

ecta



**Keys to Successful Child and Family
Outcomes: Strong EHDI & Part C
Partnerships**

EHDI 2021 Meeting

Session

March 2, 2021

Welcome

Haidee Bernstein, DaSy

haidee.bernstein@sri.com

Evelyn Shaw, ECTA

evelyn.shaw@unc.edu

Sharon Walsh, DaSy

walshtaylo@aol.com



The Center for IDEA Early
Childhood Data Systems

<https://dasycenter.org/>

Works with states to support IDEA early intervention and early childhood special education state programs in the development or enhancement of coordinated early childhood longitudinal data systems.



Improving **Systems**, **Practices**,
and **Outcomes**

<https://ectacenter.org/>

Support state/jurisdiction Part C/Section 619 programs to develop high-quality early intervention and preschool special education service systems, increase local implementation of evidence-based practices, and enhance outcomes for young children with disabilities and their families.

Intended Outcomes

Participants will **Increase understanding of:**

- Part C and EHDI purposes and requirements
- The value of strong partnerships between EHDI and Part C.
- Elements of successful partnerships between EHDI and Part C
- Resources that can assist in Part C and EHDI Collaboration

Agenda

- Introduction and Overview of the Session
- Understanding Both Programs: EHDI and Part C
- Elements of Successful Partnerships: Shared Vision and Buy-In, Infrastructure, Professional Development, Family Engagement
- Privacy and Data Sharing
- Resources

ecta

DaSy  

**Understanding Both Programs:
EHDI and Part C**

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)

Quick Overview to Part C of IDEA

State annual application to OSEP

State lead agency designated by Governor to:
Receive grant, administer the program, Interagency
Coordinating Council to advise and assist

Assure the minimum
components of the early
intervention system are in
place

Early intervention available
to every child and family

Annual funding based on
census figures of number of
children birth to three in
general population

Annual reports and data to
OSEP

Components of Part C

- Child find/referral, eligibility definition, collaboration with federal/state/local programs, timely/comprehensive multidisciplinary evaluation of child and family-directed assessment
- Individualized family service plan (IFSP) and service coordination
- Appropriate EI services, based on scientifically based research, available to all, to the maximum extent provided in natural environments
- Procedural safeguards
- Single line of authority in lead agency to carry out general administration and supervision
- Policies for contracting or arranging for services
- System for compiling data
- State Interagency Coordinating Council

Understanding Required and Optional Part C Data Collections

All states must **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 EHD**

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.

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

Successful Partnerships: Common Elements

- Shared Vision and Buy-In
- Infrastructure Considerations
- Professional Development
- Family Engagement

Shared Vision and Buy-In

- Work towards a common goal:
 - improving outcomes for infants, toddlers with hearing loss and their families
 - improving child find (earlier hearing screening, follow-up and referral to Part C)
 - Addressing gaps in data exchanges
- Willingness to partner and develop a collaborative working relationship
- Dedicated team of partners across agencies
- Co-staffing on planning groups and committees
 - EHDI Committee
 - State Interagency Coordinating Councils
- Open dialogue, realistic expectations, patience
- Persistence even when past efforts were not successful

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

Infrastructure Considerations

- Understanding the organizational structure of EHDI and Part C agencies (in same agency or two different agencies)
- Knowledge of where the data resides
- Understanding and addressing financial implications
- Improving follow-up, referral, evaluation policies and procedures for both programs. Ensuring these are comprehensive and understandable.
- Improving evaluation of the EHDI and Part C
- Ensuring the process for collaboration and data exchange is sustainable (not dependent on staff in the positions) and part of the infrastructure

Professional Development/Technical Assistance

- Identify professional development needs (e.g. local EHDI and Part C program staff, audiologists, families)
- Identify technical assistance needs for both local programs that connect infants and toddlers and their families to early detection of hearing loss, follow-up, referral and evaluation.
- Ensure technical assistance to support collaboration and agreements
- Collaborate to provide presentations to regional/local EHDI and Part C providers and programs to facilitate communication and support
- Offer educational opportunities, when available to staff from the other program.

Family Engagement

The goal is supporting families and their infants and toddlers with hearing loss to include:

- Strong family engagement, support and relationships with family-based organizations
- Communication of the vision of collaboration and data sharing with families
- **EHDI:**
 - Ensure families have access to information that is accurate, comprehensive, up-to-date, and evidence-based
 - Facilitate decisions families make for their children, including decisions with respect to the full range of assistive hearing technologies and communication modalities
 - Establish and foster family-to-family and deaf and hard of hearing consumer-to-family supports that are important after a child has been identified as deaf or hard of hearing
- **Part C:**
 - Supporting families as partners in decision making at the individual child level, at programmatic and at policy levels
 - Remembering that family partnerships in a child's early years lays the foundation for achieving the long-term intended outcomes for children and families

Privacy and Data Sharing

Three Main Privacy Laws

Part C Regulations

- IDEA (Individuals with Disabilities Education Act)
- Birth to 3 early intervention population

Family Educational Rights and Privacy Act (FERPA)

- Entities receiving U.S. Department of Education Funds
- Confidentiality of “education records”

