

Data Sharing Agreement Checklist: Early Hearing Detection, and Intervention Program (EHDI) and Part C

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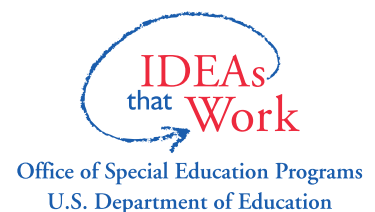
The first Early Hearing Detection and Intervention (EHDI) programs in the United States were established more than 30 years ago to identify babies who are deaf or hard of hearing (D/HH). There are increasing efforts across state systems for EHDI and Early Intervention (EI) under Part C of the Individuals with Disabilities Education Act (IDEA) 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 (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 Part C program evaluation and improvement efforts.

Data sharing can be beneficial for EHDI and Part C state programs and the children and families they serve. Identifying whether and how to share data is important. State and local programs must determine procedures for sharing data that appropriately protects personally identifiable information (PII) consistent with IDEA Part C requirements. In the absence of shared data, 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.

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Appropriate data sharing between Part C and EHDI programs is essential for continued evaluation and improvement of both programs. The following four options can be used for sharing data between EHDI and Part C programs under the IDEA Part C requirements codified in [34 CFR §303.414](#):

1. Under [34 CFR §303.414\(a\)](#), PII from a child's Part C EI records can be shared if the child's parent provides written consent according to federal IDEA Part C requirements.
2. Data can be shared without parental consent if the data are deidentified so that identification of an individual child, parent or family is not reasonably possible. This option requires careful review with legal and statistical input.
3. Data can be shared between Part C and EHDI without parent consent if the EHDI program is a "participating agency" within the Part C system. To be a participating agency, the EHDI program must provide early intervention service(s) under Part C in addition to being a referral source, for example, audiology services, service coordination; and the data that can be shared is limited to that data needed for the delivery of Part C services.
4. Part C can share PII with EHDI if the agencies develop and implement a data sharing agreement that meets an exception to parental consent reflected in the IDEA Part C regulations that cross-reference the Family Education Rights and Privacy Act (FERPA) exception for audit and evaluation. This evaluation exception is incorporated in [34 CFR §303.414\(b\)\(1\)](#) and references [34 CFR §99.31\(a\)\(3\)](#) and [34 CFR §99.35](#) (as modified by [34 CFR §303.414\(b\)\(2\)](#)). The purpose of the agreement must be "to carry out an audit or evaluation of Federal- or State-supported education programs..." The FERPA requirements at [34 CFR §99.3](#) defines an "education program" to include the IDEA Part C program. The content of the agreement must identify the evaluative components that EHDI and Part C will share to help improve the IDEA Part C program.

Regarding each of the preceding options, it is important to remember that individual states may have additional requirements regarding privacy and data sharing that may apply and must be addressed as well.

This checklist has been developed by the EHDI Outcomes Committee as a resource for state Part C and EHDI staff to use as they develop Data Sharing Agreements, consistent with the federal requirements under IDEA and 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.

Authorized Representative

Essential Components

- ☐ Identify the individual or entity authorized to share or receive data and change or terminate the agreement. In an agreement where Part C and EHDI are sharing information, Part C, as the authorized representative, is disclosing information to the EHDI program. The EHDI and the Part C programs will identify what information is needed to enable both programs to improve services to children and families.

Suggested Additions

- ☐ Provide names and contact information for people responsible for:
 - EHDI and Part C program administration;
 - IT security; and
 - FERPA, Health Insurance Portability and Accountability Act (HIPAA), and Part C Privacy compliance.

Some EHDI and Part C programs are considered “covered entities” under HIPAA and would be required to adhere to requirements under [45 CFR Part 160](#), [45 CFR Part 164—Subpart A](#), and [45 CFR Part 164—Subpart E](#).

Purpose

Essential Components

- ☐ Specify that the purpose for disclosing the PII is to evaluate the Part C and EHDI programs.

Suggested Additions

- ☐ Ensure that the purpose reflects the language in IDEA Part C and FERPA for a **program** evaluation exception.
- ☐ Specify that the Data Sharing Agreement is **necessary** to comply with Federal legal requirements that relate to the specified programs.
- ☐ Add any other purposes important to the programs as identified by EHDI and Part C (for example, improve services to children and families, promote collaboration across EHDI and Part C, promote shared understanding of the value of both programs).

Legal Authority

Essential Components

- ☐ The agreement must identify the applicable federal legal authorities.

IDEA Part C at [34 CFR §303.414\(b\)\(1\)](#), FERPA at [34 CFR §99.31\(a\)\(3\)](#), [34 CFR §99.35](#) (as modified by [34 CFR §303.414\(b\)\(2\)](#)), and [34 CFR §99.3](#).

