

DATA SHARING AGREEMENT
BETWEEN
LOUISIANA DEPARTMENT OF HEALTH, OFFICE OF PUBLIC HEALTH,
BUREAU OF FAMILY HEALTH
AND
OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES EARLYSTEPS
PROGRAM

Data Requester: Joseph Kanter, MD
Assistant Secretary
Office of Public Health, Louisiana Department of Health (LDH)

Data User/Custodian: Tri Tran, MD, MPH
BFH Senior Epidemiologist

Agency Name: Louisiana Department of Health (LDH)
Office of Public Health
Bureau of Family Health (BFH)

Program Name: Title V BFH Programs

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Phone: 504-568-5055

Data Provider: Julie Foster Hagan
Assistant Secretary
Louisiana Department of Health (LDH)
Office for Citizens with Developmental Disabilities (OCDD)

Data Custodian: Brenda B. Sharp
EarlySteps Program Manager

Agency Name: Louisiana Department of Health (LDH)
Office for Citizens with Developmental Disabilities (OCDD)

Program Name: EarlySteps Program

Address: 628 North 4th Street
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I. PURPOSE

LDH OCDD EarlySteps and OPH BFH Programs will exchange data collected through EarlySteps Program and data collected through four BFH Programs including (1) birth defects data by Louisiana Birth Defects Monitoring Network (LBDMN); (2) newborn hearing screening data by Louisiana Universal Newborn Hearing Screening and Early Identification Program (LA UNHSEI); (3) newborn screening (heel-stick) data by Genetics; and (4) the Louisiana Maternal, Infant, Early Childhood Home Visiting (LA MIECHV) Program data. The data will be used for program implementation, administration, evaluation, monitoring, and research. This agreement will define and allow data exchange between EarlySteps and BFH to enhance provision of health care services and reporting.

II. PERIOD OF AGREEMENT

This agreement is effective from January 1, 2021 to December 31, 2026. Additional data sharing agreements will be written if there is a need beyond this time period.

III. JUSTIFICATION FOR ACCESS

Coordination of information exchange between BFH and EarlySteps has occurred since September 1, 2015 and expired on December 31, 2020. Use of EarlySteps data linked with birth defects data, newborn hearing screening data, newborn screening data, MIECHV data, and developmental screening initiative data has significantly assisted the programs specified above in evaluation and research through analyses to assess utilization and cost of health and social services among children. The linked data have been used as a secondary data source to supplement medical record data and patient information not captured through the surveillance systems. The LA UNHSEI has used the linked data to identify children lost to follow-up after diagnosis of permanent childhood hearing loss who were referred to and/or received EarlySteps services. In addition, LA MIECHV will use EarlySteps linked data to evaluate the effectiveness of developmental screening, referral, and follow-up.

With this agreement, EarlySteps can access and use child specific birth defects data, newborn hearing screening, newborn screening data, and MIECHV data as secondary data sources to identify patients and update information when needed for program and service purposes.

IV. DESCRIPTION OF DATA

Birth defects data have been collected through a population-based active surveillance system conducted by LBDMN since 2005. Currently, the system seeks to identify more than 70 major structural, functional, or genetic birth defects in live births and fetal deaths over 20 weeks of gestational age; born in-state to Louisiana residents; and diagnosed prior to third birth date for live births. The data include specific types of birth defects, prenatal case history including maternal exposures and delivery information as well as the child's postnatal case history such as consultations, tests, and procedures. The ICD-10-CM (10th revision of the International Statistical Classification of Diseases and Related Health Problems – Clinical Modification) and Centers for Disease Control (CDC) coding system are used to code diagnoses for reporting.

Newborn hearing screening data have been collected by LA UNHSEI since 2002. Newborn hearing screening is conducted for all babies born in the state, prior to hospital discharge, or at outpatient clinics. The data include results of hearing screening and diagnostic testing, amplification type, and risk factors for progressive or late-onset hearing loss for children from birth to three years of age. In addition, provider information, referral and intervention data for children with permanent hearing loss, communication choice of the family, and outcome data are collected.-

Newborn Screening data are collected through statewide neonatal screenings on filter paper specimen forms (Lab-10) at public and private labs. The system seeks to early detect 28 genetic disorders within the first few weeks of age among live births born in the state and to Louisiana residents. The data include child and mother's personal identifiers, demographics, delivery information as well as information on testing, follow up, and treatment.

LA MIECHV data are collected by home visitors during or after each MIECHV home visit. The data include demographics, service utilization, health habits, and outcomes of the home visit. Data collection is designed by the two home visiting models implemented by MIECHV: 1) Nurse-Family Partnership and 2) Parents As Teachers. Data is used to monitor home visiting model fidelity and effectiveness of programs.

EarlySteps data are statewide and include demographic, diagnoses and referral concerns, developmental screening and evaluation results, eligibility determination and service authorization data for children birth to three years of age. The data comprise service utilization and payment for services paid through EarlySteps Program. The ICD-10-CM coding system is used to code diagnoses while the CPT system is used for medical procedures and social services.

