

DATA SHARING AGREEMENT

BETWEEN

**NEW JERSEY DEPARTMENT OF HEALTH (NJDOH)
Division of Family Health Services
Special Child Health and Early Intervention Services
Early Intervention Program**

AND

**NEW JERSEY DEPARTMENT OF HEALTH (NJDOH)
Division of Family Health Services
Special Child Health and Early Intervention Services
Early Hearing Detection and Intervention Program**

I. Purpose

This data sharing agreement sets forth the terms under which the Early Intervention Program agrees to share certain data with the Early Hearing Detection and Intervention Program hereinafter referred to as the “Requesting Program”. The purpose of this Agreement is limited to enabling the Requesting Program to create a combined data set to evaluate whether children diagnosed with hearing loss have referred and enrolled in Early Intervention services in a timely manner.

The Early Intervention official responsible for implementing this Agreement is Susan Evans, Acting Part C Coordinator, Early Intervention (EI) Program

The Requesting Program official responsible for implementing this Agreement is Ariel Meltzer, EHDI Coordinator, Early Hearing Detection and Intervention Program (EHDI).

The Early Intervention Data Custodian responsible for implementing this Agreement is Steve Gwozdik, Software Development Specialist 2, Early Intervention (EI) Program

II. Legal Authority

This Agreement is drafted in conformity with N.J.S.A 26 § 2-103.6 et seq. the statute that authorizes the Early Intervention Data Custodian to share data with the Requesting Program to utilize NJDOH data to create a linked data set of Early Hearing Detection and Intervention (EHDI) data and Early Intervention (EI) data to determine timeliness of early intervention referral and enrollment for children diagnosed with hearing loss. The

Statute requires the Requesting Program to have an established central registry of newborns identified as having or being at risk of developing a hearing loss.

III. Parties to the Agreement

The following are the parties to this Agreement:

- A. The Early Intervention Program, the state program that is responsible for the administration of the Early Intervention Program, Individuals with Disabilities Education Act (IDEA) Part C, which provides for the provision of early intervention services for children age birth through 2 years, and their families.
- B. The Requesting Program is responsible for the administration of the Early Hearing Detection and Intervention Program (EHDI) which is responsible for tracking the numbers on newborn hearing screening and diagnostic data to ensure infants receive timely hearing screening and diagnostic testing and appropriate habilitation services. The EHDI Program will utilize this data set.

IV. Definitions

The following terms used in this Agreement shall have the meanings set forth below:

- A. "Agreement" is this Data Sharing Agreement, including any amendments.
- B. "Disclose" or "Disclosure" refers to the release of data in accordance with the terms of this Agreement.
- C. "Personally Identifiable Information" (PII) means "any information about an individual including (1) any information that can be used to distinguish or trace an individual's identity, including but not limited to name, social security number, date and place of birth, mother's maiden name, or biometric records; and (2) any other information that is linked or linkable to an individual, such as medical, educational, financial, and employment information." GAO Report 08-536, *Privacy: Alternatives Exist for Enhancing Protection of Personally Identifiable Information*, May 2008, <http://www.gao.gov/new.items/d08536.pdf>.
- D. "Protected Health Information" (PHI) shall have the same meaning as that term defined in the Federal Privacy Rule at 45 CFR 160.103.
- E. "Workforce" shall include any staff, whether contracted, volunteer, intern or other, who have access to NJDOH data under this Agreement.

V. Responsibilities of the Parties

The parties shall have the following responsibilities in connection with the operation, management and administration of this agreement:

A. The Requesting Program shall be responsible for:

1. Maintaining forms properly executed by all Requesting Program's employees and workforce in which such employees and workforce acknowledge their understanding of the confidential nature of data, the standards and guidelines for the handling of such data as discussed in Section VII of this Agreement, and their obligation to comply with such standards and guidelines in carrying out their duties.
2. Ensuring that internal security measures currently in place at Requesting Program comply with the confidentiality provisions set forth in the Agreement that are intended to prevent the unauthorized disclosure of NJDOH data.
3. Cooperating if NJDOH is audited with regard to program confidentiality or if NJDOH is required to undergo a compliance review. This includes permitting site and record inspections related to program confidentiality during regular business hours by federal or state representatives.

