

Part C and EHDI Data Partnerships: Sharing Resources and Experiences



Improving Data, Improving Outcomes
#IDIO2022: Leadership, Equity, Impact

August 23, 2022

Welcome

Who we are:

- Eric Cahill:** Disability and Health Promotion Branch
National Center on Birth Defects and Developmental
Disabilities
Centers for Disease Control and Prevention
- Evelyn Shaw:** Technical Assistance Specialist, ECTA
- Sharon Walsh:** Consultant, ECTA and DaSy
- Karl White:** Director, NCHAM

Session Objectives

- Increase their understanding of program, confidentiality and data collection requirements of both programs
- Obtain information about the EHDI Outcomes Committee
- Learn about new products and resources that benefit states and families of young children
- Provide opportunities to learn about specific state activities

An Overview of CDC Early Hearing Detection and Intervention (EHDI) Activities

2022 Improving Data, Improving Outcomes Conference

Eric Cahill, MS

Disability and Health Promotion Branch

Division of Human Development and Disability (DHDD)

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention



CDC DHDD: Three Priorities for Health Equity



Better Data



More Inclusive Policies

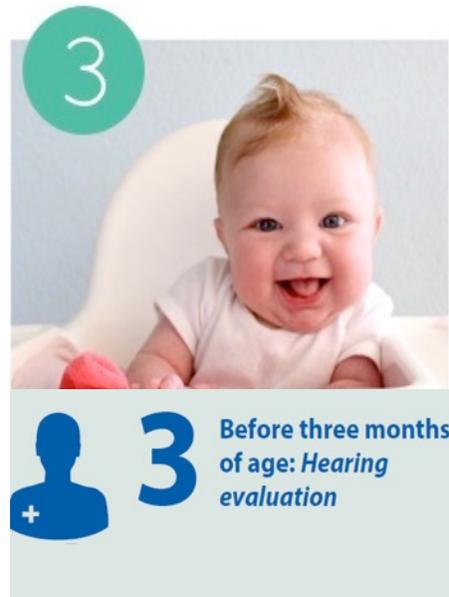


Accessible Communication

Early Hearing Detection and Intervention (EHDI)



- Nearly 1 in every 500 live born infants is born deaf or hard of hearing (DHH)
- Undetected hearing loss can cause delays in speech, language, social, and emotional development that can have a lasting impact
- EHDI 1-3-6 Benchmarks



1. Technical Assistance



Support jurisdictional EHDI programs through targeted technical assistance and evaluation

2. Data Use



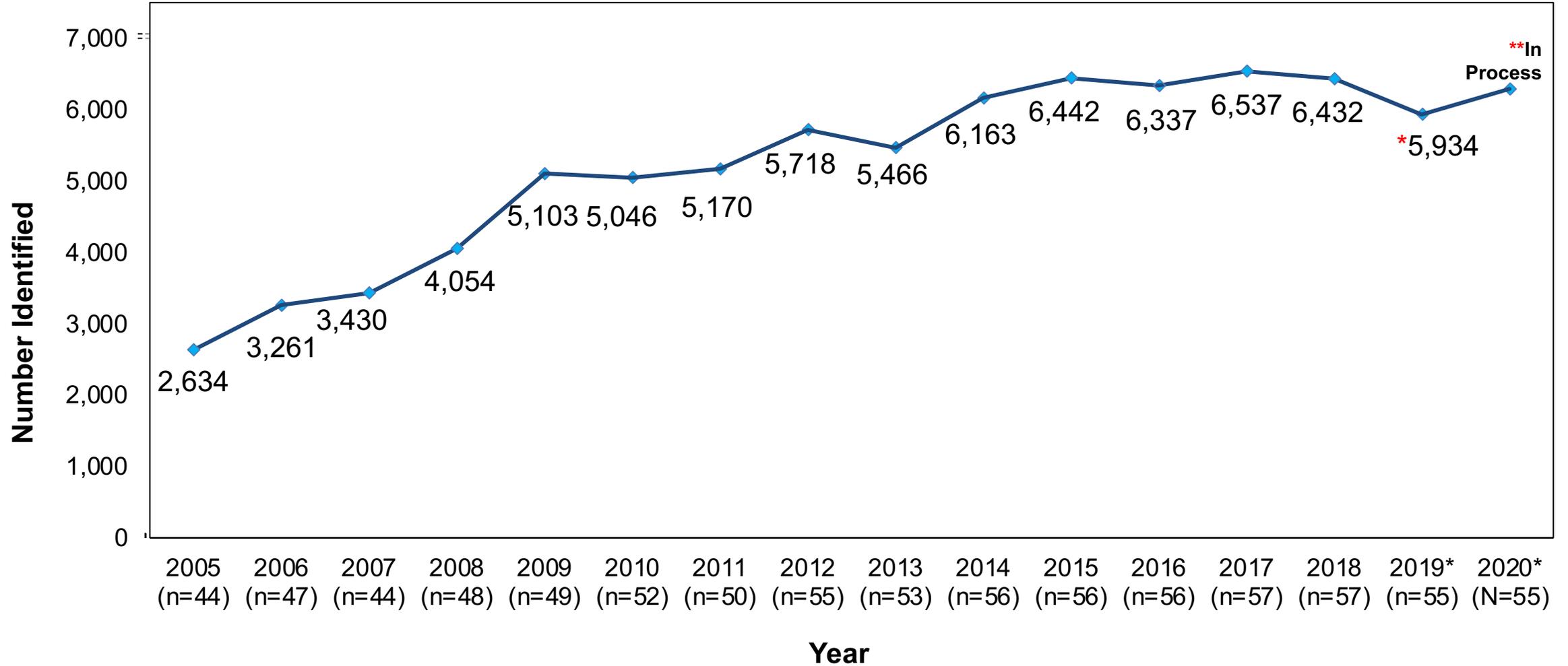
Optimize EHDI systems to support the timely exchange, analysis, and use of data to support early identification and intervention

