

**DATA SHARING AGREEMENT  
BETWEEN  
IOWA DEPARTMENT OF PUBLIC HEALTH, Bureau of Family Health,  
Early Hearing Detection and Intervention Program  
AND  
IOWA DEPARTMENT OF EDUCATION, Bureau of Learner Strategies and Supports,  
Early ACCESS Integrated System of Early Intervention Services**

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**Identity of Parties.**

**DE.** The Iowa Department of Education (referred to in this document as “DE”) is the issuing agency of this agreement.

**IDPH.** The Iowa Department of Public Health (referred to in this document as “IDPH”) is entering into this agreement for the purpose described in the following sections.

Transition Period. Effective July 1, 2022, through July 1, 2023, the Iowa Department of Public Health (IDPH) and the Iowa Department of Human Services (DHS) shall be in a transition period as the agencies develop and implement transition plans to merge the agencies and become a new state agency, the Iowa Department of Health and Human Services (DHHS). For purposes of this Agreement throughout the transition period, “Agency” or “Department” means either IDPH or DHHS. Throughout the transition period, IDPH and DHHS shall have and may exercise all legal powers and duties of IDPH, including executing all contractual rights and obligations.

Effective July 1, 2023, the Iowa Department of Public Health (IDPH) and the Iowa Department of Human Services shall merge and become the Iowa Department of Health and Human Services (DHHS). For purposes of this Agreement on and after July 1, 2023, “Agency” or “Department” or “IDPH” means DHHS. On and after July 1, 2023, DHHS shall have and may exercise all legal powers and duties of the former IDPH, including executing all contractual rights and obligations.

**Purpose.**

This agreement establishes the conditions, safeguards, and procedures the IDPH and DE shall follow in providing and using data from Iowa’s Early ACCESS Integrated System of Early Intervention Services. Iowa’s Early ACCESS Integrated System of Early Intervention Services was established to develop and implement Part C of the Individuals with Disabilities Education Act IDEA Part C (IAC 281-120.1) and is referred to as “Early ACCESS” for the remainder of the agreement.

The sharing of data identified in this agreement will support the commitments articulated in the Memorandum of Understanding for Early ACCESS (2021-2022) pertaining to the Early Hearing and Detection and Intervention (EHDI) Program's reporting requirements. Early ACCESS data provided under this agreement are for the purposes directly related to reporting of EHDI data to meet state and federal requirements. Additionally, these data may be used in reporting to the Centers for Disease Control and Prevention (CDC) as required pursuant to funding opportunity CDC-RFA-DD20-2006 and a Data Sharing Agreement between the Centers for Disease Control and Prevention and Iowa State Early Hearing, Detection, Diagnosis, and Intervention Program executed on December 29, 2020. IDPH will share data through this Agreement to be used for matching to DE data. DE will use the data provided by IDPH to complete this matching process and will input said data into a data management system. The DE will provide data referred to in this agreement.

**Legal Authority.**

IDPH and DE are authorized to establish and participate in this agreement under the following authority:

- Pursuant to IAC 281-120.414(2) and 281-801(2)(3), the IDPH is a signatory agency with a commitment to participate in the establishment and ongoing implementation of the Early ACCESS system. The state rules and federal regulation allow disclosure of personally identifiable information between the lead agency (DE) and participating agencies (IDPH) without parental consent [34 C.F.R. § 303.403(c)34 C.F.R. § 303.414(b)].
- Pursuant to 641 Iowa Administrative Code Chapter 3 and IAC 41-3.3(135), the IDPH has the authority to operate Iowa's EHDI program. The goal and outcomes of universal hearing screening of all newborns and infants in Iowa is early detection of hearing loss to allow children and their families the earliest possible opportunity to obtain appropriate early intervention services.
- Pursuant to IAC 120.302(3)a(1), the DE must ensure that the Early ACCESS child find system is coordinated with all other major efforts to locate and identify children by other state agencies responsible for administering the various education, health, and social service programs relevant to Early ACCESS.
- Pursuant to IAC 120.302(3)(2)10, the DE must ensure that the Early ACCESS child find system is coordinated with efforts of the Early Hearing Detection and Intervention (EHDI) system (42 U.S.C 280g-1) administered by the Centers for Disease Control (CDC).
- Pursuant to IAC 281-801(3), the DE and IDPH must ensure interagency coordination in the delivery of a comprehensive, integrated, interagency Early ACCESS system; this assurance is incorporated into the agreement. The Directors of DE and IDPH shall ensure compliance with this agreement and commitment to the ongoing implementation of the Early ACCESS system.
- Pursuant to IAC 641-3.12(135), reports, records, and other information collected by or provided to IDPH relating to a child's newborn hearing screening, rescreen, diagnostic audiologic assessment, and early intervention enrollment are confidential records pursuant to Iowa Code section 22.7. IDPH may release limited information as described below to DE as a representative

of a state agency to the extent the information is necessary to perform newborn hearing screening follow-up (641 IAC 3.12(3)(E)) and as information that is necessary to perform a legally authorized function of DE and IDPH (641 IAC 3.12(3)(d)). Data provided by IDPH shall not be used to market services to patients or nonpatients or identify patients for any purposes other than those expressly provided in this Agreement (641 IAC 3.12(3)(e)).

### **Duties of the Parties.**

#### **Duties of Iowa Department of Education – Early ACCESS.**

The DE must ensure the protection of the confidentiality of any personally identifiable data, information, and records collected or maintained by IDPH and received from the DE, in accordance with the protections under the Family Educational Rights and Privacy Act (FERPA). The DE must ensure that IDPH complies with the IDEA Part C confidentiality procedures in accordance with the Iowa Administrative Rules for Early ACCESS [IAC 281-402(2)], for the data shared under this Agreement.

The DE shall use a secure file transfer process to transmit data provided under this agreement. Transmitting data by non-secure methods is not allowed under this agreement.