B. The Early Intervention DATA CUSTODIAN shall be responsible for:

1. Providing the Requesting Program, a quarterly file of NJDOHs data variables identified in the Agreement.

VI. Operation of this Agreement

The following describes how the Agreement shall operate, including how requests to the Early Intervention DATA CUSTODIAN are submitted and processed:

A. The following are the Early Intervention data elements that Early Intervention Program shall provide to the Requesting Program ("NJDOH data"):

- Early Intervention Referral Date
- Individual Family Service Plan (IFSP) Date
- Exit date
- Exit reason
- Early Identification child ID Number

Access to confidential data is limited to only those variables necessary for the purpose of this agreement.

B. Description of proposed data use of NJDOH data:

The Requesting Program will use the data to conduct evaluation of whether children diagnosed with hearing loss have referred and enrolled in Early Intervention services in a timely manner.

C. Data Linkage

The following are the data elements which the Programs will use for linkage:

- Child's first name
- Child's last name
- Child's date of birth

The Early Intervention Program Data Custodian will provide the Early Hearing Detection and Intervention Data Custodian a file with matched child level data.

VII. Confidentiality/Restrictions on Use of Data

All parties to this Agreement recognize that confidentiality of the NJDOH data is of paramount importance and must be observed except where disclosure is allowed by this Agreement or by court order. All data exchange activity conducted through the Agreement will be conducted in a manner consistent with applicable State and Federal law. All such activity conducted by Requesting Program will be performed in a manner consistent with the Privacy Act of 1974¹ and the Social Security Number Privacy Act of 2004². The parties agree to take all necessary steps to protect such privacy by complying with the following provisions that are applicable to their particular entity, in governing their handling of confidential information:

NOW THEREFORE, NJDOH and Requesting Program mutually agree as follows:

A. Privacy and Confidentiality

1. Access to PII NJDOH data shall be restricted to only Requesting Program's employees or workforce who need the NJDOH DATA to perform their official duties in connection with the purpose of this Agreement.
2. Requesting Program's employee or workforce who access, disclose or use NJDOH DATA in a manner or for a purpose not authorized by the Agreement may be subject to civil and criminal sanctions contained in applicable federal and state statutes.
3. This Agreement applies to the NJDOH data elements identified in Section VI of this Agreement.

¹ Pub. L. No. 93-579, § 7, 88 Stat. 1896, 1909 (1974), 5 U.S.C. § 552a, note (Disclosure of Social Security Number).

² Social Security Act § 205(c)(2)(C)(viii), 42 U.S.C. § 405(c)(2)(C)(viii).

B. Use and Disclosure

The Requesting Program shall use and disclose the PII for only the activity described in the Agreement. The Requesting Program shall limit access to PII strictly to those individuals or classes of individuals who require access to perform the duties and responsibilities set forth in the Agreement.

1. No Requesting Program employee or workforce may disseminate data received from NJDOH, except to other Requesting Program employees or workforce specifically authorized to receive such data.
2. Requesting Program shall not extract or release information from NJDOH data provided by NJDOH for any purpose not stated in this Agreement.
3. Access to NJDOH data and to any records created from the data shall be restricted to only those Requesting Program employees or workforce who need access in their official capacity to perform duties connected with implementation of this Agreement.
4. Requesting Program shall advise Requesting Program's employees or workforce who will have access to NJDOH data of the confidential nature of the information, the safeguards required to protect the information, and the civil and criminal sanctions for noncompliance with such safeguards that are contained in federal and state laws. Prior to being able to have access to NJDOH data such Requesting Program employees or workforce shall execute a form acknowledging their understanding of the confidential nature of the safeguards with which they must comply in their handling of NJDOH data. Requesting Program employees and workforce shall be advised of the fact that they may be liable to civil and criminal sanctions for improper disclosure of NJDOH data.
5. NJDOH data shall be processed so as to protect the confidentiality of the data, and in such a way that unauthorized persons cannot retrieve such records by means of computer, remote terminal, or any other means.
6. Requesting Program shall not disclose NJDOH data obtained under this Agreement to any third parties. Requesting Program shall use NJDOH data for only the specific purpose described in this Agreement. Requesting Program is not authorized to share the NJDOH DATA received with any other program within Requesting Program or to disclose it to individuals or entities outside of the Requesting Program.
7. Requesting Program shall not disclose NJDOH data obtained under this Agreement to any employee or workforce or other parties for purposes beyond the scope of intended use identified in this Agreement.

8. Requesting Program shall not publish or disclose in any manner to the public any NJDOH data or information on individual level records or PII, statistical tables, or research or results, with or without identifiers. Additionally, Requesting Program acknowledges that release or disclosure of information where the number of observations (i.e. individual records) in any given cell of tabulated data is less than or equal to ten (10) increases the risk for identification purposes. Requesting Program shall suppress any given cell of tabulated data where the number of observations is less than or equal to ten (10).
9. NJDOH shall not be liable for any conclusions drawn in reliance upon NJDOH data.

