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# Development of a State-Wide Database of Early Intervention and Educational Outcomes for Children who are Deaf or Hard of Hearing

Alonzo T. Folger, PhD<sup>1</sup> Susan E. Wiley, MD<sup>2</sup> Allyson VanHorn, MPH, MEd<sup>3</sup> Wendy Grove, PhD<sup>4</sup> Nathan DeDino, JD<sup>5</sup> Mallory Minter-Mohr, MA<sup>3</sup> Ting Sa, MS<sup>1</sup> Jareen Meinzen-Derr, PhD<sup>1</sup>

<sup>1</sup>Cincinnati Children's Hospital Medical Center, Division of Biostatistics and Epidemiology, University of Cincinnati College of Medicine, Department of Pediatrics, Cincinnati, OH. <sup>2</sup>Cincinnati Children's Hospital Medical Center, Division of Developmental and Behavioral Pediatrics, University of Cincinnati College of Medicine, Department of Pediatrics, Cincinnati, OH. <sup>3</sup>Ohio Department of Health <sup>4</sup>Ohio Department of Education <sup>5</sup>Ohio Department of Developmental Disabilities

**Abstract:** Children who are born deaf or hard of hearing (DHH) are at increased risk for delays in language, cognitive and social-emotional development. Early identification through screening and early intervention (EI) can improve outcomes for children who are DHH. However, a need remains to evaluate the effectiveness and practices of statewide programs for children who are DHH. The Ohio Early Hearing Detection and Intervention (EHDI) Data Linkage Project was created as a state-wide collaborative that included multiple Ohio government agencies and an academic institution. The objective of the project was to develop and characterize a population-based, longitudinal database that documents state-level services and outcomes for children who are DHH identified through a state EHDI Program. The database includes information regarding birth data, EHDI program data, early intervention data, and early academic data. Children born in Ohio between 2008 and 2014 identified with permanent hearing loss (n = 1746) served as the cohort for this project; 1262 records linked with EI data and 502 records linked with education data. Multi-agency linked databases contain novel combinations of data and can be valuable resources for public health evaluative and epidemiologic research. This resource can expand our understanding of the early predictors of academic success for children who are DHH.

Key Words: deaf/hard of hearing, outcomes, early hearing detection and intervention, EHDI, data linkage

**Acronyms:** ASQ:SE = Ages and Stages Questionnaire: Social-Emotional; CCHMC = Cincinnati Children's Hospital Medical Center; CDC = Centers for Disease Control and Prevention; DHH = deaf or hard of hearing; DODD = Ohio Department of Developmental Disabilities; ECTA = Early Childhood Technical Assistance Center; EHDI = early hearing detection and intervention; EI = Early Intervention; EMIS = Education Management Information System; IEP = Individualized Education Program; IFSP = Individualized Family Service Plan; JCIH = Joint Committee on Infant Hearing; LDS = Language Development Scale; ODE = Ohio Department of Education; ODH = Ohio Department of Health

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**Correspondence concerning this article should be addressed to:** Jareen Meinzen-Derr, PhD, MPH, Cincinnati Children's Hospital Medical Center, Division of Biostatistics and Epidemiology, 3333 Burnet Ave., ML# 5041, Cincinnati, OH 45229. Phone: 513-636-7789; Email: jareen.meinzen-derr@cchmc.org

Children who are born deaf or hard of hearing (DHH) are at a significantly higher risk for delays in language, cognitive, and social-emotional development (Ching et al., 2010; Holt, Beer, Kronenberger, Pisoni, & Lalonde, 2012; Lund, 2015; Meinzen-Derr, Wiley, Grether, & Choo, 2011, 2013; Meinzen-Derr et al., 2014; Stevenson et al., 2011; Tomblin et al., 2015; Wiley, Meinzen-Derr, Grether, Choo, & Smith, 2015; Yoshinaga-Itano, 2006). In fact, deficits in language often worsen through the school years (Geers, 2003; Marschark, 2003; Stevenson, McCann, Watkin, Worsfold, & Kennedy, 2010), placing children who are DHH at severe disadvantage in many areas of development and wellness. Additionally, without appropriate interventions, these disparities can extend to adulthood, affecting academics (Luckner, Sebald, Cooney, Young, & Muir, 2005; Traxler, 2000), literacy (Traxler, 2000), and employment opportunities (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). All 50 states and the District of Columbia have established Early Hearing Detection and Intervention (EHDI) systems in order to "maximize linguistic competence and literacy development for children who are deaf or hard of hearing" (Joint Committee on Infant Hearing [JCIH] & Pediatrics, 2007, p. 898). As such the Joint Committee on Infant Hearing recommends infants receive hearing screening by one month of age, have a diagnostic evaluation by three months of age, and if diagnosed with hearing loss, receive appropriate intervention by six months of age (1-3-6).