The DE agrees to securely transmit the following variables to IDPH the first Monday of every month, following receipt of the EHDI data request from IDPH EHDI Program.

1. Individual's last name - Data provided in IDPH EHDI Program's request form;
2. Individual's first name - Data provided in IDPH EHDI Program's request form;
3. Individual's date of birth - Data provided in IDPH EHDI Program's request form;
4. Individual's gender - Data provided in IDPH EHDI Program's request form;
5. Early ACCESS referral date - Defined by DE as date Early ACCESS referral received;
6. Early ACCESS enrollment status - Defined by DE as the status of parental consent for Early ACCESS Services;
  - a. If not enrolled, reason is indicated—Defined by DE as Ending Early ACCESS Reason
7. Early ACCESS enrollment date - Defined by DE as the date parental consent for Early ACCESS Services was signed;
  - a. If not enrolled, this field should be marked as "N/A."

The DE agrees to securely transmit the following variables to IDPH every quarter, following receipt of the EHDI data request from IDPH EHDI Program.

8. Individual's last name - Data provided in IDPH EHDI Program's request form;
9. Individual's first name - Data provided in IDPH EHDI Program's request form;
10. Individual's date of birth - Data provided in IDPH EHDI Program's request form;
11. Individual's gender - Data provided in IDPH EHDI Program's request form;
12. Date exiting Early ACCESS services – first exit date: Defined by DE as the date the infant/toddler initially exited Early ACCESS services;

13. Reason exiting Early ACCESS services – first exit reason: Defined by DE as the Exiting Early ACCESS reason;
14. Date of most recent/final exit date from Early ACCESS services- Defined by DE as the date the infant/toddler most recently exited Early ACCESS services;  
**Note:** These data may be the same date reported for “Date exiting Early ACCESS services– first exit date.”
15. Reason exiting Early ACCESS services – final exit reason: Defined by DE as the Exiting Early ACCESS reason;  
**Note:** These data may be the same reason reported for “Reason exiting Early ACCESS services– first exit reason.”
16. Length of Participation in Early ACCESS services - Defined as the duration from the date parental consent for Early ACCESS Services was signed to the date exiting Early ACCESS services (or final exit).  
**Note:** If applicable, when there is more than one exit date, the total number of days in Early ACCESS will be calculated using the final date exiting Early ACCESS services.

**Duties of Iowa Department of Public Health — Early Hearing Detection and Intervention Program.**

The IDPH shall use a secure file transfer process to transmit data provided under this agreement. Transmitting data by non-secure method is not allowed under this agreement.

The IDPH agrees to submit EHDI data request to the DE for the specified Early ACCESS data elements described in this agreement on the first Monday of every month. The data request will provide the EHDI data elements as specified below:

1. Individual’s last name;
2. Individual’s first name;
3. Individual’s date of birth; and,
4. Individual’s gender.
5. ZIP code

**Duties of Both Parties**

**Administration.**

The IDPH and DE shall not disclose any confidential information contained in this data agreement to unauthorized parties, including but not limited to names and other personally identifiable information of persons who are the subject of such records, either during the period of this agreement or hereafter, except as authorized through this agreement.

All records and data provided by this agreement shall be used only for purposes as set forth in this agreement and those in agreement CDC-RFA-DD20-2006 with the Centers for Disease Control and Prevention (CDC), and Data Sharing Agreement between the Centers for Disease Control and Prevention and Iowa State Early Hearing, Detection, Diagnosis, and Intervention Program executed on December 29, 2020 (See Appendix A).

### **Physical and Technical Safeguards.**

The following physical and technical safeguards are required by FERPA, and shall apply to both Parties.

Both Parties shall institute security procedures as specified in federal and state law to ensure that adequate safeguards are established to provide protection against unauthorized access or disclosure of all information received pursuant to and in accordance with this agreement and to maintain the confidentiality of such information.

- A. Staff for both parties and their authorized contractors who request or receive information under this agreement shall be limited to those with a need to access this information for the purposes described in the section identified as "Purpose."
- B. Staff and authorized contractors for both parties who have signed user agreements whose job duties require access to the information provided under this agreement:
  - a. For the DE, designees as approved by the director of the DE
  - b. For IDPH, the job positions with authorizations are as follows:
    - EHDl Director
    - EHDl Follow-up Coordinator
    - EHDl Epidemiologist
- C. Both parties shall maintain a list of authorized staff and contractors needing access to data described in this Agreement. Both parties will ensure that access to data received from the other party through this Agreement is revoked when staff or contractors no longer have need for access, including a change in duties or termination.
- D. Both parties agree they shall not use the data referenced in this agreement for commercial or political purposes.
- E. Both parties acknowledge they may be held civilly or criminally liable for misuse of the data provided under this agreement.
- F. Both parties affirm that their staff are subject to applicable federal and state restrictions on redisclosure of protected or confidential information.
- G. Both parties shall advise all authorized individuals who access and utilize information received pursuant to this agreement:
  - a. That said information shall be utilized solely for the purposes specified in this agreement;
  - b. That the confidentiality of this information shall otherwise be maintained; and
  - c. Of the criminal penalties for the unauthorized access, use or release of this information.
- H. Both parties shall not publish any aggregate Early ACCESS data that does not comply with the other party's confidentiality guidelines.
- I. Both parties shall provide the other with a copy of all proposed publications at least thirty (30) business days in advance of the proposed dissemination date (excluding the annual report to the CDC as required by Cooperative Agreement (CDC-RFA-DD20-2006) as pre-approval is not required by the DE). Each party shall have thirty (30) business days to provide review and approval of proposed publications. If the receiving party provides no objections within the applicable time

frame, the other party shall have the right to proceed with the proposed publication. In the event that a party does not grant approval to the other for the release of a publication, the party denying approval shall outline changes that could be made for the other party to receive approval.

