



3 West Road, Virks Building #325, Cranston, RI 02920

Clarification Of Confidentiality Laws as They Apply to RI Early Intervention Records In Agencies That Have Multiple Programs In Addition To Early Intervention

This information is being provided to all Early Intervention Programs. Please share this document with personnel responsible for the development of agency specific confidentiality policies.

The purpose of this document is to provide guidance regarding confidentiality practices for Early Intervention records in agencies that have multiple programs in addition to Early Intervention.

Confidentiality Overview

Policy developers should be aware that Early Intervention confidentiality requirements are found in Part C of the Individuals with Disabilities Education Act ([IDEA](#)) [303.401 through 303.417](#). The regulations also specifically reference the protections in the Family Educational Rights and Privacy Act (FERPA) in [20 U.S.C.1232g](#) and [34 CFR Part 99](#). When reviewing the privacy and confidentiality requirements for children with disabilities, it is important to review the IDEA requirements first, because they are more restrictive about information sharing than FERPA. Confidentiality practices are outlined in the Rhode Island Early Intervention Certification Standards under Policies and Procedures IX. Procedural Safeguards. It is important to be aware that the Early Intervention record is an educational record, therefore information sharing allowed through the Health Insurance Portability and Accountability Act (HIPAA) does not apply. The HIPAA Privacy Rule specifically excludes from its coverage those records that are protected by FERPA by excluding such records from the definition of “protected health information” (See [45 CFR § 160.103 \(definition of “protected health information”\) ¶¶ \(2\)\(i\), \(ii\).](#))

The IDEA Part C regulations define “early intervention records” as all records regarding a child that are required to be collected, maintained, or used under IDEA Part C. [34 CFR § 303.403\(b\)](#). IDEA confidentiality practices apply to “...the personally identifiable information of a child and the child’s family that – (1) is contained in early intervention records collected, used, or maintained under this part by the lead agency and EIS provider...”[34 CFR § 303.401 \(c\)](#)

Confidentiality Practices Between EI And Non-EI Programs Within an Agency

It is important that agencies operating EI and Non-EI programs ensure all IDEA confidentiality requirements are met. Three IDEA regulations to understand when developing confidentiality practices between EI and non-EI programs are:

1. “A lead agency or other participating agency may not disclose personally identifiable information (...) to any party except participating agencies (including the lead agency and EIS providers) that are part of the State’s part C system without parental consent (...)” [34 CFR § 303.414\(b\)](#). This regulation means that signed consent is required in order to share any personal information about children enrolled in a Part C program with anyone who is not part of the State’s EI system.
2. “Participating agency means any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in part C of the Act and the regulations in this part with respect to a particular child. A participating agency includes the lead agency and EIS providers and any individual or entity that provides any part C services (including service coordination, evaluations and assessments, and other part C services), but does not include primary referral sources, or public agencies (such as the State Medicaid or CHIP program) or private entities (such as private insurance companies) that act solely as funding sources for part C services.” [34 CFR § 303.403\(c\)](#)

The definition of “participating agency” clarifies that “participating agency” refers to those who implement the requirements of Part C with respect to a particular child. Personnel in non-EI programs operated by an agency are not considered part of the State’s EI system because they do not implement Part C of IDEA. They implement other programs that have other regulations and rules and they do not have a role in implementing Early Intervention. Therefore, parental consent must be obtained before any information about the EI child or family is disclosed to non-EI personnel.

3. “Consent means that, (a) The parent has been fully informed of all information relevant to the activity for which consent is sought in the parent’s native language...(b) The parent understands and agrees in writing to the carrying out of the activity for which the parent’s consent is sought, and the consent form describes that activity and lists the early intervention records that will be released and to whom they will be released, and (c) the parent must understand that the granting of consent is voluntary on the part of the parent and may be revoked at any time...” [34 CFR § 303.7](#)

The process and forms for obtaining consent must be developed in accordance with this regulation.

Agencies with other community programs provide an excellent opportunity to meet the varied needs of EI families. Shared cases in EI and non-EI programs provide coordinated supportive services for EI families. Incorporating consent procedures as part of the referral process to other programs within an agency can be a seamless way to meet confidentiality requirements, while providing other needed agency services to EI families. Agencies who need technical assistance in meeting confidentiality requirements should contact Donna Novak at donna.novak@ohhs.ri.gov or Sara Lowell at sara.lowell@ohhs.ri.gov

Confidentiality Practices between EI and non-EI Programs in an Electronic Record

Early Intervention has started the process of upgrading Welligent to a fully electronic record. Confidentiality rules are the same whether the record is electronic or paper. Welligent has the capacity to be used for other non-EI programs operating within an agency. Agencies may Welligent services by establishing their own separate agreements directly with Welligent.

For programs considering Welligent, or any other electronic record for non-EI programs, it is important to review the EI confidentiality requirements that must be met when managing EI and non-EI programs within an electronic record system.

Below are 3 potential confidentiality issues when combining EI and non-EI programs in an electronic record system.

1. Ensuring that access to the EI record is protected in the system. The EI record must only be able to be accessed by personnel who have a role in implementing the EI program (EI administrators, supervisors, EI professionals, billing, data entry, etc.) In Welligent, this can be done through the permissions process for each staff. Staff in non-EI programs should not be given permission to access EI program records.
2. Ensuring that EI personally identifiable information (PII) is protected in client searches. Searches by staff in non-EI programs must not allow access to PII of EI clients. In Welligent, this can be done through the permissions which will restrict EI records from appearing in searches by non-EI staff.
3. Preventing access to the EI record when adding non-EI programs to EI records. In Welligent, staff without EI permissions will not be able to add a non-EI program to a present or past EI record. Potential solutions might be program specific but could include:
 - a. Utilize personnel that have EI permissions to add the non-EI client to the system. In agencies that use centralized staff to add both EI clients and non-EI clients to the system, those staff already meet the requirements for permission to access the EI record and would be able to add a non-EI program to the record. In agencies that operate more

separately and use program specific staff to add non-EI clients to the system, they will need to have someone with EI permissions add the non-EI record to a current EI record or a record in which there was an EI episode in the past.

- b. Create a written consent for non-EI referrals, to allow the non-EI programs to access the EI record to add the non EI Program.
- c. Explore options with Welligent that could allow a duplicate record for non-EI programs. If the non-EI program could add clients without merging with the EI record, the EI segment would not appear. This would create duplicate records when counting by total clients served, but the number would be accurate by program. Programs may not want duplicate records and whether the logic functions of Welligent to prevent duplicate records can be bypassed are yet to be determined.