C. Secure Destruction

Requesting Program shall retain NJDOH data received from Early Intervention Program for only the period required to utilize NJDOH data for the purpose authorized under this Agreement. At the end of this Agreement, Requesting Program will, and will certify in writing, that it has securely destroyed or returned all data files containing Early Intervention DATA.

D. Training

Requesting Program agrees to advise Requesting Program's employees and workforce who have access to NJDOH data of the confidentiality of the information, the safeguards required to protect the information, and the civil and criminal sanctions for non-compliance contained in applicable federal and state laws. For that purpose, Requesting Program shall:

1. Train employees and workforce and use reasonable measures to ensure their compliance with the requirements of this Agreement. Requesting Program must train all employees and workforce on the use or disclose NJDOH data; and take corrective action against such Requesting Program employees or workers who intentionally violate any provisions of the Agreement.
2. Provide privacy and security awareness training to each new Requesting Program employee or workforce within 30 days of employment or joining Requesting Program workforce and thereafter provide ongoing reminders of the privacy and security safeguards in this Agreement to all employees and workforce who access, use or disclose NJDOH DATA under this Agreement.
3. Maintain records indicating the name of each of Requesting Program's employees or workforce and the date on which the initial privacy and security awareness training was successfully completed.
4. Retain training records to inspection for a period of three (3) years after successful completion of the training.

E. Confidentiality Statement

Requesting Program agrees to ensure that all Requesting Program employees and workforce who access or use NJDOH DATA sign a confidentiality statement. The statement shall include at a minimum, General Use, Security and Privacy Safeguards, Unacceptable Use, and Enforcement Policies. The statement shall be signed by Requesting Program employees and workforce prior to access to NJDOH DATA.

F. Physical Security

The Requesting Program shall ensure that NJDOH DATA is used and stored in an area that is physically safe from access by unauthorized persons during working hours and non-working hours. The Requesting Program agrees to safeguard NJDOH DATA from loss, theft, or inadvertent disclosure and, therefore, agrees to:

1. Secure all areas of Requesting Program facilities where Requesting Program employees or workforce assist in the administration of the Requesting Program programs use or disclose NJDOH DATA. The Requesting Program shall ensure that authorized individuals only access these secure areas with properly coded key cards, authorized door keys or access authorization; and access to premises is by official identification.
2. Issue Requesting Program employee and workforce identification badges and require Requesting Program employees and workforce to wear these badges at Requesting Program facilities where NJDOH DATA is stored and used.
3. Requesting Program shall store NJDOH data in written format in an area that is always physically safe from access by unauthorized persons.
4. Store paper records with NJDOH DATA in locked spaces, such as locked file cabinets, locked file rooms, locked desks or locked offices in facilities, which are multi-use, meaning that, where Requesting Program and non-Requesting Program functions in one building in work areas that are not securely segregated from each other. Requesting Program shall have policies, which indicate that Requesting Program employees and workforce are not to leave records (paper or electronic) with NJDOH DATA unattended at any time in vehicles or airplanes and not to check such records in baggage on commercial airplanes.
5. Use all reasonable measures to prevent non-authorized workforce and visitors from having access to, control of, viewing NJDOH DATA.

G. Computer Security Safeguards

Requesting Program agrees to comply with the general computer security safeguards, system security controls, and audit controls in this section.

General Computer Security Safeguards:

1. Encrypt portable computer devices, such as but not limited to laptops and notebook computers that process and/or store NJDOH data with a solution of using a product that is recognized as an industry leader in meeting the needs for the intended solution. Use an encryption solution that is full disk unless otherwise approved by NJDOH Information Security.
2. Encrypt workstations where NJDOH data is stored using a product that is recognized as an industry leader in meeting the needs for the intended solution.
3. Ensure that only the minimum necessary amount of NJDOH data is downloaded to a laptop or hard drive when necessary for current business purposes.
4. Encrypt all electronic files that contain NJDOH data when the file is stored on any removable media type device (i.e., USB thumb drives, floppies, CD/DVD, portable hard drives, etc.) using a product that is recognized as an industry leader in meeting the needs for the intended solution.
5. Ensure that all emails sent outside Requesting Program's e-mail environment that include NJDOH data are sent via an encrypted method using a product that is recognized as an industry leader in meeting the needs of the intended solution.
6. Ensure that all workstations, laptops and other systems that process and/or store NJDOH data have a commercial third-party anti-virus software solution and are updated when a new ant-virus definition/software release is available.
7. Ensure that all workstations, laptops and other systems that process and/or store NJDOH data have current security patches applied and up to date.
8. Ensure that all NJDOH data is wiped from all systems and backups when the data is no longer legally required. Ensure in writing that the wipe method conforms to the US Department of Defense standards for data destruction.
9. Ensure that any remote access to NJDOH data is established over an encrypted session protocol using a product that is recognized as an industry leader in meeting the needs of the intended solution. Ensure all remote access is limited to minimum necessary and least privilege principles.

