have shown to be related to discrepancies in early intervention enrollment, service provision among deaf or hard of hearing children, or both (Boss, Niparko, Gaskin, & Levinson, 2011; Bush, Burton, Loan, & Shinn, 2013; Lester, Dawson, Gantz, & Hansen, 2011; Moeller, 2000).

Moeller (2000), Yoshinaga-Itano & Gravel (2001), and Yoshinaga-Itano et al. (1998) found that the earlier children enroll in early intervention programs, the better their development of vocabulary, verbal reasoning, speech, and social-emotional skills than later enrolled children. Since the most intensive period of acquiring these skills occurs during a child's first three years of life, children whose hearing loss goes undetected often have significant language, speech, and social delays (American Speech-Language-Hearing Association, n.d.; Culbertson & Gilbert, 1986; Moeller, 2000; National Institute on Deafness and Other Communication Disorders (2017). Before the implementation of universal newborn hearing screening, the average age of hearing loss detection for many children was two to three years of age (Shulman et al., 2010).

In states with large populations served by many professionals, the task of directly engaging all primary care clinicians, early intervention providers, and audiologists is significant and may not be feasible within the existing infrastructure. In New York, approximately 240,000 babies are born each year. There are over 5,200 family physicians; 6,700 pediatricians; 1,300 audiologists; and 14,000 Early Intervention Program providers. The New York State Early Hearing Detection (NYEHDI) Program identified the need to better use existing data sources, such as the state's early intervention program, to identify gaps and target technical assistance to address those gaps.

Data matching has been widely used by public health researchers to conduct routine assessments, evaluations, and research studies, such as reviewing causes of infant deaths, identifying people with co-infections for case management and epidemiologic surveillance, evaluating immunization compliance for children with Medicaid, monitoring pregnancy-associated hospitalizations, and evaluation of Medicaid program coverage and impact (Qayad & Zhang, 2009; Xia, Braunstein, Stadelmann, Pathela, & Torian, 2014). Matching has also been used to improve the completeness of registry data by adding demographic, clinical, or behavioral information obtained from other registries on cases of HIV co-infection (Xia et al., 2014). There is very little information related to the linkage of newborn hearing screening and early intervention programs.

The objective of this study was to demonstrate the feasibility of the match between the NYEHDI program and the New York State Early Intervention Program (NYSEIP) data, and demonstrate the potential to direct targeted technical assistance to improve the state system of identification of hearing loss and access to early intervention services.

Method

Data Use Agreement
A data use agreement and Memorandum of Understanding (MOU) are in place with the state's two vital record systems, Statewide Perinatal Data System and Electronic Vital Events Registration System, and NYEHDI-IS. The vital records systems include pertinent information for all newborns recorded on the birth certificate including the hearing screening results. The NYEHDI Program and NYSEIP are administered by the Bureau of Early Intervention in the New York State Department of Health (NYSDOH), so data use agreements were not required for the data match.

Data Systems
NYEHDI-IS was built by the NYSDOH as an application that is connected to and leverages the New York State (NYS) Immunization Information System and integrates the state's two vital record systems. The NYEHDI-IS was deployed statewide in June 2014. All infant records are included in NYEHDI-IS, regardless of whether they had a hearing screening, follow-up, or diagnostic evaluation recorded. Providers who conduct hearing tests can enter follow-up hearing screening results, diagnostic evaluation results, and NYSEIP referrals directly into NYEHDI-IS.

The New York Early Intervention System (NYEIS) is the repository for pertinent data related to the provision of early intervention services including referrals, eligibility, evaluations, individualized family service plan details, services provided, and providers.

Dataset Criteria
SAS 9.4 software was used to prepare the datasets for the data match. The criteria for compiling the NYEHDI-IS dataset included all infants born in calendar years 2014–2016 who had a hearing loss documented by an audiologist. The hearing loss diagnosis included bilateral, unilateral, conductive, sensorineural, and auditory neuropathy. For calendar years 2014 and 2015, the datasets included infants who had transient conductive hearing loss. Based on the CDC's Hearing Screening and Follow-up Survey hearing loss definition, transient conductive hearing loss was excluded for the dataset compiled for the 2016 data match.