Suggested Additions

- ☐ Include federal and state legal citations as applicable.

Activities and Evaluative Components

Essential Components

- ☐ Describe how activities covered by the agreement fall within the evaluation exception, including:
 - how PII from Part C will be used;
 - the methodology for sharing the data; and
 - why disclosure of PII from Part C is necessary to accomplish the evaluation activity.
- ☐ Identify the evaluative components that EHDl and Part C will share that may help improve the IDEA Part C program.

Suggested Additions

- ☐ List the activities related to the mechanics of the data transfer
- ☐ Describe the need for the data and how it will be used to evaluate and improve the program (for example, EHDl needs to know whether children referred to Part C are receiving services; and Part C needs the data to improve child find).
- ☐ Outline the responsibilities and activities of both programs that will occur as the data are shared and maintained.
- ☐ Identify the types of data, information, and analysis that EHDl will share with IDEA Part C program to provide helpful information on outcomes for hearing impaired children.

Policies and Procedures

Essential Components

- ☐ Describe how the agreement will protect PII from Part C records from:
 - further disclosure, except back to the disclosing entity; and
 - unauthorized use, including limiting use of PII only by authorized representatives with legitimate interests in the audit and evaluation.

Suggested Additions

- ☐ Describe:
 - the State's limitations on use of the PII such as linking to other data sets or redisclosing to other entities;
 - procedures for Institutional Review Board (IRB) review and approval as applicable;
 - Individuals who will have access to the data;
 - how the public will be informed about this agreement (for example, privacy statements on program websites, and inclusion in Part C family rights documents);
 - the right to audit under applicable conditions;
 - plans for responding to a data breach, including responsibilities and procedures for notification and mitigation, timelines for reporting disclosure, penalties for inappropriate disclosure; and
 - indemnification provisions.

Data Ownership and Stewardship

Essential Components

(None.)

Suggested Additions

- ☐ Describe:
 - Points of contact and data custodians;
 - State ownership of PII; and
 - Cost of additional services, for example, data interfaces, cleaning, and formatting.

Data Destruction

Essential Components

- ☐ Requirement for authorized representative to destroy shared data when it is no longer needed for the purpose specified including how and when the PII will be destroyed.

The requirements related to data destruction can be found at [34 CFR §303.416](#) for IDEA, and at [34 CFR §99.35](#) for FERPA.

Suggested Additions

- ☐ Describe:
 - the procedures, timelines, and responsible parties for destruction of the PII; and
 - how users will certify that data have been destroyed.

Information and Data Security

Essential Components

- ☐ Describe how the data will be transmitted, stored, and accessed securely.

Suggested Additions

- ☐ Describe data file format, including:
 - mechanisms for secure file transfer;
 - data display and reporting policy, for example, small numbers cell suppression, restrictions on reporting;
 - requirements for maintaining data in a secure manner, verifying that individuals with access to these data have had IDEA, FERPA and HIPAA training, and have signed agreements to protect confidentiality and security;
 - requirements for a data management plan including data storage, data will not be physically moved, transmitted or disclosed outside the plan without written approval unless required by applicable law; and
 - requirements for use of subcontractors in accessing and working with the shared data.

Data to be Disclosed

Essential Components

- ❑ Describe the specific PII from early intervention records that will be shared.

Suggested Additions

- ❑ Include within the body of the document, or as an attachment:
 - A list of data elements that will be shared; and
 - Definitions of each data element from each program.

Time Limit of the Agreement

Essential Components

- ❑ Specify any time limits to which parties have agreed including provisions for extending the time period if needed.

Suggested Additions

- ❑ Include provisions for:
 - effective dates of the agreement;
 - modifications and terminations procedures of this agreement; and
 - terms for conflict resolution.

Additional Resources

1. [Data Sharing Partnerships Improve Systems](#) includes examples of Existing State Interagency Agreements and Memoranda of Understanding Between Part C, EHDI and other Relevant Entities.
2. [Guidance for Reasonable Methods and Written Agreements](#) issued by the Family Policy Compliance Office in the US Department of Education provides guidance for schools, school districts, postsecondary institutions, and State educational authorities (such as State educational agencies) that may disclose personally identifiable information from education records. The document provides these entities with information about requirements and best practices for data disclosures under the studies exception and the audit or evaluation exception, as specified in the Family Educational Rights and Privacy Act (FERPA).
3. [Data Sharing Agreement Checklist for IDEA Part C and Part B 619 Agencies and Programs](#) by the DaSy and Privacy Technical Assistance (PTAC) Centers summarizes the requirements for the written agreements under the audit or evaluation exception¹ that is specified in FERPA and that also applies to the IDEA.
4. Technical Assistance (TA) for states involved in data sharing initiatives is available from [DaSy](#) and [ECTA](#). For more information, contact Sharon Walsh: walshtaylo@aol.com