H. System Security Controls

In order to comply with the following system security controls, Requesting Program agrees to:

1. Ensure that all Requesting Program systems containing NJDOH data provide an automatic timeout after no more than 15 minutes of inactivity.
2. Ensure that all Requesting Program systems containing NJDOH data display a warning banner stating that data is confidential, systems are logged, and system use is for business purposes only. Users shall be directed to log off the system if they do not agree with these requirements.
3. Ensure that all Requesting Program systems containing NJDOH data log successes, and failures of user authentication and authorizations granted. The system shall log all data changes and system accesses conducted by all users (including all levels of users, system administrators, developers, and auditors). The system shall have the capability to record data access for specified users when requested by authorized management workforce. A log of all system changes shall be maintained and be available for review by authorized management workforce.
4. Ensure that all Requesting Program systems containing NJDOH data provide user role-based access controls for all user authentications, enforcing the principle of least privileges.
5. Ensure that all Requesting Program data transmissions over networks outside of the Requesting Program' control are encrypted end-to-end using a Requesting Program product that is recognized as an industry leader in meeting the needs for the intended solution when transmitting NJDOH data. Requesting Program shall encrypt NJDOH DATA at the minimum of 256-bit AES or 3DES (Triple DES) if AES is unavailable.
6. Ensure that all Requesting Program systems that are accessible via the Internet or store NJDOH data actively use a comprehensive third-party real-time host-based intrusion detection and prevention program or are protected at the perimeter by a network-based IDS/IPS solution.

I. Audit Controls

In order to comply with the following audit controls, the Requesting Program agrees to:

1. Ensure that all Requesting Program systems processing and/or storing NJDOH data have at least an annual system security review. The Requesting Program review shall include administrative and technical vulnerability assessments.

2. Ensure that all Requesting Program systems processing and/or storing NJDOH data have an automated audit trail, which includes the initiator of the request, along with a time and date stamp for each access. These logs shall be read-only and maintained for a period of at least three (3) years. There shall be a routine procedure in place to review system logs for unauthorized access. Requesting Program shall investigate anomalies identified by interviewing Requesting Program employees, workforce, and witnesses and taking corrective actions.
3. Maintain an automated audit trail record identifying either the individual worker or the system process that initiated a request. Individual audit trail records shall contain the data needed to associate each query transaction to its initiator and relevant business purpose; each transaction shall be time and date stamped.
4. Investigate anomalies in NJDOH data usage identified by Requesting Program and report conclusions of such investigations and remediation to NJDOH.
5. Exercise management control and oversight, in conjunction with NJDOH, of the function authorizing individual user access to NJDOH data and over the processing of issuing and maintaining access control numbers and passwords.
6. Ensure that all Requesting Program systems processing and/or storing NJDOH data have a documented change control procedure that ensures separation of duties and protects the confidentiality, integrity and availability of data.

I. Onsite Audit

The Requesting Program shall permit NJDOH and/or its designated representative to make onsite inspections during regular business hours for the purpose of conducting program audits or compliance reviews to assure that Requesting Program is complying with the confidentiality requirements described herein. In accordance with this responsibility, Requesting Program shall make records applicable to this Agreement available to authorized persons for the purpose of inspection, review, and/or audit.

J. Notification of Breaches

Requesting Program agrees to:

1. Notify NJDOH immediately by telephone call or email upon the discovery of a breach of security of NJDOH data in computerized form if the PII was, or is reasonably believed to have been, acquired by an unauthorized person; or within 24 hours by telephone call or email of discovery of any suspected security incident, intrusion, loss or unauthorized use or disclosure of NJDOH data in violation of this Agreement or the Identity Theft Law. The Requesting Program shall submit the notification to the NJDOH Data Privacy Officer and the NJDOH Information Security Officer. If the incident occurs after business hours or on a

weekend or holiday and involves electronic NJDOH data Requesting Program shall notify NJDOH by calling the NJDOH's OITS Help Desk.

