

# Part C's Confidentiality Provisions

## Summary of Key Points

This handout summarizes Part C's requirements to protect the confidentiality of personally identifiable information about children and families involved in early intervention.

- **Where?** | Part C's confidentiality provisions can be found at §303.401—§303.417 of the Part C regulations. The entire section is entitled "Confidentiality of Personally Identifiable Information and Early Intervention Records."
- **Parent Right** | Parents of infants and toddlers referred to early intervention or receiving services under Part C have the right to confidentiality of personally identifiable information (PII).
- **State Responsibility** | Each State must have procedures to ensure that participating agencies (including the lead agency and EIS providers) comply with Part C's confidentiality provisions.
- **What's a Participating Agency?** | *Participating agency* is defined as any individual, agency, entity, or institution that collects, maintains, or uses PII with respect to a particular child in Part C. 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.
- **Informing Parents** | When a child is referred to Part C, the lead agency must provide parents with notice that fully informs them about the State's procedures for complying with Part C's confidentiality requirements. The notice in-



cludes (but is not limited to) such information as what type of PII is collected and what procedures participating agencies are required to follow regarding its storage, disclosure to third parties, retention, and destruction.

- **Parent Right** | Parents of a child referred to, or served under, Part C have the right to inspect and review all early intervention records about their child and family that are collected, maintained, or used in Part C. This includes records related to evaluations and assessments, screening, eligibility determinations, development and implementation of IFSPs, provision of early intervention services, individual complaints involving the child, or any part of the child's early intervention record.
- **For How Long?** | The confidentiality provisions apply from the point in time when the child is referred for early intervention services until the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws (whichever comes later).
- **Parent Consent for Disclosure of PII** | With limited exceptions, parental consent must be obtained before PII may be disclosed to anyone other than authorized representatives, officials, or employees of participating agencies collecting, maintaining, or using the information.
- **Training** | All people collecting or using PII in Part C must receive training or instruction regarding the State's confidentiality policies and procedures.