3. Research



Inform decisions and support improved developmental outcomes among children who are deaf or hard of hearing

CDC EHDI: Progress in Early Identification of Hearing Loss



*Note, In many regions the COVID-19 pandemic interrupted the delivery of health care services in 2020, including newborn hearing screening and follow-up services. As a result, infants born in late 2019 and needing hearing screening and/or follow-up services in 2020 may have had difficulties obtaining these services.

**Note, Data for 2020 is currently being finalized and will soon be available at <https://www.cdc.gov/ncbddd/hearingloss/data.html>

CDC Cooperative Agreement 1: Optimization of Surveillance and EHDI Information Systems



- 39 award recipients (38 states and Puerto Rico)
 - Four-year project that builds on previous work supported by CDC to expand capacity of state/territorial EHDI programs to collect and report on patient-level data
- Purpose
 - Advance capacity of programs to ensure all infants receive essential EHDI services (e.g., diagnostic testing and enrollment in early intervention)
 - Expand ability to report, analyze, and use patient-level data
 - Data standardization and validation

Strategies to Identify Children with Developmental Delays in Tribal Communities



- A collaboration with the CDC Center for State, Tribal, Local, and Territorial Support
 - Two-Year Project (currently in Year 1)

- Objective:
 - Understand and improve upon existing continuum of identification and care of children with hearing loss and developmental delays and disabilities in tribal communities
 - Identify and Connect to Key Stakeholders
 - Environmental Scan
 - Identify Strengths And Opportunities
 - Proposal to engage Tribal Communities on early identification and link to EI

CDC Cooperative Agreement 2: Outcomes and Developmental Data Assistance Center for EHDI



ODDACE Project

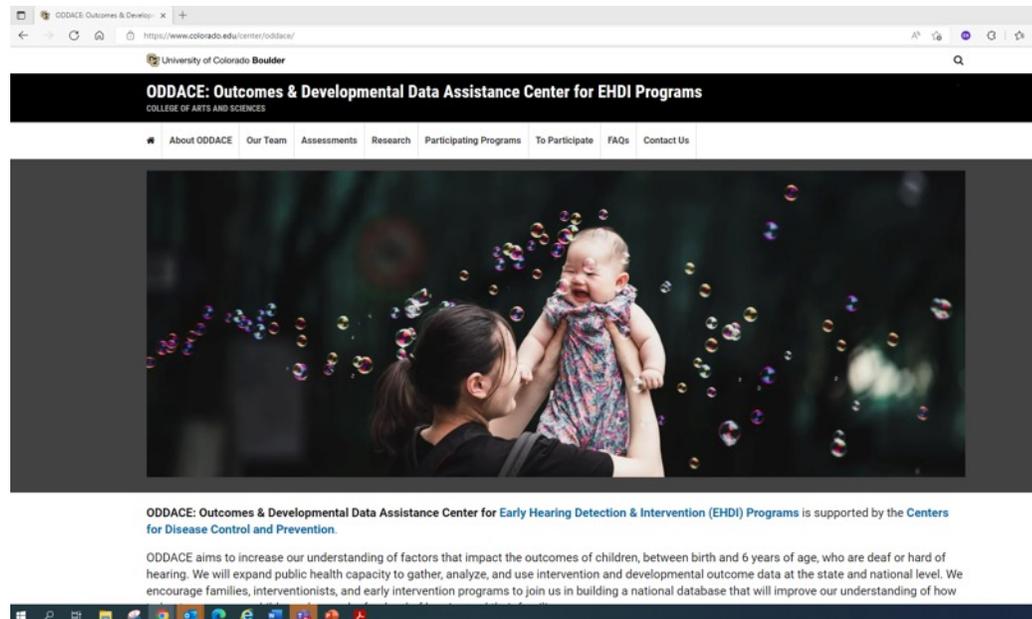
- Recent initiative by CDC/NCBDDDD
- Recipient: The Regents of the University of Colorado
- Collaborating and gathering data from multiple early intervention programs
- Need for ODDACE
 - Developmental outcomes of identified infants are often unknown, as these data are not routinely collected by CDC or state EHDI programs
- Long-term Goals
 - Standardized surveillance data related to the outcomes of children who are DHH
 - Increased understanding of factors impacting the outcomes of children who are DHH at the state and national level