Early identification through screening and early intervention (EI) can improve language development for children who are DHH and reduce discrepancies in non-verbal cognitive functioning and language development (Yoshinaga-Itano, 2003; Yoshinaga-Itano, Sedey, Wiggin, & Chung, 2017). However, a need remains to evaluate the effectiveness and practices of statewide programs for children who are DHH. Recently, Yoshinaga-Itano et al. (2017) evaluated the EHDI 1-3-6 guidelines as they applied to children with bilateral hearing loss across 12 different states. Investigators assessed the impact of the current EHDI 1-3-6 guidelines and made additional recommendations regarding the evaluation of early intervention services on outcomes (Yoshinaga-Itano et al., 2017). Further large-scale evaluations will enable policy-makers and practitioners to implement improvements to these systems and subsequently, mitigate the developmental disparities that persist for children who are DHH.

Fundamental limitations to large population-based evaluations include the lack of integrated and longitudinal data. Important EI process and outcome measures often exist across disparate state departments and databases. Further, key evaluation measures must be abstracted and integrated from these datasets at multiple intervals including birth (birth records and newborn screening outcomes), birth to 3 years (early intervention services), and school age (preschool and later academic services and outcomes). The ability to leverage multiple sources of population-based data (often stored in public health and

education departments) to support observational research is growing in feasibility. This research includes quasi-experimental studies to examine program effectiveness and epidemiological studies to determine predictors of developmental outcomes. Integrating sources of information through novel data linkages has been used to support similar, yet unrelated efforts (Folger, 2013; Hall et al., 2014). Briefly, the process of data linkage involves deterministic and/or probabilistic algorithms to join databases that contain common individuals (e.g., children who are DHH), and unique measures such as sociodemographic characteristics, service utilization (e.g., types and intensity of preventive services), and health and academic outcomes. These linked databases contain novel combinations of data and can be valuable resources for public health evaluative and epidemiologic research.

The U.S. Department of Education mandates that states evaluate the effectiveness of EI and early childhood special education programs. In the state of Ohio, the following outcomes are priorities and mirror the national outcomes identified by the Early Childhood Technical Assistance Center (ECTA): (a) positive social-emotional skills (including social relationships); (b) acquisition and use of knowledge and skills (including early language/communication); and (c) use of appropriate behaviors to meet their needs (Early Childhood Technical Assistance Center & FPG Child Development Institute of the University of North Carolina at Chapel Hill, 2019). As part of Ohio's State Systemic Improvement Plan, the El program has emphasized the acquisition and use of knowledge and skills (including early language/communication) for children who are DHH. However, these outcomes are not available to state EHDI programs, hindering robust evaluation efforts. In Ohio, separate departments manage data that document newborn screening, EI service, and education outcomes. These departments do not currently share a common data system. However, approximately 200 children are identified annually with permanent hearing loss, and these children will cross over departments/programs as they age.

Our objective was to develop a population-based database of linked records across multiple state systems for children identified with permanent hearing loss in the state of Ohio who had been served by the EHDI system. The public data sources included records from the newborn hearing screening program (Ohio's EHDI program), EI, and educational records. We characterize the process and challenges of developing a state-level, population-based DHH resource and share findings from an initial data linkage.

**Participants** 

Method

The target population included children born in Ohio between January 1, 2008 and December 31, 2014 who were identified with permanent hearing loss through the EHDI program. A cohort of 1,746 children were born during the study period, identified with permanent hearing loss, and entered into the EHDI tracking and surveillance system for the state of Ohio. These initial records were linked to data available through public health and educational data systems.