NJDOH Data Privacy Officer
c/o: Office of Ethics and Data Privacy Compliance
New Jersey Department of Health
P.O. Box 360
Trenton, NJ 08625
Email: privacy.officer@doh.nj.gov
Telephone: (609) 292-4372

NJDOH Information Security Officer
c/o: Office of Information Technology Services
New Jersey Department of Health
P.O. Box 360
Trenton, NJ 08625
Email: iso@doh.nj.gov
Telephone: NJDOH OITS Help Desk (609) 984-0224

2. Ensure that the initial notification includes contact and component information; a description of the breach or loss with scope, numbers of files or records, type of equipment or media, approximate time and location of breach or loss; description of how the data was physically stored, contained, or packaged (e.g., password protected, encrypted, locked briefcase, etc.); whether any individuals or external organizations have been contacted; and whether any other reports have been filed.
3. Take prompt corrective action to mitigate any risks or damages involved with the breach and to protect the operating environment.
4. Investigate the breach and produce a written breach report with ten working days of the incident, detailing what data elements were involved; a description of the unauthorized persons known or reasonably believed to have improperly used or disclosed NJDOH data; a description of where NJDOH data is believed to have been improperly transmitted, sent, or used; a description of the probable cause of the breach; a detailed corrective active plan including measures that were taken to halt and/or contain the breach. The Requesting Program shall submit the breach report to the NJDOH Data Privacy Officer and NJDOH Information Security Officer.
5. Notify individuals of the breach or unauthorized use or disclosure of NJDOH data maintained by Requesting Program when notification is required under state or federal law. Requesting Program shall obtain the approval of the NJDOH Data Privacy Officer for the time, manner and content of any such required notifications. Requesting Program shall be responsible for the cost of such notification to the extent that such breach or unauthorized use or disclosure is

due to the negligence or intentional misconduct of Requesting Program. To the extent, such breach or unauthorized use or disclosure is due to the negligence or intentional misconduct of NJDOH, NJDOH shall be responsible for notifying individuals and Requesting Program shall not be responsible for any costs of notification. If there is any question as to whether NJDOH or Requesting Program is responsible for the breach, NJDOH shall issue a notice and NJDOH and Requesting Program shall subsequently determine responsibility for purposes of allocating the costs of such notices.

VIII. Compliance by Requesting Program Agents

The Requesting Program shall require that any agents, including contractors, subcontractors, and all employees or workforce thereof which assist Requesting Program in its functions and to which Requesting Program provides NJDOH data agree to the same privacy and security safeguards as are contained in this Agreement; and to incorporate, when applicable, the relevant provisions of the Agreement into each subcontract or sub-award to such agents, contractors, or subcontractors.

IX. Duration of Agreement

This Agreement shall become effective upon the signing of both parties and shall expire on 12/31/2025 unless otherwise terminated in accordance with this section. This Agreement may be terminated in one of the following ways:

- A. Upon mutual agreement of Requesting Program and NJDOH at any time.
- B. Upon disclose of NJDOH data by Requesting Program in violation of this Agreement.
- C. This Agreement also may be terminated immediately, upon written notice, should governing state or federal laws or regulations render performance hereunder illegal, impracticable, or impossible.

X. Entire Agreement

This Agreement, including any amendment executed by all parties and incorporated into this Agreement, is complete and contains the entire understanding among the parties relating to the subject matter contained herein, including all the terms and conditions of the parties' agreement. The Agreement supersedes any and all prior understandings, representations, negotiations, and agreements between the parties relating hereto, whether written or oral.

XI. Severability

If any terms and conditions of this Agreement are held to be invalid or unenforceable as a matter of law, the other terms and conditions hereof shall not be affected thereby and shall remain in full force and effect. To this end, the terms and conditions of this Agreement are declared severable.

XII. Applicable Law

The terms of this Agreement shall be governed by the law of New Jersey.

XIII. Effective Date of Agreement

This Agreement shall take effect upon the date on which it is fully executed by all the parties identified below and shall continue in force and effect until the date specified in Section IX of this Agreement, unless terminated in accordance with the terms of the Agreement.

APPROVALS

Now, therefore, in consideration of the mutual promises and undertakings contained herein, the parties hereto consent to the provisions of this Agreement.

SIGNATURES

New Jersey Department of Health

By: _____ Date: _____
Ariel Meltzer

Title: Early Hearing Detection and Intervention Coordinator

By: _____ Date: _____
Susan Evans

Title: Acting Part C Coordinator, Early Intervention (EI) Program