ODDACE: Participation



How to participate

- If you are interested in participating and/or learning more, contact:
 - Allison.Sedey@colorado.edu
- Visit the ODDACE website at: www.colorado.edu/center/oddace



- Coordination
- Technical Assistance
 - States and Territories
- Collaboration
 - Articles
 - Provider Engagement and Education
- Idea and Information Sharing



DHDD: Working Towards Health Equity



Better Data



Inclusive Policies



Accessible Communication



Thank You



For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348



The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

EHDI Outcomes Committee Background

- Formed in April 2016 with first meeting in May 2016
- Meetings held on a monthly basis
- Partnership between CDC and ECTA at FPG Center at UNC Chapel Hill with the addition of the DaSy Center in 2018
- Membership in 2016 included a small group of EHDI state coordinators, a couple of Part C state coordinators, CDC staff, Hands & Voices, and ECTA staff
- Current active membership includes EHDI state coordinators (approx. 20), Part C coordinators (approx. 10), CDC and HRSA staff, NCHAM, Hands & Voices and the FL3 Center representatives, ODDACE, researchers, ECTA and DaSy staff

Original Goals of the Committee

- Make recommendations to CDC EHDI program about potential outcomes data EHDI programs could collect, including from Early Intervention/Part C programs
- Identify challenges with collecting EI/Part C data for EHDI reporting
- Review and make recommendations about modifications, additions and/or recommendations to the functional standards related to EI

EHDI Outcomes Committee Work 2021 - 2022

- Two workgroups formed
 - Group 1: Develop guidance from state EHDI and Part C to local agencies regarding the importance of data sharing, why it is needed and strategies for sharing data
 - Group 2: Develop a data sharing agreement checklist and a data sharing agreement template
- Other work
 - Collect data sharing agreements and with consent of states, provide a central location to post these agreements
 - Provide encore presentations

Accomplishments

1. Funding for IDEA state staff to attend the EHDI conference with the EHDI Coordinator as part of the state team*
2. Develop a data sharing agreement template for EHDI/Part C*
3. Develop guidance from state EHDI and Part C to local agencies on the importance of and strategies for sharing data*
4. With consent from each state, provide a central location to post state data agreements*
6. Provide encore presentations/ webinars from EHDI conferences or other relevant topics to state Part C and EHDI staff*
7. Provide TA on data sharing to states (EHDI, Part C and Part B)*

Committee Products

🏠 ▶ Resources ▶ Topics ▶ [Early Identification](#) ▶ Data Sharing Partnerships Improve Systems

Data Sharing Partnerships Improve Systems

📄 Download PDF

Produced in collaboration with:

Updated March 8, 2022, 12:23 PM

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.