### Procedures

Partners. A state-wide collaborative was formed under the auspices of an initiative launched by the Centers for Disease Control and Prevention (CDC) EHDI and implemented by Cincinnati Children's Hospital Medical Center (CCHMC). The Ohio EHDI Data Linkage Project included participation among multiple Ohio government agencies including the Ohio Department of Health (ODH), the Ohio Department of Developmental Disabilities (DODD), and the Ohio Department of Education (ODE). The collaboration among multiple agencies required data sharing agreements between CCHMC and each agency (i.e., ODH, DODD and ODE). In 2017, agreements were executed, and institutional review board approval granted by the CCHMC and ODH. Subsequently, data were provided to integrate multiple sources of data including vital records and hearing screening, EI, and early education (i.e., preschool to 2nd grade) educational records.

Data Linkage. The creation of an integrated database required two distinct interdepartmental data linkages performed across three data systems. The first data linkage was performed between newborn hearing screening/follow-up data and El records. Newborn screening data were stored in the HiTrack (version 4.6.1) surveillance system and were provided by ODH. HiTrack is an EHDI database for managing EHDI tracking and follow-up (HiTrack EHDI Data Management System). The EI data were collected and managed by the Ohio DODD and stored in the Early Track data system (Early Track Early Intervention Data System). Early Track data contained information on developmental assessments and eligibility, diagnosed conditions, and El service engagement. Further, Early Track contained a unique student school identification number that served as a unique master student index used to link both EI and Ohio public schools data. The linkage between the HiTrack and Early Track systems was performed onsite at ODH and under supervision of both ODH and Ohio DODD program staff. Following this data linkage described in detail below, all personal identifiers were removed.

The initial data linkage (i.e., HiTrack-Early Track) was a multistep process that required matching records on multiple personal identifiers. The SAS server via Enterprise Guide 7.1 was used to maximize computational resources. The SAS SQL (Structured Query Language) procedure was used to match records with a deterministic algorithm that used child characteristics (i.e., gender, date of birth, first name, and last name) and maternal characteristics (i.e., first name, last name, and date of birth). Prior to running the matching algorithm and classifying the links, we removed all special characters and spaces from the infant name and mother name fields and converted all characters to uppercase. Matched pairs of records were classified according to the number of shared maternal-child identifiers. This approach was adapted from similar past research that used Ohio data sources (Bowers et al., 2018). The classification methodology is depicted in Figure 1. Records were classified as (a) complete matches on all identifiers, (b) maternal partial matches (complete matches except for mother's date of birth), and (c) matches of only child's information. First, we selected records that had a perfect match on all criteria. Next, we selected maternal partial matches. Maternal partial matches were largely due to missing dates of birth. Finally, we selected records that matched only on all infant identifiers; this was the least specific approach, but allowed for manual review of potential matches (where either the mother's first or last name matched). Following each stage of matching, we manually verified records that linked only using infant characteristics (did not link on mother's first or last name). Using this linking methodology, nearly 20% of records from HiTrack were successfully linked to Early Track records using all of the mother-infant matching variables. An additional 47.1% of the records were matched using all variables except for mother's date of birth (Figure 1). Nearly 3% of records were matched using only infant characteristics. Once the linkage between HiTrack and Early Track was complete, a unique identifier was assigned to each individual and the identifiers used in the linkage were removed from the final dataset. A separate dataset was created that contained both the unique identifiers assigned to individuals and the identifiers that were used in the linkage process; ODH maintained the database and served as the gatekeeper. This dataset functioned to verify records for outliers and missing values as necessary. Only ODH and DODD had access to the key identifier.

The second data linkage was performed to merge the academic outcomes including early educational



*Figure 1.* Criteria for the linkage of newborn screening/follow-up data and early intervention data. \* Indicates records that required manual verification. DOB = date of birth. assessments, socio-emotional assessments, and disability codes provided by the ODE through the Education Management Information System (EMIS). EMIS is a statewide data collection system for Ohio's primary and secondary education. The EMIS data were de-identified and provided in Microsoft Excel file format. The unique student identification number was used to perform a simple merge of the HiTrack Early Track combined data to the EMIS data.

#### Analysis

Simple descriptive analyses were conducted to compare the full cohort of children who were identified as DHH relative to those who enrolled in EI and those with data linked to education outcomes. Because this study was focused on successful data linkages and not the testing of a specific hypothesis, we did not conduct any statistical testing.

