

## DATA SHARING AGREEMENT

This data sharing agreement (“Agreement”) by and between the Baby Watch Early Intervention Program on behalf of the Utah Department of Health (“Department”) and the Department’s Early Hearing Detection and Intervention (EHDI) Program (“Recipient”) establishes the terms and conditions under which Recipient may access, use, and disclose the data described herein.

The purpose of data sharing activities will be to comply with Utah Code 26-10-6 Testing of Newborn Infants and its accompanying Rule R398-2 Newborn Hearing Screening, whose purpose is to facilitate early detection, prompt referral, and early habilitation of infants with significant, permanent hearing loss. Specifically under R398-2-6. Reporting to Utah Department of Health, it is stated that (3) Persons who conduct any procedure necessary to complete an infant’s hearing screening or audiological diagnostic assessment as a result of a referral from an institution or primary care provider, shall report the results of these procedures to the institution where the infant was born and to the Department; and (4) The Utah Department of Health shall have access to infant’s medical records to obtain information necessary to ensure the provision of timely and appropriate follow-up diagnostic and intervention services. This is in alignment with Part C of the Individuals with Disabilities Education Act Federal Regulations §303.302 (4) (b), implementation of a Comprehensive Child Find System. The Part C lead agency (Department) must ensure that all infants and toddlers with disabilities in the State who are eligible for Part C early intervention services are identified, located, and evaluated.

Additionally, the Recipient is charged with reporting aggregate data to the Centers for Disease Control and Prevention comprehensive information for their annual Hearing Screening and Follow-up Survey (HSFS). It is federally mandated that as a part of the HSFS, Utah is required to report Early Intervention (EI) Data the # and % of infants:

- Referred to Part C EI
- Enrolled in Part C EI
- Who Received Part C EI Services
- Who Received Services from Non-Part C EI Only
- Who Received Monitoring Services Only
- With No Documented Intervention Services/Undetermined
- Referred to Part C EI Before Six Months of Age
- With a Signed IFSP Before 6 Months of Age; plus

Please see attachment for entire EI Recipient HSFS federal reporting requirements (pages 14-19). Efficacy of EHDI 1-3-6 milestone attainment in relation to communication assessment outcomes.

### 1. Definitions

“Data” means information about individuals, both identifiable and non-identifiable, within the Department’s possession, custody, or control, and any data that the Department has disclosed to Recipient.

“Identifiable data” means any item, collection, or grouping of data that, either from the data disclosed or in combination of other data, identifies the individual described in it or the individual or organization that supplied the data.

“Non-identifiable data” means any item, collection, or grouping of data that does not include sufficient information, either from the data disclosed or in combination with other data, to allow a person to identify the individual described in it or the individual or organization that supplied the data.

## **2. Data Transmission**

The Department agrees to disclose the following data to the Recipient.

Individual infant EI information, to include:

- EI Referral Date
- EI Enrollment Date (First Signed IFSP Date)
- EI Service Date (First Service Provision after IFSP)
- EI Eligibility / Monitoring Status
- EI Declination or not Enrolled status including Reason, if known
- Communication assessment outcomes in order to determine relationship to on-time/early EHDI milestone attainment.
- Other items as delineated on EI Recipient HSFS federal reporting requirements (pages 14-19)
- Infant demographic data to complete EHDI record or other necessary information as requested in order to ensure the provision of timely and appropriate follow-up diagnostic and intervention services.

All transmissions or exchange of data between parties shall be performed using a mutually agreed upon secure transfer method.

## **3. Disclosure of Department Data**

- A. Recipient shall only access, use, or store data solely for the above compliance with state mandate and/or federal reporting requirements, including the assurance of the provision of timely and appropriate follow-up services, this could include parent-to-parent support and/or care coordination.[Describe the public health activities, research, or health care operation activities that will be performed by Recipient with enough particularity to provide rationale for the types of information to be disclosed to Recipient.]
- B. Recipient shall not access, use, or disclose data to any person or entity, except: (1) employees or agents, including subcontractors, who actually and legitimately need to access or use the data in the performance of Recipient’s duties under this Agreement; or (2) any other third party with prior written approval by the Department. Recipient shall require any agent or subcontractor to whom Recipient provides data to agree to comply with the same restrictions and conditions on data as required by this Agreement.
- C. Recipient may not combine non-identifiable data with other data sources in order to attempt to identify the individuals whose information is contained in the non-identifiable data without prior written approval by the Department.