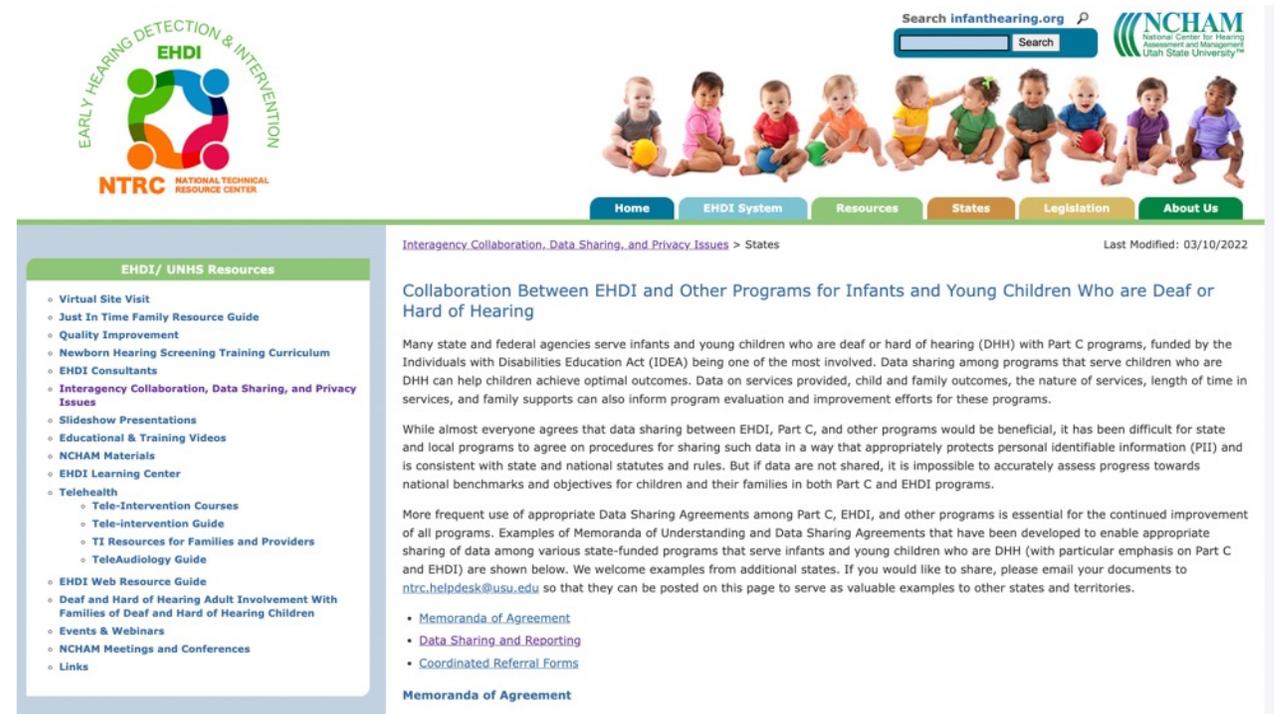
Access to information on webpage and downloadable flyer

<https://ectacenter.org/topics/earlyid/ehdidata.asp>

Committee Products: Data Sharing Agreements

- Memoranda of Understanding and Data Sharing Agreements (shared with permission)
- Developed to enable appropriate sharing of data among various state-funded programs that serve infants and young children who are DHH (with particular emphasis on Part C and EHDI)

<https://www.infanthearing.org/privacy/states.html#data>



The screenshot displays the website for the National Center for Hearing Assessment and Management (NCHAM) at Utah State University. The top navigation bar includes a search function, the NCHAM logo, and menu items for Home, EHD/ System, Resources, States, Legislation, and About Us. A row of diverse young children is featured below the navigation. The main content area is titled 'EHD/ UNHS Resources' and lists various materials such as 'Virtual Site Visit', 'Just In Time Family Resource Guide', 'Quality Improvement', 'Newborn Hearing Screening Training Curriculum', 'EHD/ Consultants', 'Interagency Collaboration, Data Sharing, and Privacy Issues', 'Slideshow Presentations', 'Educational & Training Videos', 'NCHAM Materials', 'EHD/ Learning Center', 'Telehealth' (with sub-items for Tele-Intervention Courses, Tele-Intervention Guide, TI Resources for Families and Providers, and TeleAudiology Guide), 'EHD/ Web Resource Guide', 'Deaf and Hard of Hearing Adult Involvement With Families of Deaf and Hard of Hearing Children', 'Events & Webinars', 'NCHAM Meetings and Conferences', and 'Links'. To the right, a page titled 'Interagency Collaboration, Data Sharing, and Privacy Issues > States' is shown, dated 03/10/2022. The page content discusses the importance of data sharing between EHD/ and other programs for infants and young children who are deaf or hard of hearing, mentioning the Individuals with Disabilities Education Act (IDEA) and the need for appropriate Data Sharing Agreements. It includes a list of links for 'Memoranda of Agreement', 'Data Sharing and Reporting', and 'Coordinated Referral Forms'.

Committee Products: Data Sharing Checklist





Draft Data Sharing Agreement Checklist Between Part C and EHDI

March 1, 2022



The first Early Hearing Detection and Intervention (EHDI) programs in the United States were established more than 30 years ago to identify babies who are deaf or hard of hearing (D/HH). There are increasing efforts across state EHDI and Early Intervention (EI) under Part C of the Individuals with Disabilities Education Act (Part C) systems to collaborate and share information to ensure that all newborns meet the Joint Committee on Infant Hearing (JCIH) recommendations of being screened before one month of age, being diagnosed before three months of age, and being enrolled in early intervention supports before six months of age (often referred to as 1-3-6 goals).

Both Part C and EHDI programs serve children from birth to three years of age. Data sharing between these programs can support efforts to achieve 1-3-6 goals. In addition, data on program characteristics, services provided, child and family outcomes, the nature of services, length of time in services, and family supports can inform EHDI and EI program evaluation and improvement efforts.