The criteria for compiling the NYEIS dataset included infants who were born in the calendar year who were referred and enrolled in the NYSEIP with a diagnosis of hearing loss as specified in Table 1. In New York, a diagnosis of transient hearing loss does not establish eligibility for the NYSEIP, so this diagnosis was not included in the criterion for selection of records from NYEIS.

Table 1
International Classification of Diseases (ICD) Codes Included in the NYEIS Dataset

ICD9 Diagnosis	ICD10 Diagnosis
315.34 Speech and language developmental delay due to hearing loss	F80.4 Speech and language development delay due to hearing loss
389.00 Conductive Hearing Loss	H90.2 Conductive hearing loss, unspecified
389.01 Conductive hearing loss, external ear	
389.02 Conductive hearing loss, tympanic membrane	
389.03 Conductive hearing loss, middle ear	
389.08 Conductive hearing loss of combined types	
	H90.42 Sensorineural hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side
389.14 Central hearing loss	H90.5 Unspecified sensorineural hearing loss
389.15 Sensorineural hearing loss, unilateral	H90.41 Sensorineural hearing loss, unilateral, right ear, with unrestricted hearing on the contralateral side
	H90.42 Sensorineural hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side
389.18 Sensorineural hearing loss, bilateral	H90.3 Sensorineural hearing loss, bilateral
389.20 Mixed Conductive and Sensorineural Hearing Loss	H90.8 Mixed conductive and sensorineural hearing loss, unspecified
389.21 Mixed hearing loss, unilateral	H90.71 Mixed conductive and sensorineural hearing loss, unilateral, right ear, with unrestricted hearing on the contralateral side
	H90.72 Mixed conductive and sensorineural hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side
389.22 Mixed hearing loss, bilateral	H90.6 Mixed conductive and sensorineural hearing loss, bilateral
744.00 Unspecified anomalies of the ear with hearing impairment	Q16.9 Congenital malformation of ear causing impairment of hearing, unspecified
744.02 Congenital absence, atresia, and stricture of auditory canal (external)	Q16.1 Congenital absence, atresia, and stricture of auditory canal (external)
744.09 Other anomalies of ear causing impairment of hearing	Q16.9 Congenital malformation of ear causing impairment of hearing, unspecified

Note. NYEIS = New York Early Intervention System

NYEIS data were matched to New York Early Hearing Detection and Intervention Information System (NYEHDI-IS) data to identify infants documented in NYEIS who were not documented with a hearing loss diagnosis in NYEHDI-IS. In addition, NYEHDI-IS data were matched to NYEIS data to identify infants with hearing loss in NYEHDI-IS who were not documented in NYEIS.

The Link King
Matching was completed using The Link King, a free record linkage software that uses a combination of probabilistic and deterministic algorithms to link and de-duplicate records (Campbell, 2005). The Link King

program allows the user to select one of three blocking levels (low, medium, high) and must be specified prior to the blocking of the data. In this analysis, a medium blocking level was used and the first and last name, date of birth, and gender variables were used to block and match the datasets.

Paired records were included in the blocked dataset if any one of the following criteria matched in a pair: date of birth and last name; date of birth, gender, and first name; gender and first and last name; first and last names and either birth month and year, birth month and day, or birth day and year match (The Link King, 2004).

Manual Review

A paired record was considered a match if it had a perfect match on all four variables and no further review was conducted. All non-matched pairs were manually reviewed and researched in both the NYEHDI-IS and NYEIS systems. Unmatched records were considered matched pairs if they had an obvious typographical error or misspelling in one of the matching variables, the first and last name or first and middle name were found to be transposed, the last name changed or was missing a hyphen, and both records had the same residence address and maternal information.

Results

Record linkage results are shown in Table 2. For the NYEIS to NYEHDI-IS match, Link King identified 84 direct matched pairs and 313 non-matched records for 2014, 94 direct matched pairs and 167 non-matched records for 2015, and 66 direct matched pairs and 94 non-matched records for 2016 in the NYEIS to NYEHDI-IS data match process. In the NYEHDI-IS to NYEIS data match process, the Link King identified 84 direct matched pairs and 130 non-matched records for 2014, 94 direct matched pairs and 122 non-matched records for 2015, and 66 direct matched pairs and 79 non-matched records for 2016 (Table 2).