All records and data received pursuant to this agreement and stored at IDPH or DE shall be stored in a secure locked area with access restricted to project personnel for purposes only as set forth in this agreement. The records will be stored in compliance with the standards of *Security Rules for IDPH Data*. The EHDI program shall comply with department and state information technology standards. Current state information technology standards are accessible online at <https://ocio.iowa.gov/standards>.

- Data Backup Standard: Applicable to Entities which utilize data systems to process, store, transmit or monitor information.
- Data Stewardship Standard: Applicable to Entities which utilize data systems to process, store, transmit or monitor information.
- Interconnectivity Standard: Applicable to Entities which utilize data systems to process, store, transmit or monitor information.
- Laptop Data Protection Standard: Applicable to Entities which utilize laptops to process, store, transmit or monitor data.
- Removable Storage Encryption Standard: Applicable to Entities which utilize removable storage devices to process, store, transmit or monitor information.

Data shared with the Centers for Disease Control and Prevention will be stored according to the terms specified within the Data Sharing Agreement between the Centers for Disease Control and Prevention and Iowa State Early Hearing, Detection, Diagnosis, and Intervention Program executed on December 29, 2020 within the appendix of this agreement.

#### **Breach of Security.**

- Both parties shall immediately report to the other party any suspected or unauthorized use or disclosure of confidential information not provided for by this agreement. Such disclosure shall be grounds for immediate termination of this agreement.
- Breach Notification Obligations: Both parties agree to comply with all applicable laws that require the notification of individuals in the event of unauthorized use or disclosure of confidential information or other event(s) requiring notification in accordance with applicable law. In the event of a breach of the parties security obligations or other event requiring notification under applicable law, each party agrees to follow the other party's directives, which may include assuming responsibility for informing all such individuals in accordance with applicable laws, and to indemnify, hold harmless, and defend the State of Iowa against any claims, damages, or other harm related to such breach.
- Breach of security communication from IDPH shall be addressed to the Bureau Chief of the Bureau of Early Childhood at the DE. Breach of security communications from DE shall be addressed to the IDPH Privacy Officer at IDPH.

**Destruction.**

Both parties shall destroy all raw data received from the other Party and any files created by linking these data files at the termination of the project or in any case within ten years of execution of this agreement, unless need for further retention is explained in the project description and approved in writing by the disclosing party through addendum to this agreement. Destruction shall be by means which render data and any files created by linking the data files, unidentifiable and useless. Both parties shall provide written notification to the other party of the destruction of the records.

DE, Early ACCESS shall destroy all raw files received from IDPH immediately following the completion of the matching process and input into the DE's data management system, unless need for further retention is explained in the project description and approved in writing by DE, Early ACCESS through addendum to this agreement. Destruction shall be by means which render EHDI data and any files created by linking the data files, unidentifiable and useless. DE, Early ACCESS shall provide written notification of the destruction of the records to the Bureau of Family Health—EHDI Program.

**Future Requests.**

Future data requests relative to the described project shall refer to the above agreement number.

**Modifications.**

If during the process of implementing this project there is a modification to the project or if the project is terminated, notice shall be sent to the DE, Early ACCESS or explaining the modifications or stating date of termination. The Bureau of Family Health—EHDI Program shall not modify the use of the DE, Early ACCESS records or data from that contained in this agreement without prior written approval from DE, Early ACCESS.

**Re-Release.**

IDPH, Bureau of Family Health—EHDI Program may release the variables provided in this agreement to the CDC as required by Cooperative Agreement (CDC-RFA-DD20-2006) "Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems." Bureau of Family Health—EHDI Program may not re-release data provided by this agreement without explicit reference to "Family Health—EHDI Program only" for the purposes outlined in this agreement. DE, Early ACCESS shall not re-release the data files provided by IDPH, Bureau of Family Health—EHDI Program without prior written approval from IDPH, Bureau of Family Health—EHDI Program.

**Aggregate Data Publication.**

Publications created by the CDC will follow the guidelines provided within the Data Sharing Agreement between the Centers for Disease Control and Prevention and Iowa State Early Hearing, Detection, Diagnosis, and Intervention Program executed on December 29, 2020 (CDC-RFA-DD20-2006). IDPH, Bureau of Family Health—EHDI Program will share CDC notifications of publications with the DE upon receipt from CDC.

### Agreement Administration.

- **Amendments.** This agreement may be amended in writing from time to time by mutual consent of the parties. All amendments to this agreement must be in writing and fully executed by the parties.
- **Third-Party Beneficiaries.** There are no third-party beneficiaries to this agreement. This agreement is intended only to benefit the state, IDPH Bureau of Family Health—EHDl Program and DE, Early ACCESS.
- **Integration.** This agreement represents the entire agreement between the parties. The parties shall not rely on any representation that may have been made which is not included in this agreement.
- **Headings or Captions.** The paragraph headings or captions used in this agreement are for identification purposes only and do not limit or construe the contents of the paragraphs.
- **Supersedes Former Contracts or Agreements.** This agreement supersedes all prior contracts or written agreements between the DE, Early ACCESS program and Bureau of Family Health—EHDl Program governing the use and transfer of the records and data which are the subject of this agreement.
- **Dispute Resolution.** Disputes between the Parties under this agreement will be brought to the attention of the DE, as Early ACCESS lead agency. An unaffiliated individual or individuals, chosen by the Parties and based on the nature of the dispute, shall attempt to help the Parties resolve the dispute, and both Parties commit to pursue good faith efforts to resolve disputes voluntarily. In resolving a dispute, the Parties may request technical assistance from a variety of sources, including the Office of Special Education Programs, Consortium for Appropriate Dispute Resolution in Special Education (CADRE), the CDC, the Centers for Medicare and Medicaid Services, the Federal Interagency Coordinating Council, and/or the Early Childhood Technical Assistance Center. If the dispute involves legal issues, the parties to the dispute may request available assistance from the Office of the Attorney General. If all other attempts at dispute resolution fail, the dispute shall be submitted to a board of arbitration pursuant to Iowa Code section 679A.19 (2013). The decision of the board of arbitration shall be final.