While data sharing can be beneficial for EHDI and Part C state programs and the children and families they serve, it has been difficult for state and local programs to agree on procedures for sharing such data in a way that appropriately protects personally identifiable information (PII) and is consistent with state and national statutes and rules. But if data are not shared, it is not possible to accurately assess progress towards national benchmarks and objectives for children and their families in both Part C and EHDI programs.

More frequent use of appropriate data sharing between Part C and EHDI programs is essential for the continued improvement of both programs. These data can be shared if a child's parent provides written consent according to federal IDEA and FERPA requirements. Additionally, data can be shared without parental consent if the data are deidentified so that identification of an individual child or family is not possible. Data can also be shared without parental consent between "participating agencies" within Part C system.

Without parental consent, Part C can share PII with EHDI if the agencies develop and implement a data sharing agreement that meets the FERPA exception for audit and evaluation as contained at 34 CFR 99.31(a)(3) and 34 CFR 99.35. According to these FERPA regulations, the purpose of such an agreement must be "to carry out an audit or evaluation of Federal- or State-supported education programs..." It is important to note that individual states may have additional requirements regarding data sharing that must be addressed as well.

This checklist has been developed by the EHDI Child Outcomes Committee as a resource for state Part C and EHDI staff to use as they develop Data Sharing Agreements, consistent with the federal Individuals with Disabilities Education Act (IDEA) and the Family Education Rights and Privacy Act (FERPA). Part C and EHDI program staff are encouraged to examine the required and recommended practices in the checklist below and tailor these as necessary and appropriate to their specific circumstances, including any additional state requirements, with the guidance of their legal counsels.

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Table 1 Checklist of Essential Components and Suggested Additions

Essential Components	Suggested Additions
<p>1. Authority Requirements: Specify the individual or entity authorized to review or access data and change, or terminate the agreement.</p> <p>2. Purpose: Specify that the purpose for which the PI from EI records is being disclosed to the relevant jurisdiction is to carry out an audit or evaluation of Federal- or state-supported education programs.</p> <p>3. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p> <p>4. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p>	<p>1. Privacy Impact and Risk Assessment: Conduct a privacy impact and risk assessment of the PI from Part C, EHDI and Part C program administration data.</p> <ul style="list-style-type: none"> • FERPA, HIPAA, and PII Privacy <p>2. Data Security: Specify that the Data Sharing Agreement is consistent with the security requirements that apply to the program.</p> <p>3. Add any other applicable requirements to the program as outlined by state and local laws and regulations (e.g., FERPA, HIPAA, and PII Privacy).</p> <p>4. Add any other applicable requirements to the program as outlined by state and local laws and regulations (e.g., FERPA, HIPAA, and PII Privacy).</p>
<p>5. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p> <p>6. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p>	<p>5. Data Security: Specify that the Data Sharing Agreement is consistent with the security requirements that apply to the program.</p> <p>6. Add any other applicable requirements to the program as outlined by state and local laws and regulations (e.g., FERPA, HIPAA, and PII Privacy).</p>
<p>7. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p> <p>8. Authority: Specify that authority is granted to the agreement by the state and local laws and will be used to evaluate and improve programs.</p>	<p>7. Data Security: Specify that the Data Sharing Agreement is consistent with the security requirements that apply to the program.</p> <p>8. Add any other applicable requirements to the program as outlined by state and local laws and regulations (e.g., FERPA, HIPAA, and PII Privacy).</p>

Table 1 Checklist of Essential Components and Suggested Additions

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Resource

Resource Methods and Other Agreements Issued by the Family Policy Compliance Office at the US Department of Education at <https://doe.gov/office-of-policy-compliance/resource-methods-and-other-agreements>

Data Sharing Agreement Checklist for IDEA Part C and Part B-19 Agencies and Programs by the DaSy and PIFAC Centers
https://www.ncham.org/communications/Data_Sharing_Agreement_Checklist_Article

Getting Technical Assistance
 Technical assistance for states involved in data sharing activities is available from DaSy, ECTA, and NCHAM. Contact: Sharon.Watson@ncham.org

Suggested Citation
 ECTA, DaSy, and NCHAM (2022). Data Sharing Agreement Checklist Between Part C and EHDI. 9th Edition.

About Us
 The contents of this document were developed under a grant from the U.S. Department of Education, #H2019000, and a cooperative agreement, #H2019000, between the National Center for Hearing Assessment and Management (NCHAM) and the Utah State Office of Education (OSOE). The contents of this document are not intended to be used as a substitute for legal advice.

Table 1 Checklist of Essential Components and Suggested Additions

Committee Products: Data Sharing Agreements Template

In final draft under committee review and discussion.



