

Data Sharing Partnerships Improve Systems

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Partnerships between the **Early Hearing Detection and Intervention (EHDI)** program and Part C of the **Individuals with Disabilities Education Act (IDEA)** program can support and improve outcomes for children who are deaf or hard of hearing (DHH) and their families. Collaboration between these programs is specified in the IDEA Part C Regulations [34 CFR §303.302\(c\)\(ii\)\(J\)](#) and strengthened in [P.L. 115-71, EHDI Act of 2017](#).



Federal Requirements

IDEA requires that the state child find system is coordinated with specific agencies including the EHDI programs. The primary referral sources must refer a child to the [Part C](#) program as soon as possible but not later than seven days after the child has been identified. [Screening, evaluation and assessment](#), and the initial [IFSP](#) meeting must be completed within 45 days.

EHDI programs were designed to assure that all deaf or hard of hearing children born in the United States and U.S. territories receive the services they need to prevent developmental delay as early in life as possible.

EHDI programs work to accomplish this objective by promoting hearing screening in the first month of life, diagnosis and hearing loss identification no later than three months of age, and entry into Early Intervention (EI) no later than six months of age.

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Data Sharing Agreements Between EHDI and Part C

Data sharing agreements should include a description of activities with sufficient specificity to make clear what will and what will not be shared between the two programs, and the safeguards needed to protect the privacy of the child and family. This must include a description of how any Personally Identifiable Information (PII) from Part C early intervention records will be used.



See also: [Procedural Safeguards: Confidentiality, Technology and Privacy](#)



When data sharing between systems is seamless, **families can focus on the supports they need** rather than the process.



For State and local entities, data sharing leads to data-informed decisions and **greatly reduces guesswork**.



Providing and sharing data **promotes informed decisions to evaluate and improve programs**, services, and meaningful Stakeholder Engagement.



Data that is shared publicly is aggregated, therefore, no personally identifiable information is released.

The Bridge Between EHDI and IDEA

The effectiveness of early identification of children who are deaf or hard of hearing (DHH) rests in what happens after the initial identification has been completed. The EHDI system focuses on early identification and then bridges to the early intervention system that is supported by law:



"Congress finds that there is an urgent and substantial need— to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life."

— *The Individuals with Disabilities Education Act (IDEA), 2004*

The link between these two systems is the shared recognition of the child as a unique individual whose strengths and needs must be clearly and accurately identified and whose family is empowered to express their questions, concerns, knowledge, hopes, and dreams that ultimately inform decisions made by the family.

The use of quality EHDI, early intervention and education data enables policymakers, administrators, educators, service providers and parents to design and implement effective practices to improve child and family outcomes.

See also: *Data Culture Toolkit*, <https://dasycenter.org/data-culture-toolkit>

EHDI programs were designed to assure that all DHH children born in the United States and its territories receive the services they need to prevent developmental delay as early in life as possible. IDEA Part C also assures that all eligible children receive services.

Data Sharing Resources: Centers and Documents



The Early Childhood Technical Assistance Center (ECTA) supports IDEA Part C (infants and toddler) and Section 619 (preschool) programs in developing high quality early intervention and preschool special education service systems, increasing local implementation of evidence-based practices, and enhancing outcomes for young children with disabilities and their families.

<https://ectacenter.org>



The Center for IDEA Early Childhood Data Systems (DaSy) works with states to support IDEA early intervention and early childhood special education state programs in building high quality data systems and using data to improve results for young children with disabilities and their families.

<https://dasycenter.org>



Hands & Voices is a parent-driven organization that supports families with children who are deaf or hard of hearing without bias. They also promote family engagement and leadership programs through The H&V Family Leadership in Language & Learning Center.

<https://handsandvoices.org>



The National Center for Hearing Assessment and Management (NCHAM) at Utah State University serves as the Early Hearing Detection and Intervention, National Technical Resource Center (EHDI NTRC) funded by Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) at the United States Department of Health and Human Services. The purpose of the EHDI NTRC is to provide support to EHDI programs in states and territories also funded by HRSA. The EHDI NTRC helps EHDI programs ensure that children who are deaf or hard of hearing are identified through newborn, infant, and early childhood hearing screening and receive the diagnostic and early intervention services they need.

<https://infanthearing.org>

Position Statements from the Joint Committee on Infant Hearing

Year 2019 Position Statement: Principles and Guidelines for Early Hearing and Detection and Intervention Programs *Journal of Early Hearing Detection and Intervention*, 4(2), 1-44. DOI: <https://doi.org/10.15142/fptk-b748>

EHDI Guidance Manual

Chapter 1 of this CDC guidance manual can help you to understand the purpose of having a complete EHDI Information System (EHDI-IS), define what a basic and complete EHDI-IS looks like with regard to its data and functional requirements, understand the importance of the link between planning and evaluation, think about the role of program stakeholders, and consider the critical elements important to your system's sustainability.

<https://www.cdc.gov/ncbddd/hearingloss/guidancemanual/chapter1.html>