### Notice.

Any and all legal notices, designations, consents, offers, acceptances or any other communication provided for herein shall be given in writing by registered or certified mail, return receipt requested, by receipted hand delivery, by overnight delivery, courier or other similar and reliable carrier which shall be addressed to each party as set forth as follows:

If to Iowa Department of Public Health:  
Iowa Department of Public Health  
Sarah Reisetter, J.D.  
Lucas State Office Building, 6<sup>th</sup> Floor  
321 E. 12th Street  
Des Moines, IA 50319  
Email: [sarah.reisetter@idph.iowa.gov](mailto:sarah.reisetter@idph.iowa.gov)



If to the Iowa Department of Education:

Iowa Department of Education  
Ann Lebo, PhD, Agency Director  
Grimes State Office Building  
400 E. 14th Street  
Des Moines, IA 50319  
Email: ann.lebo@iowa.gov

Each such notice shall be deemed to have been provided:

- At the time it is actually received; or,
- Within one day in the case of overnight hand delivery, courier or services such as Federal Express with guaranteed next day delivery; or,
- Within five (5) days after it is deposited to the U.S. Postal Service in the case of registered U.S. Postal Mail Service.

From time to time, the parties may change the name and address of a party designated to receive notice. Such change of the designated person shall be in writing to the other party and as provided herein.

**Severability.**

If any provision of this agreement is determined by a court of competent jurisdiction to be invalid or unenforceable, such determination shall not affect the validity or enforceability of any other part or provision of this agreement.

**Authorization.**

Each party to this agreement represents and warrants to the other parties that:

- It has the right, power and authority to enter into and perform its obligations under this Agreement.
- It has taken all requisite action (corporate, statutory or otherwise) to approve execution, delivery and performance of this Agreement, and this Agreement constitutes a legal, valid and binding obligation upon itself in accordance with its terms.

**Successors in Interest.**

All the terms, provisions, and conditions of the agreement shall be binding upon and inure to the benefit of the parties hereto and their respective successors, assigns and legal representatives.

**Termination.**

Either party may terminate this agreement upon thirty days written notice to the other party. The unauthorized disclosure of confidential information shall be grounds for immediate termination of this agreement.

**Term.**

IDPH Agreement Number: 588DSA2021-40

This data sharing agreement shall be from January 1, 2021, through June 30, 2024, unless terminated early in accordance with the terms written within this agreement.

**Execution**

**IN WITNESS WHEREOF**, in consideration of the mutual covenants set forth above and for other goods and valuable consideration, the receipt, adequacy and legal sufficiency of which are hereby acknowledged, the parties have entered into the above agreement and have caused their duly authorized representatives to execute this agreement.



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Dr. Ann Lebo, PhD, Director  
Iowa Department of Education

October 19, 2022

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Date

Sarah G.  
Reisetter



Digitally signed by Sarah  
G. Reisetter  
Date: 2022.10.06  
10:24:32 -05'00'

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Sarah Reisetter, J.D., Deputy Director  
Iowa Department of Public Health

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Date

IDPH Agreement Number: 588DSA2021-40

**Appendix A**

Data Sharing Agreement between the Centers for Disease Control and Prevention and Iowa Early Hearing, Detection, Diagnosis, and Intervention Program executed on December 29, 2020.

**Agreement between  
the Centers for Disease Control and Prevention and  
Iowa State Early Hearing, Detection, Diagnosis, and Intervention Program**

This Agreement (the “Agreement”) is entered into and made effective the 21st day of December, 2020 (the “Effective Date”), by and between the Iowa State EHDI Program (“State EHDI”) and the Centers for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) Program (“CDC EHDI”) (each a “Party” and collectively the “Parties”).

Whereas, the CDC EHDI works to ensure jurisdictions can identify all infants with hearing loss early and receive recommended follow-up services, supports states in the maintenance and enhancement of tracking and surveillance systems, and collects and maintains a database with aggregate-level hearing screening and follow-up data, CDC also recognizes the limits of this aggregate-level data. To that end, CDC seeks to further strengthen and expand the capacity of jurisdictional EHDI programs and their existing EHDI Information Systems (“EHDI-IS”) to capture, report, analyze, and use individual level EHDI data.

Whereas, in furtherance of that mission and consistent with its authority, CDC awarded additional funding to State EHDI for a set of expanded activities under Cooperative Agreement CDC-RFA-DD20-2006, *“Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems”* (“Cooperative Agreement”), wherein State EHDI, consistent with the terms of the Cooperative Agreement, will construct, validate, and submit certain defined data sets of information from its EHDI-IS to CDC EHDI. See Exhibit A, attached hereto.

Whereas, to the extent State EHDI may be considered a “covered entity” as that term is defined by the Health Insurance Portability and Accountability Act of 1996 and the regulations promulgated thereunder (“HIPAA”), CDC is conducting these surveillance and prevention activities in its capacity as a public health authority as defined by the HIPAA Standards for Privacy of Individually Identifiable Health Information, found at 45 CFR §164.501.

Whereas, birth certificate records and data are confidential under Iowa law (Iowa Code Section 144.43) and may be released to government agencies as necessary to administer official duties of the agency (641 IAC 95.12(1) and 641 IAC 175.10(2)(e)). Confidential information transferred to another government entity shall maintain its confidential status and shall not be rereleased by the receiving entity (641 IAC 175.10(2)(e)), except as provided in the Cooperative Agreement or as may be required by applicable federal law.