Data Sharing Agreements: Examples from EHDI and Early Intervention Programs

Draft: 8/17

Instructions

The purpose of this document is to provide users with suggested components and possible descriptions and examples for data sharing agreements and memoranda of understanding between among parties that provide services for children that are deaf or hard of hearing. The most likely state parties are those that administer the Part C of IDEA and EHDI programs but may also include other programs (e.g., birth defects registry, children with special healthcare needs, Autism registry, Home Visiting).

The components, descriptions, and examples included in the template have been gathered from existing state data sharing agreements or memoranda of understanding (MOU). Users of this template may include any of the listed components, and add additional components as prioritized in their state. Suggested resources are also included in this document.

See the considerations below when using this template.

Considerations:

- Use the suggested descriptions and examples as guidance when developing your state agreement language
- Refer to the state data sharing agreements referenced within this template for additional context. These can be found at: [NCHAM Link](#)
- Review IDEA, FERPA, HIPAA, and other federal and state laws specific to your state and terms of agreement.
- Consult with the appropriate legal authority with your party, such as your party's legal team.

1. Introductory paragraph

a. **Description:** Introduce the data sharing partners and give the official name of each organization. For this agreement, the most likely parties are Part C and [EHDI](#) but other parties may be involved such as The State School for the Deaf and private programs the party where Early Intervention (Part C) data are stored and the party where Early Hearing Detection and Intervention (EHDI) data are stored.

b. **Example:**

- i. This Data Sharing Agreement ("Agreement") is between the Department of Health, Early Hearing [Detection](#) and Intervention Program ("EHDI Program") and the Department of Health and Human Services Early Intervention Program ("Part C Program").

2. Purpose

- a. **Description:** Provide the reason(s) and intent for the agreement.
- b. **Example:**

1 | Page

Early Hearing Detection and Intervention Program

Goal: To support the development of state/territory programs and systems of care to ensure:

- Children who are deaf or hard of hearing are identified through newborn, infant and early childhood hearing screening
- Receive diagnosis and appropriate early intervention to optimize language, literacy, cognitive, social and emotional development.

The program focuses on:

- Improving access to early intervention services and language acquisition;
- Increasing health professionals' engagement in and knowledge of the EHDI system; and
- Improving family engagement, partnership, leadership, and support.

Early Hearing Detection and Intervention Program

The mission of the EHDI Program is to ensure that all newborns in each jurisdiction **meet the 1-3-6 Benchmarks** which include:

- 1 – receiving a hearing screening by 1 month of age,
- 3 – receiving a follow-up diagnostic test (if they do not pass the hearing screening) by 3 months of age, and
- 6 – be enrolled in early intervention services (if diagnosed with a permanent hearing loss) by 6 months of age.

This also allows the EHDI Program to:

- identify infants who are deaf and hard-of-hearing
- ensure these infants are receiving necessary services,
- assess progress towards meeting the 1-3-6 Benchmarks, and
- report data to CDC on an annual basis through the Hearing Screening and Follow-Up Survey.

Early Hearing Detection and Intervention Program

- In 2020, CDC awarded multiple states and territories a new four-year award: “Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems.”
- Purpose: To advance the capacity of jurisdictions to actively track infants to ensure they receive essential diagnostic services and enrolled in early intervention by:
 - optimizing their (EHDI) Information Systems (EHDI-IS) and
 - expanding their ability to report, analyze, and use patient-level data.
- Focus on tracking data, analyzing data and to inform decision-making and improvement
- Allow reporting of de-identified child specific data with no Personally Identifiable Information (PII)

Goal Statement 4: Document the enrollment status, delivery and outcome of EI services for infants and children with hearing loss < 3 years old.

4.1 The EHDI-IS **SHALL** provide the ability to identify infants/children who need EI services
4.2 The EHDI-IS **SHALL** receive and document information about referrals to Part C services
4.3 The EHDI-IS **SHALL** receive and document information about eligibility to Part C services
4.4 The EHDI-IS **SHALL** receive and document information on Part C EI (i.e., date when the Individual Family Service Plan or IFSP is signed).
4.5 The EHDI-IS **SHALL** receive and document information on other non-Part C early intervention services enrollment, in accordance with scope of practice, organizational policy and jurisdictional law.

4.6 The EHDI-IS **SHOULD** receive and document recommended audiologic intervention method upon a hearing loss diagnosis from providers.
4.7 The EHDI-IS **SHOULD** provide the ability to receive and document data on early intervention outcomes.
4.8 The EHDI-IS **SHOULD** provide the ability to receive information from Part C on children who have a hearing loss that were identified in Part C but were not previously reported to EHDI.
4.9 The EHDI-IS **SHOULD** provide the ability to notify parents, healthcare and EI providers of infants' need for EI services.
4.10 The EHDI-IS **SHOULD** provide the ability to receive and document information about co-morbidity – e.g., a child who is automatically in Part C for an established condition that is NOT hearing loss, but the child is later diagnosed with hearing loss.
4.11 The EHDI-IS **SHOULD** receive and document information about a child in the EHDI-IS transitioning out of or leaving Part C services.
4.12 The EHDI-IS **MAY** receive and document information about what Part C Early Intervention services are planned for children with a diagnosed hearing loss.
4.13 The EHDI-IS **MAY** document the referral disposition for children in the EHDI-IS who are eligible for Part B 619 services.