Table 2

New York Early Intervention and Early Hearing Detection and Intervention Data Match Results, 2014-2016

Data Match		2014	2015	2016
	NYEIS sample size	397	261	160
	Direct matched pairs from Link King	84	94	66
	Results needing further review	313	167	94
	No permanent hearing loss diagnosis	270	150	84
	Late onset*	155	31	24
	Lost to follow-up†	87	35	49
	No results recorded‡	27	72	4
	Transient conductive	1	12	7
NYEIS to NYEHDI-IS	Infant born out of state or country	30	11	4
	Parent refusal of screening, follow-up, or diagnostic testing	3	0	0
	Changes in infant DOB or name	6	2	3
	Other§	4	0	1
	True matched records missed	0	4	2
	NYEHDI sample size	214	216	145
	Direct matched pairs from Link King	84	94	66
	Results needing further review	130	122	79
	No hearing loss diagnosis documented in NYEIS	93	93	45
	Infant moved out of state or country	0	0	2
NYEHDI-IS to NYEIS	Parent refused referral to Early Intervention	8	9	6
	Changes in infant DOB or name	5	9	4
	Record not found in Early Intervention	13	6	21
	Not referred to Early Intervention	6	2	13
	Provider did not complete referral process	7	4	8
	True matched records missed	11	5	1

Note. DOB = date of birth; NYEHDI-IS = New York Early Hearing Detection and Intervention Information System; NYEIS = New York Early Intervention System.
* Infant passed their initial, follow-up, or diagnostic evaluation and were later found to have permanent hearing loss.
† Infant failed their initial or follow-up screening and never received a diagnostic evaluation.
‡ Infant did not have any results recorded.
§ Infant cannot be found in NYEHDI-IS.

Based on manual reviews, reasons for records from NYEIS not matching records from NYEHDI-IS include the infant not having a hearing loss diagnosis documented in NYEHDI-IS; the infant was born out of state or country; parent refusal of screening, diagnostic evaluation, or referral to NYSEIP; or there were major changes to any one of the matching variables. Those changes included data entry corrections made to the birthdate or gender, name changes such as "Twin A" or "Baby Boy X" to a permanent name, or last name changes from a maternal last name to a paternal last name that were not reflected in the other system. The "Other" category contains infants that were not found in NYEHDI-IS and there is insufficient information in NYEIS to determine a specific reason. This resulted in a total of six true matched pairs missed (99% matching success rate) for 2014–2016. Complete results for the 2014–2016 NYEIS to NYEHDI-IS data match can be seen in Table 2 and Table 3.

Table 3
Degree of Accuracy for Link King Data Match between NYEIS and NYEHDI-IS Datasets, 2014-2016*

Data Match	2014	2015	2016
NYEIS to NYEHDI-IS	100%	98%	99%
NYEHDI-IS to NYEIS	95%	98%	99%

Note. NYEHDI-IS = New York Early Hearing Detection and Intervention Information System; NYEIS = New York Early Intervention System.

* $\frac{\text{true matched records}}{\text{Dataset sample size}}$

Non-matched records from NYEHDI-IS to NYEIS datasets were also manually reviewed. Reasons for records from NYEHDI-IS not matching records from NYEIS include infant not having a hearing loss diagnosis documented in NYEIS, infant moved out of state or the country, the parent refused referral to NYSEIP, changes were made to an infant's date of birth or name, or there was no record of the infant in NYEIS. This resulted in a total of 17 true matched pairs missed (97% matching success rate) for 2014–2016. Complete results for the 2014–2016 NYEHDI-IS to NYEIS data match can be seen in Table 2 and Table 3.

As a result of the match, there were also 504 infants identified who had no permanent hearing loss recorded in NYEHDI-IS, but had a permanent hearing loss diagnosis recorded in NYEIS by an NYSEIP evaluator for 2014–2016. Among those infants, there were 210 infants with late-onset hearing loss, which was defined as infants with a diagnosis of hearing loss in NYSEIP as determined by the evaluator but who had passed their initial or follow-up hearing screening or diagnostic evaluation in NYEHDI-IS.

Discussion

The purpose of this study was to match records from NYEHDI-IS and NYEIS to identify areas in the state where hearing screening, follow-up services, and referrals to the NYSEIP were not documented.