Whereas, Iowa Early Hearing Detection and Intervention (EHDI) reports, records, and other information collected by or provided to the Iowa Department of Public Health relating to a child’s newborn hearing screening, rescreen, diagnostic audiologic assessment, and early intervention enrollment are confidential records pursuant to Iowa Code Section 22.7 and may be released to CDC EHDI in accordance with the terms of the Cooperative Agreement CDC-RFA-DD20-2006 (641 IAC 3.12(3)(d)).

NOW, THEREFORE, the parties agree as follows:

1. Consistent with the terms of the underlying Cooperative Agreement, State EHDI will provide CDC EHDI with the data elements set forth in Exhibit A, attached hereto. These data sets will purposefully exclude certain direct identifiers to protect the identity of individual children and families, such as names, addresses, and social security numbers.

2. CDC EHDI intends to use data for analysis purposes consistent with the underlying Cooperative Agreement, the legal authorities cited therein, and other activities, including but not limited to:
  - a. To identify methods to assess and improve data quality and usability, progress towards benchmarks, receipt of services, and factors related to the data reporting process; and
  - b. To perform descriptive, geo-spatial, and statistical analyses on defined EHDI data sets. Findings will be reviewed once available with State EHDI.
3. With respect to the data provided to CDC, CDC EHDI will protect the privacy and confidentiality of any individually identifiable information contained in the data consistent with the Privacy Act of 1974, to the extent applicable, HIPAA, and other applicable laws, regulations, and policies.
  - a. CDC EHDI will not re-release or use individual level data for activities out of the scope of this Cooperative Agreement, unless otherwise required by law.
  - b. Except as may be required by law, third parties outside of CDC EHDI will not be given access to the individual level information contained in the data provided to CDC.
  - c. Where and whenever possible CDC EHDI will make IDPH EHDI aware in advance of products (e.g., publications) that include Iowa data derived from the data provided as part of this Cooperative Agreement in order to help ensure that no confidential or individually identifiable information is disclosed.
4. CDC EHDI may provide data access to appropriate employees, contractors, and other authorized users, consistent with federal law and CDC policies and procedures concerning such data access to ensure the privacy and confidentiality of such data. Except as may be required in a public health emergency to protect life and health of individuals and populations, CDC EHDI will not attempt to identify records contained in the data provided under this Agreement, link this data with other data sources for identification purposes, or establish contact with an identified individual .
5. Transmission of the data from the State EHDI to CDC shall be done in accordance with acceptable practices for ensuring the protection, confidentiality, and integrity of the contents. CDC EHDI may coordinate with State EHDI to implement methods to achieve these outcomes consistent with procedures already in place for similar data exchanges between CDC and States. CDC EHDI shall maintain the data in confidence, using that same degree of care that CDC uses with its own confidential information.
6. Data that has been provided to CDC EHDI under this Agreement will be archived, stored, protected, or disposed of in accordance with relevant federal records requirements.
7. Nothing contained in this Agreement shall be read to conflict with the terms and conditions of the underlying Cooperative Agreement.
8. The State EHDI program retains ownership rights to the specified data provided as set forth in Exhibit A, and CDC EHDI has the right to use the data furnished in accordance with the terms of and purposes set forth in the underlying Cooperative Agreement and this Agreement.

Iowa Department of Public Health,  
Division of Health Promotion and  
Chronic Disease Prevention:

**Nalo Johnson, PhD** Digitally signed by Nalo Johnson,  
PhD  
Date: 2020.12.22 12:30:02 -06'00'

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Date of Signature:

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Signature of CDC EHDI Official:

**Stuart** Digitally signed by  
Stuart Shapira -S  
**Shapira -S** Date: 2020.12.29  
11:19:49 -05'00'

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Date of Signature:

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Exhibit A

<b>ESSET Category</b>	<b>Tier</b>	<b>Variable Name</b>	<b>Long Name</b>	<b>Description</b>
General > Infant	1	IID	Unique ID	A unique 15-digit number identifying each infant in the data file. The first two digits are the FIPS code of the state submitting the data , followed by a 13 digit number issued by each state.
General > Infant	1	IDOB	Date of birth	Date of infant's birth.
General > Infant	1	ISEX	Gender	Gender of infant.
General > Infant	1	IBPLACE_ST	Birth state	Identifies, using a FIPS code, state where infant was born.
General > Infant	2	IBPLACE_ZIP	Zipcode	5-digit US zipcode indicating location of infant's birth (home or hospital).
General > Infant	2	IBPLACE_FCD	Facility type	Classification of facility type where infant was born.
General > Infant	2	ITRAN	Transferred	An indication of whether infant was transferred to another facility.

General > Infant	2	ITRAN_24	Transferred - 24 hours	An indication of whether infant was transferred to another facility within 24 hours of delivery.
General > Infant	2	INICU	NICU baby	An indication of whether the infant was in the NICU (any unit other than well baby unit).
General > Infant	2	IB_WT	Birth weight	Infant's weight at birth, in grams.
General > Infant	2	ICHIP	CHIP enrollment	An indication of whether the infant is enrolled in the CHIP (Children's Health Insurance Program).
General > Mother	2	MRSDC_ST	Mother's state	Identifies, using a FIPS code, state in which infant's mother resides.
General > Mother	2	MRSDC_ZIP	Mother's zip code	5-digit US zipcode indicating location of mother's residence.
General > Mother	1	MDOB	Mother's birthdate	Date of mother's birth.
General > Mother	2	MMAR	Marital status	An indication of whether the mother was married.
General > Mother	2	MWIC	WIC food receipt	An indication of whether mother received WIC food packages.