Federal Privacy Regulations Related to EHDI

➤ HIPAA

- ❖ Written consent NOT needed for hospitals and/or health care providers to share screening or diagnostic information with EHDI programs, other health care providers and/or Part C, because:
 - ❖ Is needed for public health activities (e.g., surveillance, program improvement, etc)
 - ❖ Is needed for facilitating ongoing health care

➤ FERPA

- ❖ Does not apply until children are enrolled in programs that receive federal education funding.
- ❖ Written consent required for education agencies to share individual info with non-participating entities.

➤ Part C Privacy Regulations

- ❖ Does not apply until children are referred to Part C
- ❖ Once children are referred to Part C, information possessed by the Part C cannot be shared with **non-participating** entities without written consent

HIPAA (Health Insurance Portability and Accountability Act of 1996)

- ❖ **Covered entity:** A health plan, clearinghouse, or health care provider who conducts financial and administrative transactions electronically (i.e., bills for provision of services)
- ❖ **Protected Health Information (PHI):** Individually identifiable health information transmitted or maintained by covered entities
- ❖ **Sharing information**
 - ❖ Signed consent required to use PHI for marketing or research
 - ❖ Signed consent is NOT required:
 - ❖ For health providers to exchange information for treatment, payment, health care operations.
 - ❖ To share information for Public Health purposes
 - ❖ Providers must keep a record of information that is shared

Benefits to Both Programs for Partnerships

EHDI

- Complete Data on infants/toddlers with Permanent Childhood Hearing Loss and those who are Lost to Follow-up or In-Process of Diagnosis
- Achieve 1-3-6 milestone
- Meet all EHDI-IS Functional Standards
- Analyze data to identify gaps and needs

Part C

- Timely referrals for infants/toddlers with hearing loss
- Improving child find – identifying gaps in referral, hearing screening, and identification
- Shared data leads to informed decision making

Understanding Required and Optional Part C Data Collections

All states report 4 tables annually

- **number of children served** (single day or point in time and cumulative)
- the **settings in which most of their services are provided** (single day) and
- the **number and reason for any child who exits** (during the reporting year)
- **data on disputes** – *not related to EHDI*

Some states collect other data elements

- Children who are referred
- Children who are evaluated
- Children who are not found eligible
- Reason for/type of eligibility
- Whether the child has a diagnosed hearing loss
- Early intervention services included on all IFSPs,
- Other services included on IFSPs,
- Date IFSP is signed
- Date the child exits from Part C

Child and Family Outcomes: Annual Performance Reporting

Part C Child Outcomes: infants and toddlers with Individualized Family Service Plans (IFSPs) or preschool-age children with Individualized Education Plans (IEPs) who demonstrate improved:

- Children have positive social-emotional skills (including social relationships)
- Children acquire and use knowledge and skills (including early language, communication, and early literacy)
- Children use appropriate behaviors to meet their needs.

Part C Family Outcomes: the percent of families participating in Part C who report that early intervention (EI) services have helped their family:

- Know their rights;
- Effectively communicate their children's needs; and
- Help their children develop and learn.

When Do Requirements Apply Under Part C?

Confidentiality procedures apply to the personally identifiable information (PII) of a child/family that:

- ❖ Are contained in early intervention records collected, used, or maintained under Part C by the **lead agency or an EIS provider**; and
- ❖ Apply **from the point in time when the child is referred for early intervention** services under Part C until the later of when the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws.

You can always release data with parental consent or if the data are properly de-identified data (no PII)

Part C Privacy Regulations

- ❖ Signed consent **IS** required for Part C to share any personal information with “non-participating entities” (i.e., entities outside the Part C system who contribute substantially to multiple components of the system --- not just to Child Find)
- ❖ Signed consent **IS NOT** needed for anyone to refer a child to Part C (name, contact info, reason for referral)
- ❖ Signed consent **IS NOT** needed for Part C to share info with “participating entities”
- ❖ Part C is more restrictive than either HIPAA or FERPA

IDEA Part C Participating Agency

- ❖ PII data **can only be shared** outside of participating agencies **with parental consent**
- ❖ Any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in Part C.
- ❖ Includes LA, EIPs, and any individual/entity that provides any part C services.
- ❖ **Does not include primary referral sources** or public agencies or private entities that act solely as funding sources for Part C services.