#### Results

There were 1,746 babies identified as DHH through the Ohio EHDI program between January 1, 2008 and December 31, 2014. Among the identified infants, 1,262 (72.3%) were linked to an enrollment record within EI and 502 unique individuals had matched education records (Figure 2). Four hundred eighty-four EHDI records did not have a corresponding Early Track record. Infants who did not have documentation of enrolling into EI would not have data within the Early Track system. Of the 1,262 successfully linked Early Track records, 760 records could not be linked to EMIS (education data). Likely reasons for our inability to link these records to EMIS include a child (a) was not enrolled into preschool, (b) was not of school age, (c) attended a private school but did not have an Individualized Education Program, and/or (d) no longer lived within the state of Ohio. Table 1 describes the characteristics of the infants by linked groupings.





#### Table 1

Characteristics of DHH Infants in Ohio by Data Linkage Status

Characteristics	All infants N = 1746	Linked to El <i>n</i> = 1262	Linked to EMIS <i>n</i> = 502
Gender- Male	892 (51.1%)	684 (54.2%)	281 (56%)
Race			
Caucasian Black/African American	1227 (70.3%) 228 (13.1%)	952 (75.4%) 155 (12.3%)	397 (79.1%) 68 (13.6%)
Asian Other Unknown	34 (2%) 75 (4.3%) 182 (10.4%)	24 (1.9) 49 (3.9%) 82 (6.5%)	9 (1.8%) 13 (2.6%) 15 (3.0%)
Ethnicity-Hispanic	80 (4.6%)	55 (4.4%)	14 (2.8%)
Gestational age in weeks <i>(SD)</i>	37.3 (3.5)	37.3 (3.5)	37.3 (3.4)
Birth weight in grams <i>(SD)</i>	2952 (836)	2959 (845)	2951 (859)
Born Premature	367 (21.0%)	270 (21.4%)	118 (23.5%)
Maternal Education Less than high school	219 (12.5%)	147 (11.7%)	59 (11.8%)
High school	390 (22.3%)	271 (21.5%)	117 (23.3%)
College graduate	413 (23.7%)	343 (27.2%)	148 (29.5%)
Missing	251 (14.4%)	132 (10.5%)	33 (6.6%)
Median [IQR] age in months of hearing loss confirmed	3.9 [1.9-9.6]	3.9 [1.9-9.0]	4.0 [1.8-9.0]
Has risk indicator for hearing loss	674 (38.6%)	507 (40.2%)	229 (45.6%)
Bilateral hearing loss	1285 (73.6%)	897 (72.5%)	393 (78.3%)
Degree of loss in worse ear			
Slight/Mild	538 (30.8%)	380 (30.1%)	159 (31.7%)
Mod-Severe	203 (13.1%) 229 (13.1%)	194 (15.4%) 170 (13.5%)	60 (15.9%) 60 (12.0%)
Severe	117 (6.7%)	84 (6.7%)	40 (8.0%)
Profound Unknown	486 (27.8%) 113 (6 5%)	364 (28.8%) 70 (5 5%)	132 (26.3%) 31 (6.2%)
	1.10 (0.070)	(0.070)	0.270

Note. DHH = deaf or hard of hearing; EI = Early Intervention; EMIS = Education Management Information System; mod-severe = moderately severe.

#### Education

#### **Final Linked Database**

**Birth and screening data.** The Ohio EHDI Data Linkage Project resulted in a comprehensive database containing a large number of birth, hearing screening, and El variables. Demographic fields included maternal age (at child's birth), race and ethnicity, education level of the mother and the father, and insurance status/payer. Fields that characterized the birth included gestational age at birth (weeks), birthweight (grams), Apgar score, risk factors specific for hearing loss, and pregnancy-related risk factors. Hearing-specific information was characterized in

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fields including age at screening and diagnosis (screening and diagnosis dates), laterality of hearing loss (unilateral/bilateral), and degree of loss in each ear (e.g., mild, moderate, moderate-severe, severe, and profound).