General > Mother	2	MPAY_CD	Payment type	Payment classification of mother's primary method of payment for services.
General > Mother	1	MEDUC	Mother's education	Classification of mother's highest level of education.
General > Mother	1	METHNIC	Mother's ethnicity	An indication of whether the mother is Spanish/Hispanic/Latino, and specified group.
General > Mother	1	MRACE1	Mother's race - White	An indication of whether the mother is White.
General > Mother	1	MRACE2	Mother's race - Black or African American	An indication of whether the mother is Black or
General > Mother	1	MRACE3	Mother's race - American Indian or Alaskan Native	An indication of whether the mother is American Indian or Alaskan Native.
General > Mother	1	MRACE4	Mother's race - Asian Indian	An indication of whether the mother is Asian
General > Mother	1	MRACE5	Mother's race - Chinese	An indication of whether the mother is Chinese
General > Mother	1	MRACE6	Mother's race - Filipino	An indication of whether the mother is Filipino.
General > Mother	1	MRACE7	Mother's race - Japanese	An indication of whether the mother is Japanese.
General > Mother	1	MRACE8	Mother's race - Korean	An indication of whether the mother is Korean.
General > Mother	1	MRACE9	Mother's race - Vietnamese	An indication of whether the mother is
General > Mother	1	MRACE10	Mother's race - Other Asian	An indication of whether the mother is Other Asian (not Asian Indian, Chinese, Filipino,

General > Mother	1	MRACE11	Mother's race - Native Hawaiian	An indication of whether the mother is Native
General > Mother	1	MRACE12	Mother's race - Guamanian or Chamorro	An indication of whether the mother is Guamanian
General > Mother	1	MRACE13	Mother's race - Samoan	An indication of whether the mother is Samoan.
General > Mother	1	MRACE14	Mother's race - Other Pacific Islander	An indication of whether the mother is Other Pacific Islander (not Nation Hawaiian,
General > Mother	1	MRACE15	Mother's race - Other	An indication of whether the mother is Other race.
General > Mother	1	MRACE16	Mother's race - Multiracial, not specified	An indication of whether the mother is Multiracial but not specified racial group.
General > Mother	1	MRACE17	Mother's race - Unknown	An indication of whether the mother's race is unknown.
General > Father	2	FEDUC	Father's education	Classification of father's highest level of education.
General > Father	2	FETHNIC	Father's ethnicity	An indication of whether the father is Spanish/Hispanic/Latino, and specified group.
General > Father	2	FRACE1	Father's race - White	An indication of whether the father is White.
General > Father	2	FRACE2	Father's race - Black or African American	An indication of whether the father is Black or African American.
General > Father	2	FRACE3	Father's race - American Indian or Alaskan Native	An indication of whether the father is American Indian or Alaskan Native.

General > Father	2	FRACE4	Father's race - Asian Indian	An indication of whether the father is Asian Indian.
General > Father	2	FRACE5	Father's race - Chinese	An indication of whether the father is Chinese
General > Father	2	FRACE6	Father's race - Filipino	An indication of whether the father is Filipino.
General > Father	2	FRACE7	Father's race - Japanese	An indication of whether the father is Japanese.
General > Father	2	FRACE8	Father's race - Korean	An indication of whether the father is Korean.
General > Father	2	FRACE9	Father's race - Vietnamese	An indication of whether the father is Vietnamese.
General > Father	2	FRACE10	Father's race - Other Asian	An indication of whether the father is Other Asian (not Asian Indian, Chinese, Filipino,
General > Father	2	FRACE11	Father's race - Native Hawaiian	An indication of whether the father is Native Hawaiian.
General > Father	2	FRACE12	Father's race - Guamanian or Chamorro	An indication of whether the father is Guamanian or Chamorro.
General > Father	2	FRACE13	Father's race - Samoan	An indication of whether the father is Samoan.
General > Father	2	FRACE14	Father's race - Other Pacific Islander	An indication of whether the father is Other Pacific Islander (not Nation Hawaiian, Guamanian or
General > Father	2	FRACE15	Father's race - Other	An indication of whether the father is Other race.
General > Father	2	FRACE16	Father's race - Multiracial, not specified	An indication of whether the father is Multiracial but not specified racial
General > Father	2	FRACE17	Father's race - Unknown	An indication of whether the father's race is unknown.

Risk Factors	2	RFCC	Caregiver concern	An indication of whether
Risk Factors	2	RFFHPCHL	family history of permanent childhood hearing loss	An indication of whether there is a family history of permanent childhood hearing loss.
Risk Factors	2	RFRIC	Neonatal intensive care for more than 5 days	An indication of whether the infant was in the NICU for more than five days.
Risk Factors	2	RFECMO	ECMO or Assisted ventilation	
Risk Factors	2	RFEOM	Exposure to ototoxic medications (e.g., Chemotherapy*, gentamicin and tobramycin, furosemide/Lasix)	
Risk Factors	2	RFHPBLBNM	Hyperbilirubinemia that requires exchange transfusion	
Risk Factors	2	RFUINF	In utero infections (e.g., CMV, Herpes, Rubella, Syphilis, Toxoplasmosis)	

Risk Factors	2	RFANM	Craniofacial anomalies or syndrome	
Risk Factors	2	RFPNINF_CP	Culture-positive postnatal infections > Confirmed bacterial and viral (especially herpes viruses and varicella) meningitis	
Risk Factors	2	RFPNINF_OTH	Culture-positive postnatal infections > Other(s)	
Risk Factors	2	RFHDTRM	Head trauma	
Hearing Screening	1	HSDATE	Final inpatient screening date	For hospital births: date of final inpatient screening conducted prior to discharge. For non- hospital births: date of first outpatient screening conducted after birth.
Hearing Screening	1	HSRSLT_RIGHT	Final inpatient screening result-right	Identifies the result of the final inpatient screening, for the infant's right ear.
Hearing Screening	1	HSRSLT_LEFT	Final inpatient screening result-left	Identifies the result of the final inpatient screening, for the infant's left ear.