All participating agencies (including the lead agency and EIS providers) must comply with the Part C confidentiality procedures

Disclosure of PII Under FERPA Without Consent

- [FERPA](#) permits disclosure of PII without parental consent under several exceptions including:
- To authorized representatives of federal, state, and local educational authorities conducting an audit, evaluation, or enforcement of education programs;
- To school officials with legitimate educational interests (defined in annual notification);
 - Staff or employees who need access to perform duties
 - School official exception
 - “Legitimate educational interest”
 - External entities
 - Studies exception
 - [Audit or evaluation exception](#)
 - Uninterrupted Scholars Act
 - Other (e.g., court order, health or safety emergency)

What Is Required in a Data Sharing Agreement?

- ❖ Can be called different names: MOU, MOA, Contract, Written Agreement, etc.
- ❖ Must include:
 - ❖ Designation of individual or entity as an authorized representative;
 - ❖ The PII from education records to be disclosed;
 - ❖ The purpose for which the PII is disclosed for an audit or evaluation of Federal or State supported education programs, or to comply with Federal requirements;
 - ❖ A description of the activity with sufficient specificity to be clear the work falls within the exception, including a description of how the PII will be used

What Is Needed in a Data Sharing Agreement?

- ❖ Require the authorized representative to destroy PII when the information is no longer needed for the purpose specified;
- ❖ Specify the time period in which the information must be destroyed; and
- ❖ Establish policies and procedures, to protect PII from further disclosure (except back to the disclosing entity) and unauthorized use, including limiting use of PII to only authorized representatives with legitimate interests in the audit or evaluation.

Guiding Beliefs

- The core values are the same for both EHDI and Part C: the desire to improve child and family outcomes.
- Developing and maintaining a strong partnership between EHDI and Part C is essential to achieve the core values at their highest level.
- We know that successful partnerships have common elements

Recommended Strategies

1. Well informed families are given copies of consents and medical/educational records to share as needed
2. Coordinated consent forms (and training) so that a single signature gives permission to share info with various of providers.
3. Memoranda of Agreement (MOA's) among EHDI, Part C, Family Support Programs and others
4. Designation of "participating entities " as part of Part C system.
5. Integrate public health information systems (e.g., immunization, blood-spot screening, hearing screening)

Group Discussion

State and Participant Sharing

Table Discussion

Discussion Questions:

- What is one short term activity you would like to implement and one longer term and why did you pick those?
- What challenges are you anticipating? Ask others for any solutions/ideas/opportunities?
- How could the TA centers/other states/other entities assist you in those plans?

Wrap-Up

- Group Sharing
- Availability of TA
- Resources
- Session Evaluation – Please complete

Thank you!

Resources

- American Academy of Pediatrics/Bright Future – Implementation Tip Sheet Promoting Early Hearing and Detections and Intervention:
https://downloads.aap.org/AAP/PDF/BF_EHDI_TipSheet.pdf
- Data Sharing Agreement Checklist for IDEA Part C & Part B 619 Agencies:
https://dasycenter.sri.com/downloads/DaSy_papers/DaSy_Data_Sharing_Agreement_Checklist_Acc.pdf
- DaSy Resources: Special Collections on Privacy/Confidentiality and Linking Data:
<https://dasycenter.org/resources/topics/privacy-and-confidentiality/>
- Data Sharing Partnerships Improve Systems:
<https://ectacenter.org/topics/earlyid/ehdidata.asp>

Resources

- Examples of State Data Sharing Agreements:
<https://www.infanthearing.org/privacy/states.html#data>
- Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs Frequently Asked Questions (FAQs)
<https://dasycenter.org/early-childhood-privacy-and-confidentiality-faq/>
- US Department of Education: Protecting Student Privacy
<https://studentprivacy.ed.gov/?src=rn>
- Health Insurance Portability and Accountability Act (HIPAA) Frequently Asked Questions, May 2016, DaSy Center
https://dasycenter.sri.com/downloads/DaSy_papers/PCY309_HIPAAFAQ_FINAL_2016_0502.pdf



Websites

Centers:

ECTA: <https://ectacenter.org>

DaSy: <https://dasycenter.org/>

NCHAM: <https://www.infanthearing.org/index.html>

PTAC: <https://studentprivacy.ed.gov/about-us>

Thank you



dasycenter.org

Twitter: [@DaSyCenter](https://twitter.com/DaSyCenter)



Early Childhood
Technical Assistance Center

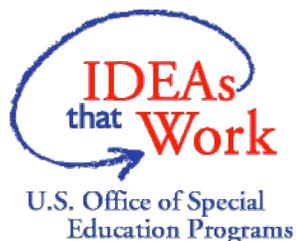
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