Data Sharing Agreement Checklist Between Part C and EHDI

March 2022

Please note this document is currently under review by The Office of Special Education Programs (OSEP) and is shared as a draft at this time

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 ensure services are being provided to children in need and accurately assess progress toward 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 ensuring the needs of children are being met and 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.

Table 1 Checklist of Essential Components and Suggested Additions

	Essential Components		Suggested Additions
❑	**Authorized Representative**: Identify the individual or entity authorized to share or receive data and change, or terminate the agreement.	❑	Provide names and contact information for people responsible for: • EHDI and Part C program administration • IT security • FERPA, HIPAA, and Part C Privacy compliance
❑	**Purpose:** Specify that the purpose for which the PII from EI records is being disclosed to the authorized representative is to carry out an audit or evaluation of Federal- or state-supported education programs.	❑	Ensure that the purpose reflects the language in FERPA for a program evaluation and audit exception.
		❑	Specify that the Data Sharing Agreement is necessary to enforce or 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 (e.g., promote collaboration across EHDI and Part C, promote shared understanding of the value of both programs)
		❑	**Legal Authority:** Include federal and state legal citations as applicable.
❑	**Activities:** Describe how activities covered by the agreement fall within the audit or 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 audit and evaluation activity	❑	Description of the activities related to the mechanics of the data transfer
		❑	Description of the need for the data and how it will be used to evaluate and improve the program
		❑	Outline the responsibilities and activities of both programs that will occur as the data are shared and maintained.

Essential Components	Suggested Additions
☐ **Policies and Procedures:** Describe how the agreement will protect PII from Part C records from: • Further disclosure, except back to the disclosing entity • Unauthorized use, including limiting use of PII only by authorized representatives with legitimate interests in the audit and evaluation.	☐ Specify state limitations on use of the PII such as linking to other data sets or redisclosing to other entities ☐ Specify procedures for Institutional Review Board (IRB) review and approval as applicable. ☐ Specify individuals who will have access to the data ☐ How the public will be informed about this agreement (e.g., privacy statements on program websites, inclusion in Part C family rights documents). ☐ The right to audit under applicable conditions. ☐ Describe plans for responding to a data breach, including responsibilities and procedures for notification and mitigation, timelines for reporting disclosure, penalties for inappropriate disclosure ☐ Indemnification
	Data Ownership & Stewardship: Specify: ☐ Points of contact and data custodians ☐ State ownership of PII ☐ Cost of additional services such as data interfaces, cleaning, and formatting, etc.
☐ **Data Destruction:** 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.	☐ Describe the procedures, timelines, and responsible parties for destruction of the PII ☐ Describe how users will certify that data have been destroyed.

Essential Components		Suggested Additions
❏ **Security:** Describe how the data will be transmitted, stored and accessed securely.		As appropriate, describe:
	❏	Data file format
	❏	Mechanisms for secure file transfer
	❏	Data display and reporting policy (e.g., 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 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
	❏	Requirements for use of subcontractors in accessing and working with the shared data
❏ **Data to be Disclosed:** Describe the specific PII from early intervention records that will be shared.	❏	Include a list of data elements that will be shared
	❏	Include definitions of each data element from each program
❏ **Time Limit of the Agreement:** Specify any time limits to which parties have agreed including provisions for extending the time period if needed.		Include provisions for:
	❏	Effective dates of the agreement
	❏	Modifications and terminations procedures of this agreement.
	❏	Terms for conflict resolution

Resources

Reasonable Methods and Written Agreements issued by the Family Policy Compliance Office in the US Department of Education at: https://studentprivacy.ed.gov/resources/guidance-reasonable-methods-and-written-agreements

Data Sharing Agreement Checklist for IDEA Part C and Part B 619 Agencies and Programs by the DaSy and PTAC Centers
https://dasycenter.sri.com/downloads/DaSy_papers/DaSy_Data_Sharing_Agreement_Checklist_Acc.pdf

Getting Technical Assistance

Technical assistance for states involved in data sharing initiatives is available from DaSy, ECTA, and NCHAM. Contact: Sharon Walsh; walshtaylo@aol.com

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