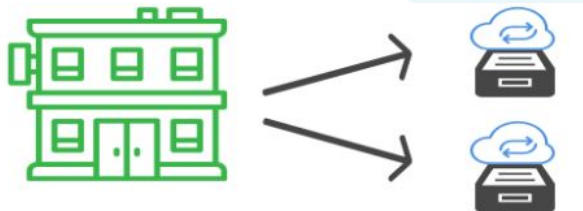
Health Insurance Portability and Accountability Act (HIPAA)

- Title II, Privacy Rule
- Use of Protected Health Information by covered entities

Consider Two Scenarios

Scenario A

- *Single lead agency, Health Department, two separate data systems for Part C and EHDI



Scenario B

- *Two different lead agencies, Health for EHDI and Non-Health for Part C, each has its own data system



State laws, regulations, and practices:

- Can provide **MORE** privacy protections, but not **less** (i.e., state laws seldom, if ever, enable sharing of education and health related information that is not already allowed under HIPAA, FERPA and/or Part C)
- Can encourage (or discourage) reporting

When Do Requirements Apply Under Part C?

Confidentiality procedures apply to the PII of a child/family that:

- ❖ Is contained in early intervention records collected, used, or maintained under Part C by the **lead agency or an EIS provider**; and
- ❖ Applies **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.

***Can always release data with parental consent
and properly de-identified data (no PII)***

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

Part C Privacy Regulations

- ❖ 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”
- ❖ Signed consent **IS** needed 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)
- ❖ Part C is more restrictive than either HIPAA or FERPA

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)

Brief Reminders: IDEA and FERPA

- Obtaining written **parental consent** is always the safest way to share data
- If you are sharing **aggregate data** without releasing personally identifiable data (PII) **no consent is needed**
- Must follow regulations under **IDEA Part C at 34 CFR Part 303** (Consent and Confidentiality Provisions)
- IDEA requires states to also follow the regulations for the **Family Education Rights and Privacy Act (FERPA) at 34 CFR Part 99** (Consent and Exceptions to Consent)
- FERPA consent exception for **evaluation and audit** permits data sharing without parental consent with development of a data sharing agreement
- Check with your privacy office regarding any HIPAA implications for your state

Preparation for Data Sharing Discussions

- Identify benefits to both programs
- Secure willingness to partner and appoint cross-agency team
- Focus on what would demonstrate value early on
- Identify the key policy questions and how these relate to improved outcomes?
- Determine data elements are needed to answer your questions?
- Understand structure of the agencies, where data reside and how it flows
- Discuss how do you both currently share data? What agreements are in place?
- Secure funding and TA needed
- Be patient and don't underestimate how long it can take!

Important Steps In Data Sharing

- Understand privacy considerations - IDEA, FERPA and HIPAA
- Decide approach - Aggregate data? Parent consent? Data sharing agreement?
- Plan how records will be matched and how data will be transmitted securely
- Plan how data will be accessed, made available and stored after being shared
- Make data sharing sustainable and equitable
- Consider future data sharing across early childhood (ECIDS) and longitudinal (SLDS K-12)
- Continue discussions exploring additional critical questions related to outcomes
Answering critical questions like: Are we making a difference?

Resources

- DaSy Center <https://dasycenter.org/>
- ECTA Center <https://ectacenter.org/>
- NCHAM <https://www.infanthearing.org/>
- Privacy TA Center Early Childhood Data
<https://www.ed.gov/open/plan/privacy-technical-assistance-center>
- IDEA Infant and Toddler Coordinators Association (ITCA)
<https://www.ideainfanttoddler.org/>

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 and Programs
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/>
- Critical Questions About Early Intervention and Early Childhood Special Education
<https://dasycenter.org/resources/critical-questions/>

Resources

- Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs Frequently Asked Questions (FAQs)
<https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/idea-confidentiality-requirements-faq.pdf>
- 2014 side-by-side guide of the IDEA and FERPA Confidentiality Provisions
https://studentprivacy.ed.gov/sites/default/files/resource_document/file/IDEA%20FERPA%20Confidentiality%20Provisions%20Comparison%20Chart%2006.06.14.pdf
- US Department of Education: Protecting Student Privacy <https://studentprivacy.ed.gov/>
- Joint Guidance on the Application of the *Family Educational Rights and Privacy Act (FERPA)* And the *Health Insurance Portability and Accountability Act of 1996 (HIPAA)* To Student Health Records December 2019
https://studentprivacy.ed.gov/sites/default/files/resource_document/file/2019%20HIPAA%20FERPA%20Joint%20Guidance%20508.pdf
- Health Insurance Portability and Accountability Act (HIPAA) Frequently Asked Questions, May 2016, DaSy Center
https://dasycenter.sri.com/downloads/DaSy_papers/PCY309_HIPAAFAQ_FINAL_20160502.pdf
- US Department of Education: Protecting Student Privacy <https://studentprivacy.ed.gov/>

Thank You

- The DaSy Center is a program of SRI International, funded through cooperative agreement number H373190002 from the Office of Special Education Programs, U.S. Department of Education. Opinions expressed herein do not necessarily represent the Department of Education's position or policy. Project Officers: Meredith Miceli & Richelle Davis
- The ECTA Center is a program of the FPG Child Development Institute of the University of North Carolina at Chapel Hill, funded through cooperative agreement number H326P170001 from the Office of Special Education Programs, U.S. Department of Education. Opinions expressed herein do not necessarily represent the Department of Education's position or policy. Project Officer: Julia Martin-Eile

Find out more at ectacenter.org and dasycenter.org