Hearing Screening	2	HS_MTHD	Final inpatient screening method	Classification of the method used to conduct the infant's final inpatient screening.
Hearing Screening	1	HSN_REASON	Reason for no final inpatient screening	Classification for the reason why infant did not receive a final inpatient screening.
Hearing Screening	1	HSMRNT_DAT	Final outpatient screening date	Date of infant's final/most recent outpatient follow-up screening as a result of referred on initial screening.
Hearing Screening	1	HSMRNT_RSL	Final outpatient screening result-right	Identifies the result of the final/most recent outpatient screening, for the infant's right ear.
Hearing Screening	1	HSMRNT_RSL	Final outpatient screening result-left	Identifies the result of the final/most recent outpatient screening, for the infant's left ear.

Hearing Screening	2	HSMRNT_MTH	Final outpatient screening method	Classification of the method used to conduct the infant's final/most recent outpatient screening.
Hearing Screening	2	HSMRNT_LOC	Final outpatient screening location	Classification of the location where the infant's final/most recent outpatient screening was conducted.
Hearing Screening	2	HSMRNT_ZIP	Final outpatient screening location zipcode	5-digit US zipcode indicating location of infant's final/most recent outpatient screening.
Hearing Screening	2	HSMRNT_PRV	Final outpatient screening location screener type	Classification of the person who conducted the infant's final/most recent outpatient screening.
Hearing Screening	1	HSMRNT_REA	Final/most recent outpatient/follow-up > Reason not received (only one reason can be selected)	Classification for the reason why infant did not receive a final/most recent outpatient screening.

Diagnostic Testing	1	HDFRCVD	Receipt of diagnostic testing	An indication of whether the infant received diagnostic testing.
Diagnostic Testing	1	HDFST_TEST	First diagnostic test visit date	Date of first visit to an audiologic facility for diagnostic testing.
Diagnostic Testing	2	HDFST_TEST	First visit - test type : ABR with tone burst	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : ABR with click	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : other diagnostic ABR	
Diagnostic Testing	2	HDFST_TEST	First visit - test type - bone conduction	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : ASSR	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : OAE	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : Tympanometry 1000 HZ	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : Tympanometry Other	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : Reflexes	
Diagnostic Testing	2	HDFST_TEST	First visit - test type: audiometry	
Diagnostic Testing	2	HDFST_TEST	First visit - test type : Sound field	



Diagnostic Testing	2	HDFST_TEST_	First viisit - test type: Earphone	
Diagnostic Testing	2	HDFST_TEST_	First visit - test type : behavioral test	
Diagnostic Testing	2	HDFST_TEST_	First visit - test type : other test	
Diagnostic Testing	2	HDFST_TEST_	First visit - test type : test method unknown	
Diagnostic Testing	2	HDFST_TEST_	First visit - was the infant sedated during test	
Diagnostic Testing	2	HDFST_TEST_	First diagnostic test visit zipcode	5-digit US zipcode indicating location of infant's first diagnostic test
Diagnostic Testing	1	HDFST_TEST_	First diagnostic test visit result	Identifies the result of the first diagnostic test.
Diagnostic Testing	1	HDFST_DX_DA	First completed diagnosis date	Date of first completed diagnosis.
Diagnostic Testing	2	HDFST_DX_AB	First completed diagnosis - test type : ABR with tone burst	
Diagnostic Testing	2	HDFST_DX_AB	First completed diagnosis - test type : ABR with click	
Diagnostic Testing	2	HDFST_DX_AB	First completed diagnosis - test type : other diagnostic ABR	
Diagnostic Testing	2	HDFST_DX_BC	First completed diagnosis - test type - bone	
Diagnostic Testing	2	HDFST_DX_AS	First completed diagnosis - test type : ASSR	
Diagnostic Testing	2	HDFST_DX_OA	First completed diagnosis - test type : OAE	
Diagnostic Testing	2	HDFST_DX_TY	First completed diagnosis - test type : Tympanometry 1000 HZ	
Diagnostic Testing	2	HDFST_DX_TY	First completed diagnosis - test type : Tympanometry Other	

Diagnostic Testing	2	HDFST_DX_REF	First completed diagnosis - test type : Reflexes	
Diagnostic Testing	2	HDFST_DX_AUD	First completed diagnosis - test type: audiometry	
Diagnostic Testing	2	HDFST_DX_SF	First completed diagnosis - test type : Sound field	
Diagnostic Testing	2	HDFST_DX_EA	First completed diagnosis - test type: Earphone	
Diagnostic Testing	2	HDFST_DX_BEH	First completed diagnosis - test type : behavioral test	
Diagnostic Testing	2	HDFST_DX_OT	First completed diagnosis - test type : other test	
Diagnostic Testing	2	HDFST_DX_UM	First completed diagnosis - test type : test method unknown	
Diagnostic Testing	2	HDFST_DX_SE	First completed diagnosis - was the infant sedated during test	
Diagnostic Testing	2	HDFST_DX_ZIP	First completed diagnosis zipcode	5-digit US zipcode indicating location of infant's first completed diagnosis.
Diagnostic Testing	1	HDFST_DX_RS	First completed diagnosis result	Identifies the result of the first completed diagnosis.
Diagnosis: Type/Severity	1	HLFST_LTR	First completed diagnostic test laterality	Identifies the laterality of first diagnosis.

Diagnosis: Type/Sever	1	HLFST_TP_RI GHT	First completed diagnosis right ear HL type	Identifies the result of the first completed diagnosis for the right ear.
Type/Severity	1	HLFST_DGR_ RIGHT	First completed diagnosis right ear severity	Identifies the severity of the first completed diagnostic test for the right ear using the American Speech- Language-Hearing Association (ASHA) classification system.
Type/Severity	1	HLFST_TP_L EFT	First completed diagnosis left ear HL type	Identifies the result of the first completed diagnosis for the left ear.