**El specific data.** The El service fields included dates of evaluation and individualized family service plan (IFSP), documented developmental delays and disabilities, types of services, frequency and duration of services (dates of service), and the presence of diagnosed conditions. The file indicated whether a child scored >1.5 standard deviations below the population mean on standardized assessments in the categories of cognitive, social-emotional, communication and language, and gross and fine motor development. Because of the El system specific for children who were DHH at the time of data collection, language development was captured within the HiTrack system. At the time, language was assessed using the SKI\*HI Language Development Scale (LDS; Tonelson & Watkins, 1979).

Academic data. Data pertaining to the Individualized Education Program (IEP) were obtained from the educational record, such as the disability eligibility category, dates of the IEP, and grade level and age of the child. Multiple outcomes were available for children who were served in a preschool classroom. The Ages and Stages Questionnaire: Social-Emotional (ASQ:SE; Squires, Bricker, & Twombly, 2002) was used to measure the outcome of social-emotional development of children. The ASQ:SE is a well-validated, parentcompleted screening tool that contains items to assess the dimensions of self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people. The Get it! Got it! Go! is a preschool assessment used to assess critical early literacy skills (i.e., picture naming, rhyming, and alliteration), and is administered multiple times during the academic year after the age of 3 years (Early Childhood Research Institute on Measuring Growth and Development, 1998).

The Early Childhood Outcome Summary assesses socialemotional skills, acquiring and using knowledge and skills, and taking appropriate action to meet needs. The Early Learning Assessment measures awareness & expression of emotion, cooperation with peers, phonological awareness, communication, coordination, safetyinjury prevention, relationships with adults, vocabulary, numbers, and personal care in preschool children. Ohio's Kindergarten Readiness Assessment (KRA) measures school readiness aligned to Ohio's Early Learning and Development Standards (birth to kindergarten) and is intended to be used by teachers to improve outcomes for all kindergarten children enrolled in public or community schools. The Language and Literacy area of the KRA may be used for the K diagnostic requirement of the Third Grade Reading Guarantee as it measures students' skills in the areas of early reading, letter recognition and using words in conversations. The KRA includes 50 questions

that address a child's growth and development in four main areas, Language and Literacy, Social Foundations, Mathematics, and Physical Well-Being and Motor Development.

#### Discussion

The Ohio EHDI Data Linkage Project demonstrates the successful development of an integrated data source to support observational research that is needed to improve outcomes for children who are DHH. The resulting process has established a roadmap for expanding these efforts to states beyond Ohio. The need for evaluation is apparent as deficits in language development persist despite the implementation of newborn screening programs for hearing loss and EI programs for children birth to 3 years of age with the focus of mitigating developmental risks for children who are DHH.

To our knowledge, this is the first study to characterize the successful development of a population-based, longitudinal database that documents state-level services and outcomes for children who are identified as DHH through a state EHDI Program. This new resource can provide novel integrated data to support program evaluation and epidemiologic research with a focus on key child developmental and family outcomes important for El services (Early Childhood Technical Assistance Center & FPG Child Development Institute of the University of North Carolina at Chapel Hill, 2019). Through this project, we were able to demonstrate the feasibility of developing a resource that could enable Ohio and other states to evaluate the effectiveness of early age EI enrollment (i.e., by six months of age, meeting the EHDI benchmark) to improve language outcomes and early academic outcomes, such as pre-literacy and kindergarten readiness. Such studies can provide evidence for the advent of the 1-3-6 EHDI benchmarks while addressing fundamental questions regarding the types and intensities of different El services. This resource may also simulate opportunities to measure the successful and unsuccessful connection points between important programs for children who are DHH. Cross-system linkages provide the data that can facilitate system-level quality improvement efforts that promote quality interface between entities such as EI and the education system.

Although many studies address language and communication skills, the literature is lacking in understanding broader domains of development and early predictors of academic success. A comprehensive longitudinal database is an innovative resource that has the potential to address questions about predictors of social-emotional development and academic success in children who are DHH. Because we were able to link to the education system, we have the opportunity to assess outcomes beyond language and beyond the birth to 36 month period; and provide a picture of the educational trajectory for children who are DHH as they grow. Once this picture is provided, these data can provide powerful evidence in support of state-based EHDI and EI systems.

# **Project Challenges**

We encountered several challenges regarding the project. Although we had established collaborations across the 3 state agencies involved with the project, these agencies were disparate, operating as independent entities in mission, data systems, and policy. This required approximately six months of various approvals for data use agreements and memoranda of understanding between the agencies and our academic institution.