The EarlySteps data will be linked with birth defects, newborn hearing screening, newborn screening, MIECHV, and developmental screening initiative data. All parties will use the linked data. Variables required for data linkages will include the mother and child's first and last name, date of birth, social security number, and current residence address. Mother and service coordinator contact information including phone numbers, fax numbers, and email addresses are used for contacting the mother and service coordinator, respectively, and also for tracking children lost to follow-up for the EHDI system after diagnosis of permanent hearing loss. The ICD-10-CM diagnosis codes and utilization data are used for analyses to assess utilization and cost of early intervention services among children born with birth defects, genetic disorders, and/or hearing loss. See Appendix A for a full list of variables requested from EarlySteps data.

V. METHOD OF DATA ACCESS OR TRANSFER

At present, the EarlySteps database is housed on one of LDH servers. Brenda Sharp or a designee will extract data files from the LDH server and provide it to Tri Tran or his designee, who will conduct the linkages. The received data files are saved in a secured shared drive located within the OPH server.

With this agreement, the LDH program offices can directly access birth defects data, newborn hearing screening, and newborn screening data through web-based database systems where

those data are stored and managed. The authorized users must submit applications for data use to program managers of Title V BFH Programs and attend required trainings before they can access databases.

VI. LOCATION OF MATCHED DATA AND CUSTODIAL RESPONSIBILITY

The BFH Programs serve as the "Custodian" of the data linkages; are responsible to observe all conditions for use; and maintain confidentiality of the data as specified in this agreement to prevent unauthorized use.

This agreement represents and warrants further that, except as authorized in writing, the data file and all individually identified information contained in such data file shared between the OCDD and BFH Programs shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned or accessed by anyone other than LDH authorized users. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this section and only to those individuals who need the information in order to achieve the stated purpose of this agreement.

Any summary results or non-identifying aggregate level data can be shared by EarlySteps and BFH Programs. Summary results are defined as those items which cannot be used to identify any individual.

VII. CONFIDENTIALITY

Information shared through this agreement is confidential. The parties agree to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use of access to it. The safeguards shall provide a level and scope of security that is not less than the level and scope of confidentiality currently established internally by each party. The parties further agree to comply with all applicable state and federal confidentiality laws including but not limited to LA R.S. 46:56, 42 USC 5106a, 42 USC 671(a)(8), 42 CFR 431.300 et seq., the HIPAA Privacy Rule (45 C.F.R. Part 164, Subpart E), and the HIPAA Security Rule (45 C.F.R. Part 164, Subpart C) and 34 CFR §§ 303.400-417 and 34 CFR Part 99 § 444.

VIII. DISPOSITION OF DATA

After the linkage, all data files provided by EarlySteps will continue to be maintained on the secure shared drive on the OPH server for availability to use for any further program administration when needed.

IX. DATA-SHARING PROJECT COSTS

Salary and expenses for LDHL OPH BFH Programs and OCDD staff will be absorbed with no extra expenses assumed.

X. RESOURCES

Staff resources will be the responsibility of LDH OPH BFH Programs and OCDD EarlySteps.

XI. SIGNATURES

In witness whereof, the Programs' authorized representatives as designated by OCDD EarlySteps and the OPH BFH Director attest to and execute this agreement effective with this signing for the period set forth.



Date 2/1/21

Joseph Kanter, MD
Assistant Secretary
LDH, Office of Public Health



Date 02/25/2021

Julie Foster Hagan, Assistant Secretary
LDH, Office for Citizens with Developmental Disabilities

APPENDIX A DATA ELEMENT LIST

CHILD MASTER

Child ID
Family child master ID
Medicaid ID
Last name
First name
AKA last name
AKA first name
Date of birth (DOB)
Gender
Race
Ethnicity
Social security number (SSN)
Mother's maiden name
Mother's last name
Mother's first name
Mother's DOB
Mother's SSN
Home address (street, city, parish)
Mother's race
Mother's ethnicity
Referral date
Name of the primary referral source
Source of the primary referral
Reason for the primary referral
Name of the secondary referral source
Source of the secondary referral
Reason for the secondary referral
Termination date
Reason for termination

EI OUTCOMES

Battle Developmental Inventory (BDI) results for at least three domains: Communication, Cognitive, and Personal-Social. The results include standard scores (developmental quotients) for domains and raw scores for their subdomains for all assessments.
Person Completing Assessment and Title/Agency

ELIGIBILITY

Eligibility type
Start date
End date

DIAGNOSIS & PROCEDURE

ICD-10 code
ICD-10 Description
CPT code
CPT description

AUTHORIZATIONS

Service type description
Start date
End date
Cancel effective date
Provider's last name
Provider's first name
Provider's address (street, city, zip code, parish)
Provider's specialty
Provider's degree
Organization name
Service type
Service frequency
Service intensity

MEDICAL INFORMATION

Physician's last name
Physician's first name
Physician's address (street, city, zip, parish)
Type of screen administered
Date of last screen

IFSP AND INTERIM IFSP

IFSP type
Start date
End date