Type/Severity	1	HLFST_DGR_LEFT	First completed diagnosis ear severity	Identifies the severity of first completed diagnosis for the left ear using American Speech-Language-Hearing Association (ASHA) classification system.
Diagnosis Testing	2	HLFST_ONSET	First completed diagnosis: congenital or late-onset	indicate whether the hearing loss is congenital or late-onset/progressing
Diagnostic Testing	1	HDRCNT_DX_	Most recent completed diagnosis test date	Date of most recent diagnosis
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type : ABR with tone burst	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type : ABR with click	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : other diagnostic ABR	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type - bone conduction	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : ASSR	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : OAE	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : Tympanometry 1000 HZ	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : Tympanometry Other	

Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : Reflexes	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type: audiometry	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : Sound field	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type: Earphone	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type : behavioral test	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis - test type : other test	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- test type : test method unknown	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis- was the infant sedated during test	
Diagnostic Testing	2	HDRCNT_DX_	Most recent completed diagnosis test zipcode	5-digit US zipcode indicating location of infant's final/most recent
Diagnostic Testing	1	HDRCNT_DX_	Most recent completed diagnosis result	Identifies the result of the most recent diagnosis
Diagnosis: Type/Sever	1	HLRCNT_LTR	Most recent completed diagnostic test laterality	Identifies the laterality of the final/most recent diagnosis.

Diagnosis: Type/Sever	1	HLCNT_TP_RIGHT	Most recent diagnosis right ear HL type	Identifies the result of the final/most recent diagnosis for the right ear.
Type/Severity	1	HLCNT_DG_R_RIGHT	Most recent diagnosis right ear severity	Identifies the severity of the final/most recent diagnostic test for the right ear using the American Speech-Language-Hearing Association (ASHA) classification system.
Type/Severity	1	HLCNT_TP_LEFT	Most recent diagnosis left ear HL type	Identifies the result of the final/most recent diagnostic test for the left ear.

Type/Severity	1	HLRCNT_DG R_LEFT	Most recent diagnosis ear severity	Identifies the severity of the final/most recent diagnostic test for the left ear using American Speech-Language-Hearing Association (ASHA) classification system.
Diagnosis Testing	2	HLRCNT_ON SET	Most recent completed diagnosis: congenital or late-onset	indicate whether the hearing loss is congenital or late-onset/progressing
Diagnostic Testing	2	HD_DISP_EV AL	Disposition after the most recent diagnosis - further evaluation	Classification to determine infant's disposition after completion of final/most recent diagnostic test: whether additional evaluation is needed
Diagnostic Testing	2	HD_DISP_MN T	Disposition after the most recent diagnosis - audiologic monitoring for possible late onset hearing loss	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether continue audiologic monitoring for possible
Diagnostic Testing	2	HD_DISP_RE C_PC	Disposition after the most recent diagnosis - recommend referral to primary care provider	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether recommend referral to primary care provider
Diagnostic Testing	2	HD_DISP_RE C_ENT	Disposition after the most recent diagnosis - recommend referral to ENT	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether recommend referral to ENT

Diagnostic Testing	2	HD_DISP_RE C_GEN	Disposition after the most recent diagnosis - recommend referral to genetics evaluation	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether recommend referral to genetics evaluation
Diagnostic Testing	2	HD_DISP_RE C_PS	Disposition after the most recent diagnosis - recommend referral to parent support services	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether recommend referral to parent support services
Diagnostic Testing	2	HD_DISP_RE C_HA	Disposition after the most recent diagnosis - recommend referral to hearing aid services	Classification to determine infant's disposition after completion of final/most recent diagnosis: whether recommend referral to hearing aid services
Diagnostic Testing	1	HDEI_REF	Early intervention referral	An indication of whether the infant was referred to early intervention
Diagnostic Testing	1	HDEI_REFDA TE	Early intervention referral date	Date infant was referred to early intervention.
Early Intervention	1	EIENRL_DATE	Initial early intervention enrollment date	Date of infant's enrollment in early intervention services.



Early Intervention	1	EIPARTC_ENRDL	Enrolled in Part C services	An indication of whether the infant was enrolled in Part C services.
Early Intervention	1	EIIFSP_DATE	Date of IFSP	Date of signed IFSP.
Early Intervention	2	EINPARTC_ENRDL	Enrolled in non-Part C services	An indication of whether the infant was ever enrolled in Non-Part C services (e.g., private or other state intervention services).
Early Intervention	2	EICO_SELECT	Has one or more communication options been selected or not?	An indication of whether one or more communication options have been selected or not
Early Intervention	2	EICO_LSL	Communication options - Listening and Spoken language	
Early Intervention	2	EICO_CS	Communication options - Cued Speech/language	

Early Intervention	2	EICO_TC	Communication option - Total communication (English-based sign system and speech)	
Early Intervention	2	EICO_AS	Communication option - American Sign Language	
Medical Intervention	2	MIHA	Hearing aid	An indication of whether the patient uses hearing aid
Medical Intervention	2	MIHA_FTDATE	Hearing aid > Date fitted	Date of fitting hearing aid
Medical Intervention	2	MIHA_MB	Hearing aid > Monaural / binaural	
Medical Intervention	2	MIPLT	Implant	And indication of whether the patient received coclear implant
Medical Intervention	2	MIPLT_SGRD	Implant > Date of surgery	
Medical Intervention	2	MIPLT_LTR	Implant > Laterality	
Medical Intervention	2	MIPLT_ACTDA	Implant > Date of	
Early Intervention	2	EIPARTC_FST	Date of exiting Part C service - first exit	first time the kid exit pa
Early Intervention	2	EIPARTC_FST	Reason of exiting Part C service - first time	
Early Intervention	2	EIPARTC_FNL	Date of most recent/final exit from Part C	

	2	EIPARTC_FNL	Reason of final exiting Part C service	
Early Intervention	2	EIPARTC_DUR	total # of days the kid was enrolled in EI	