## **4. Safeguarding Data**

Recipient shall implement and maintain administrative, technical, and physical safeguards necessary to protect the confidentiality of the data and to prevent unauthorized use or access. Such safeguards include,



as appropriate and without limitation: (i) securing Recipient's facilities, data centers, paper files, servers, back-up systems and computing equipment, including all mobile devices and other equipment with information storage capability; (ii) implementing network, device application, database and platform security; (iii) securing information transmission, storage and disposal; (iv) implementing authentication and access controls within media, applications, operating systems and equipment; (v) encrypting identifiable data stored on any mobile media and devices and computers/servers that allow remote access; (vi) encrypting identifiable data transmitted over public or wireless networks; (vii) strictly segregating identifiable data from information of other unauthorized customers so that Department data is not commingled with any other types of information where required; (viii) implementing appropriate personnel security and integrity procedures and practices, including, conducting background checks consistent with applicable law; (ix) providing appropriate privacy and information security training to Recipient's employees; and (x) any other measures reasonably necessary to prevent unauthorized use or access. Infant demographic data will be only viewed by State EHDI staff, controlled by rule-based access. This data will not be released to any other individuals without written approval from BWEIP. EHDI staff are trained to identify and not re-release data in accordance with FERPA law.

#### **5. Breach of Privacy or Security Obligations**

Recipient shall report to the Department any privacy or security incident involving the use or disclosure of data not permitted by this Agreement of which it becomes aware. An "Incident" is any successful unauthorized access, use, disclosure, modification, or destruction of information or interference with system operations in a system that involves data which compromises the security or privacy of that data. Recipient shall report to the Department within three (3) days of the Recipient becoming aware of such incident. Recipient shall immediately take actions as may be necessary to mitigate or correct the incident. Upon the Department's request, Recipient shall provide the Department information about what Recipient has done or plans to do to mitigate any effects of the incident. Recipient agrees to consult and cooperate with the Department in a timely fashion regarding appropriate steps for remediation and any applicable reporting requirements.

#### **6. Data Ownership**

The Department retains all ownership rights to the data. Recipient does not obtain any right, title, or interest in any data furnished by the Department. For purposes of this Agreement, data does not cease to be the Department's data solely because it was transferred or transmitted beyond the Department's immediate possession, control, or custody.

#### **7. Disposition of Data**

Within thirty (30) days after the effective date of termination of this Agreement, Recipient shall immediately return or destroy all identifiable data, including all copies of and any data or compilations derived from and allowing identification of any individual who is a subject of the identifiable data, in any form or medium, and at any location such information resides.

If such return or destruction is not feasible, Recipient shall promptly notify the Department. Recipient agrees to extend the protections, limitation, and restrictions of this Agreement to any identifiable data retained after termination and shall limit further uses and disclosures to those purposes that make the return or destruction of the identifiable data infeasible. This provision shall survive termination of this Agreement.

**8. Risk Assessments and Audits**

Upon reasonable request by the Department, Recipient and its agents shall allow the Department to conduct an inspection of the facilities, systems, books, records, agreements, policies and procedures relating to the use or disclosure of identifiable health data in order to determine Recipient’s compliance with this Agreement. The Department may require Recipient to conduct a risk assessment that addresses administrative, technical, and physical risks, if reasonable and appropriate. If requested by the Department, Recipient shall provide a copy of the risk assessment finding and results.

**9. Term and Termination**

This Agreement shall be effective upon signing and remains in effect through March 2023. Either party may terminate this Agreement with or without cause upon thirty (30) days’ written notice to the other party. The Department may terminate this Agreement at any time if the Department has any reason to believe or know that Recipient has violated any of the conditions set forth herein.

**10. Indemnification**

- A. If Recipient is a governmental entity, the parties mutually agree that each party assumes liability for the negligent and wrongful acts committed by its own agents, officials, or employees, regardless of the source of funding for the agreement. Neither party waives any rights or defenses otherwise available under the Governmental Immunity Act.
- B. If Recipient is a non-governmental entity, Recipient shall be fully liable for the actions of its agents, employees, officers, partners, and subcontractors. Recipient shall fully indemnify, defend, and save harmless the Department and the State of Utah from all claims, losses, suits, actions, damages, and costs of every name and description arising out of Recipient’s performance of the agreement caused by any intentional act or negligence of Recipient, its agents, employees, officers, partners, or subcontractors, without limitation; provided, however, that Recipient shall not indemnify for that portion of any claim, loss, or damage arising hereunder due to the sole fault of the Department.

IN WITNESS WHEREOF, the parties have caused this Agreement to be signed and entered into by their authorized representative.

**Utah Department of Health, BWEIP**  
By: *Lisa A. Davenport*  
Date: *4-16-18*

Lisa A. Davenport, PhD  
BWEIP Program Manager

**Utah Department of Health, EHDI Program**  
By: *Stephanie B. McVicar, Au.D., CCC-A*  
Date: *4-25-18*

Stephanie B. McVicar, Au.D., CCC-A  
EHDI Program Manager

**Bureau for Children with Special Health Care Needs**  
By: *Noël Taxin*  
Date: *4/25/18*

Noël Taxin  
CSHCN Bureau Director