By matching NYEIS data to NYEHDI-IS data, 274 infants were identified as having a diagnosis of permanent hearing loss documented in NYEIS and receiving early intervention services, but not documented as having a diagnostic evaluation in NYEHDI-IS (Table 2). These children received services from 72 audiologists who had not documented diagnostic evaluations in NYEHDI-IS. NYEHDI Program staff provided education on NYS Public Health Law reporting requirements and ensured that the audiologists had access to NYEHDI-IS to report. The average amount of time needed for education and training of these providers ranged from 30 minutes to two hours, depending on provider technical skill and previous experience with data reporting to the NYS Department of Health.

Conversely, by matching NYEHDI-IS data to NYEIS data, 40 infants with a documented diagnosis of hearing loss in NYEHDI-IS did not have a documented referral to NYSEIP. Nineteen of these infant's providers documented the referral in NYEHDI-IS, but did not complete the referral process (Table 2). The infant referral process is not automated in NYS so the provider must contact the municipal Early Intervention Official based on the infant's county of residence (NYSDOH, 2017). These infants were served by 22 audiologists. The NYEHDI program provided information about the benefits of referring children for early intervention services, as well as training on the referral process to the audiologists to ensure infants diagnosed with hearing loss were referred to NYSEIP in a timely manner. The time spent providing education and training to these providers ranged from 10 to 30 minutes depending on their knowledge of NYSEIP and NYEHDI-IS.

Strengths
The results of this study indicate that the Link King can successfully match newborn hearing screening and early intervention records with a high degree of accuracy (Table 3). The initial number of non-matched records in the NYEIS to NYEHDI-IS data match was reduced from 574 total non-matched records for 2014–2016 to six missed matched records after manual review. The initial number of non-matched records for the 2014–2016 NYEHDI-IS to NYEIS data match was also reduced from 331 total non-matched records to 17 missed matched pairs. Upon manual review of the initial non-matched records, it was found that the high number of non-matched records in 2014 was due to the broad criteria used to prepare the datasets which included infants referred to the Early Intervention Child

Find Program as a result of a missed initial hearing screening. The criteria were revised for subsequent years' data, which resulted in better matching.

The Link King software was user friendly and the program's website contains informative walk-through videos, a user manual, and extensive online help that makes it easy for the user to familiarize themselves very well with the program (The Link King, 2016). The Link King program is free to download, but does require a SAS license to run.

The efforts implemented as a result of this analysis have also improved the timeliness, accuracy, and completeness of data reporting to the CDC in the annual Hearing Screening and Follow-Up Survey.

Limitations
More questions were raised than answered by these analyses. There was a noticeable increase between 2014 and 2015 in the number of infants with no results recorded. It is not evident to the NYEHDI program as to why this may have happened.

Both birth record data and data entered into NYEHDI-IS by providers were used for the data match process. For infants with late-onset hearing loss, hearing screening results submitted on the birth certificate were used. However, the hearing screening results obtained from the birth certificates were not verified individually at the hospital. The matching process relies upon accurate data reporting and although a review of original hospital and NYSEIP records would provide quality assurance, this was not feasible for the current study.

Similarly, the data match relied on complete and accurate information entered into NYEIS. Infants may be determined eligible for NYSEIP for reasons other than hearing loss and depending on local data entry practices, hearing loss diagnosis codes may not have been recorded.

The time needed to research the unmatched infant records depended on the completeness of documentation and accessibility of the diagnostic hearing result in both information systems, the service provider, and the need for higher level staff to assist in the research, which varied from five minutes to two hours. Two part-time temporary staff were hired by the NYEHDI Program to assist with the research of unmatched infants' records. The process of reviewing unmatched records from three birth cohort years took staff approximately 250 hours to complete.

However, documentation of the data match procedures and subsequently conducting the data match on a monthly basis helped streamline the review process. The amount of time spent reviewing unmatched infant records decreased to approximately two hours per month.

Identifying, contacting, and educating providers so they comply with NYS Public Health Law requires staff time. Working with providers and ensuring they are following reporting requirements is an ongoing process. Approximately eight hours were spent providing education and training about the importance of referral to NYSEIP and explaining the process for referring infants after confirmed hearing loss diagnosis. Approximately 90 hours were spent educating providers about the need to report diagnostic hearing results in NYEHDI-IS and providing access to and training of NYEHDI-IS.