Our linkage methodology was based on an algorithm that required a perfect match of infant records. Employing a strict algorithm potentially misses infants in the linkage process. The solution would require additional manual verification of all infants believed to have received EI services. This activity would have been a large endeavor and would not be a feasible model if this program were to be replicated regularly for state-level program evaluation. An alternative approach would be to use probabilistic algorithms to facilitate additional matches (Mneimneh et al., 2013); however, deterministic methods (as employed in our study using names) likely mitigate misclassification of matches (Kotelchuck et al., 2014). Further, more complex matching algorithms often require special expertise in statistical methodology and would not necessarily preclude manual verification of matches. These more complex methods may not be as accessible or readily adopted by programs, diminishing the overall feasibility of this project in public health practice.

Certain sub-populations such as transient families may require collaboration across state systems to ensure adequate linkage. Although documentation of every record achieves a population-based approach, conditioning the sample on linked individuals represents the vast majority engaged in the system. The linkage to the EI database, Early Track, resulted in 1,252 matches, providing a robust sample available to form important questions regarding the impact of the system on child outcomes. Modest enhancements to state systems could also facilitate these linkages. For example, maternal date of birth, an important linkage variable, was absent in most records within the HiTrack system (i.e., newborn screening program). Although this did not greatly inhibit the linkage process, the same may not be true in other state systems. Additionally, misspellings in the mother's last name required manual verification of "near matches" (matches that were close with the exception of the mother's last name). Creating or adapting current systems to better capture the appropriate spellings would decrease the need for manual verifications. Other reasons for the inability to link records on the mother's identifiers include name changes (e.g., due to marriage or divorce) as well as alternative caregivers (e.g., foster care, in the care of other guardians). Misclassification of true matches as non-matches results in a reduced total sample, but if occurring infrequently and randomly, could still result in

a large, unbiased sample to support evaluation. Manual review would be necessary to ensure appropriate linkage and classification in these instances, but ultimately improved documentation, data exchange, and data archiving within state systems will improve interdepartmental/system linkages. Through collaborations across system and states, independent research efforts could be used to identify the extent and reasons for missing data. Subsequently, quality improvement approaches could be pursued to ensure higher data accuracy at the time of collection; however, we must acknowledge that without shared systems of data capture, the potential for missing records will remain using linkage approaches.

Although novel population-based data may stimulate the evaluation of state systems designed to support DHH children, data are largely collected for administrative purposes and can lack the rigor required within research protocols. Relatedly, the Ohio EHDI Data Linkage Project currently lacks data on certain family characteristics and comprehensive measures of service engagement. Nevertheless, opportunities remain to refine the data capture by programs such as EI to document the quantity and content of service visits relative to expectations. Although some challenges that families face (e.g., poverty and other adversity) can be reasonably identified from existing data (e.g., insurance status), there remains limited information collected on the array of family factors such as involvement and parenting stress. Gaps identified in data may inform states on how to optimize new system-level data collection procedures.

This project has several strengths including (a) the collaboration of multiple state agencies and academic institutions; (b) integration of population-based data on children who are DHH; (c) the development of a roadmap for promoting the necessary inter-agency collaborations and commitments; and (d) demonstration of real-world outcomes data available for both evaluation and epidemiologic analyses.

## **Conclusion and Implications for Future Work**

Through collaborations with state agencies, we were able to demonstrate that an integrated data system is feasible. The availability of such a comprehensive data system can help investigators, whether public health or academic, address relevant and important topics regarding short and long-term outcomes for children served in state EHDI programs. Not only does this project demonstrate that partnerships and innovative data linkages across state information systems can serve as a model for other state EHDI programs, it can also serve as a model for public health programs serving the broader population of children with disabilities. This work has broad implications for public health practice regarding infants who are DHH based on findings showing the positive impact of early entry into El on language and a possible sustaining effect on early academic outcomes.

In our next phase of data analysis, we will further characterize the population of DHH children in the linked statewide database. This will include describing the observed early social-emotional and literacy skills (preschool), kindergarten readiness, and important early education outcomes (namely, emergent literacy skills). We also plan to use quasi-experimental approaches to evaluate the impact of EI services on key child outcomes.

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