Memorandum of Agreement Between the Pennsylvania Department of Human Services And the Pennsylvania Department of Health

Whereas, this Memorandum of Agreement (the "Agreement") is made and entered into by the Pennsylvania Department of Human Services, Office of Child Development and Early Learning, Bureau of Early Intervention Services and Family Support (BEISFS) and the Pennsylvania Department of Health, Bureau of Family Health, Division of Newborn Screening and Genetics (DNSG) for the purpose of sharing individual-level data related to the identification of newborns, infants, and toddlers suspected of or diagnosed with a permanent hearing loss to confirm their receipt of Early Intervention (EI) services; and

Whereas, BEISFS oversees implementation of Part C of the Individuals with Disabilities Education Act (IDEA) and directs the Infant Toddler Early Intervention Program; and

Whereas, DNSG oversees the Newborn Hearing Screening Program (NBHS). Pursuant to the Infant Hearing Education, Assessment, Reporting and Referral Act (IHEARR Act) (11 P.S. §§ 876-1 – 876-9), the NBHS Program is responsible for screening all newborns born in Pennsylvania for hearing loss and for referring at the earliest opportunity newborns and infants identified as having a hearing loss for treatment and intervention services so that newborns, infants and their families can obtain services in a timely manner; and

Whereas, BEISFS has access to information about all newborns, infants and toddlers referred for EI services through its PELICAN-EI data system for documentation, reporting and record review purposes; and

Whereas, DNSG documents all newborns and infants diagnosed with permanent hearing loss in the newborn screening iCMS data system for follow-up, reporting, and record review purposes; and

Whereas, pursuant to the IHEARR Act (11 P.S. §§ 876-6), the Department of Health is required to "implement a reporting and early intervention referral system that links hearing screening, if necessary, with expert diagnostic services and available early intervention services."

Now, therefore, the parties agree as follows:

1. Within the first five business days of each month, DNSG will share with BEISFS data in the form of a Microsoft Excel file on newborns, infants, and toddlers that have been identified as having a confirmed hearing loss. The data will include the following information: the

newborn's, infant's, or toddler's first and last name, date of birth, and hospital of birth; the facility that screened the newborn, infant, or toddler; and the newborn's, infant's, or toddler's mother's first and last name, address, and phone number.

- 2. BEISFS will confirm that all newborns, infants, and toddlers identified in the file are receiving EI services. If the newborn, infant, or toddler is receiving EI services, BEISFS will add to the file the date the newborn, infant or toddler was referred for EI services, the date of the initial Individualized Family Service Plan (IFSP), and the county EI program that is responsible for serving the newborn, infant, or toddler. BEISFS will return the updated file to DNSG within 5 business days of receipt of the file.
- 3. If a parent or guardian has signed the Authorization to Release Information for Infants/Toddlers with Hearing Concerns, BEISFS will identify in the file returned to DNSG newborns, infants, and toddlers receiving EI services that have a diagnosis of a hearing loss that were not included in the file received from DNSG. BEISFS will include in the file the newborn's, infant's, or toddler's first and last name, date of birth, and hospital of birth; the newborn's, infant's, or toddler's mother's first and last name, address, and phone number; the date the newborn, infant, or toddler was referred for EI services; the date of the initial IFSP; and the county EI program that is responsible for serving the newborn, infant, or toddler.
- 4. BEISFS and DNSG will enter, store, and maintain any new data it receives within either the PELICAN data system or the newborn screening iCMS data system.
- 5. DNSG will use the data received from BEISFS to monitor the timeliness of the initiation of EI services for newborns, infants, and toddlers with hearing losses. DNSG will use the analysis of the data to improve identification of newborns, infants, and toddlers who are deaf and hard of hearing and referral to BEISFS for EI services.

Confidential Data Handling Procedure

- 1. DNSG and BEISFS agree that they will require their employees, contractors and agents to comply with all applicable federal and state laws concerning the confidentiality of data that is being shared pursuant to this Agreement, including the Family Educational Rights and Privacy Act (FERPA) (20 U.S.C.A. § 1232g) and the privacy standards contained in the Health Insurance Portability and Accountability Act (HIPAA) rules (45 C.F.R. Parts 160 and 164).
- 2. DNSG and BEISFS agree that only staff that have signed a HIPAA confidentiality statement will have access to data shared under this Agreement.
- 3. BEISFS and DNSG agree to use appropriate safeguards to prevent the use or disclosure of data shared under this Agreement by their employees, contractors and agents, including but

not limited to implementation of administrative, physical and technical safeguards to reasonably and appropriately protect the privacy and integrity of data that is created, received, maintained or transmitted under this Agreement.

- 4. BEISFS and DNSG agree to use the following safeguards to protect the confidentiality of data received pursuant to this Agreement:
 - a. Physical security measures, including the use of locks, badges, passwords, and similar measures to control access to paper files, computers, and related equipment.
 - b. Technical security measures including the implementation and review of access controls including the appropriate use of unique user IDs, strong passwords, antivirus software, and the appropriate use of encryption to protect portable media and/or data in transit.
 - c. Administrative security measures including training for data users on best security practices and signing of data usage policies that require users of data to agree with and abide by all policies concerning the safeguarding of data.
- 5. BEISFS and DNSG further certify that all personnel having access to data under this Agreement have been instructed regarding the governing privacy and data practices; are trained to protect the privacy and integrity of the data shared in this Agreement; and are subject to adequate supervision to ensure compliance with applicable federal and state data confidentiality laws.

Terms of Agreement

The effective date of this Agreement shall be upon execution. This Agreement can be modified at any time by the written agreement of both parties and may be canceled by either party after giving a 30-day notice in writing to the other party.

Pennsylvania Department Human Services	
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Deborah Noel	Date
Division Chief	
Bureau of Early Intervention Services and Family Support	
Pennsylvania Department of Health Kelly L. Holland	
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Kelly L. Holland	Date
Director	
Division of Newborn Screening and Genetics	