The data match is not a one-time analysis to validate the data. The match must be repeated on an ongoing basis. The initial set-up of the data match required development of SAS code to extract data from both information systems. Furthermore, setting up a blocking algorithm in the Link King software takes technical skill and time. Once set up is complete, the SAS code and matching algorithms can be used for future matches and the amount of time staff spend reviewing unmatched infant records will decrease significantly.

Conclusion

Data matching is an effective and evidence-based method to identify gaps in data and in states' systems of screening, diagnosing, and referring infants for Early Intervention Program services. The NYEHDI Program has integrated the process of linking data from the two data systems into routine monthly processes. By conducting a monthly data match, the NYEHDI program can continue to identify gaps in reporting and target technical assistance to areas in need of improvement.

References

American Speech-Language-Hearing Association. (n.d.). Effects of hearing loss on development. Retrieved from http://www.asha.org/public/hearing/Effects-of-Hearing-Loss-on-Development/

Boss, E. F., Niparko, J. K., Gaskin, D. J., & Levinson, K. L. (2011). Socioeconomic disparities for hearing-impaired children in the United States. *Laryngoscope, 121(4),* 860–866. doi: 10.1002/lary.21460

Bush, M. L., Burton, M., Loan, A., & Shinn, J. B. (2013). Timing discrepancies of early intervention hearing services in urban and rural cochlear implant recipients. *Otology & Neurotology, 34*(9)*,* 1630–1635. doi: 10.1097/MAO.0b013e31829e83ad

Campbell, K. M. (2005). Rule Your Data with The Link King© (a SAS/AF® application for record linkage and unduplication). Proceedings of the Thirtieth Annual SAS® Users Group International Conference.

Centers for Disease Control and Prevention. (2016a). Infants with permanent hearing loss enrolled in Early Intervention (EI) before 6 months of age in 2014. Retrieved from https://www.cdc.gov/ncbddd/hearingloss/2014-data/2014_EI_6Month_Web-B.pdf

Centers for Disease Control and Prevention. (2016b). Summary of infants diagnosed before 3 months of age in 2014. Retrieved from https://www.cdc.gov/ncbddd/hearingloss/2014-data/Diag_2014_3Month_Web_C.pdf

Centers for Disease Control and Prevention. (2017). Annual data early

hearing detection and intervention (EHDI) program. Retrieved from https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

Culbertson, J. L., & Gilbert, L. E. (1986). Children with unilateral sensorineural hearing loss: Cognitive, academic, and social development. *Ear and hearing, 7*(1)*,* 38–42.

Lester, E. B., Dawson, J. D., Gantz, B. J., & Hansen, M. R. (2011). Barriers to the early cochlear implantation of deaf children. *Otology & Neurotology, 32*(3), 406–412. doi: 10.1097/MAO.0b013e3182040c22

Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics, 106*(3)*,* e43–e43. doi: 10.1542/peds.106.3.e43

National Institute on Deafness and Other Communication Disorders [NIDCD]. (2017). Speech and language development milestones. Retrieved from https://www.nidcd.nih.gov/health/speech-and-language

New York State Department of Health. (2017). Municipal/county contacts for the early intervention program. Retrieved from https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.html

Qayad, M. G., & Zhang, H. (2009). Accuracy of public health data linkages. *Maternal and Child Health Journal, 13*(4)*,* 531–538. doi: 10.1007/s10995-008-0377-6

Shulman, S., Besculides, M., Saltzman, A., Ireys, H., White, K. R., & Forsman, I. (2010). Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics, 126*(Suppl. 1), S19–S27. doi: 10.1542/peds.2010-0354F

The Link King. (2004). Link King User Manual v5.2.4. Retrieved from http://www.the-link-king.com/user_manual.zip

The Link King. (2016). The Link King Record Linkage and Consolidation Software.   Retrieved from http://www.the-link-king.com/

Xia, Q., Braunstein, S. L., Stadelmann, L. E., Pathela, P., & Torian, L. V. (2014). The effect of case rate and coinfection rate on the positive predictive value of a registry data-matching algorithm. *Public Health Reports, 129*(Suppl. 1),79–84.

Yoshinaga-Itano, C., & Gravel, J. S. (2001). The evidence for universal newborn hearing screening. *American Journal of Audiology, 10*(2)*,* 62–64.

Yoshinaga-Itano, C., Sedey, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics, 102*(5)*,* 1161–1171.