

Philadelphia Intellectual disAbility Services Infant Toddler Early Intervention

Parental Consent, Rights, Confidentiality and FERPA Policy

Policy

All children referred for Early Intervention services are entitled to receive a timely and comprehensive Multidisciplinary Evaluation (MDE) and services with Parent Consent. Parental consent must be obtained by the local Infant Toddler EI Program before personally identifiable information is disclosed to anyone other than authorized representatives, officials, or employees of the local Infant Toddler EI Program or used for any purpose other than meeting a requirement of federal and state requirements with the exception of those conditions in FERPA 34 CFR §99.31 and §303.401(d).

All information gathered about the child and family will be handled confidentially. Each provider agency will have a confidentiality policy to guide their staff's handling of case related information.

Any information that is collected and shared (with parental release/permissions) will be done so following all FERPA guidelines.

Procedures:

Consent

1. The parent, guardian or surrogate parent for a child may give consent
2. The County will insure that:
 - The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent's native language, as defined in §303.25;
 - 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 (if any) that will be released and to whom they will be released; and
 - The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.
 - If a parent revokes consent, that revocation is not retroactive (i.e., it does not apply to an action that occurred before the consent was revoked).
3. It is the County expectation that the Service Coordination and Provider agency consent forms and policy will include language for parents specifying the four points outlined above.
4. One person within Service Coordination and each provider agency are assigned to manage the confidentiality procedures of personally identifiable information.
5. AT the initial home visit, Service Coordination will ensure that parents are provided with the "Understanding Early Intervention Data Systems" document which indicates that BEIS uses Electronic information management systems to maintain individual child records in the EI Program.
6. Service Coordination and Provider Agencies will maintain a current listing for public inspection, of the names and positions of those employees within the program who may have access to personally identifiable information;

7. Service Coordination and Provider Agencies will provide upon request from the parent, a list of the types and locations of EI records collected, maintained, or used by the agency that are not included in the statewide data information system (PELICAN);
8. In order to proceed with the Early Intervention intake referral, ASQ screening and MDE, the family needs to give consent.
9. The intake coordinator will get verbal consent from the parent/guardian before proceeding with the Early Intervention Referral, regardless of who made the referral to EI.
10. The Service Coordinator and intake coordinator will obtain the family's permission to begin collecting health and developmental information about the child and information about the family. It is voluntary for families to provide this information and the parent/guardian has a right to decline sharing any information.
11. AT the initial home visit, Service Coordination will ensure that parents are provided with the "Understanding Early Intervention Data Systems" document which indicates that BEIS uses Electronic information management systems to maintain individual child records in the EI Program.
12. During the initial home visit, the SC will also review certain information with the family, obtain written consent and document the family's decision to proceed on various levels with the early intervention screening, family assessment (FAQ), child assessment,(CAQ) the administering of any other developmental assessments (M-CHAT) and arranging the multidisciplinary evaluation
13. a Parent may accept or decline any EI service at any time, and may decline a service after first accepting it, without jeopardizing other EI services under this part. The County will not use due process to challenge a parent's refusal to provide consent.
14. If a parent revokes consent, the revocation is not retroactive.
15. When a family expresses their option NOT to proceed with an MDE, they are asked to sign the *"Consent Not to Have a Multidisciplinary Evaluation completed"* and will be given the corresponding materials for this option. They will have the right to request At Risk Tracking if their child meets one or more of the five At Risk criteria. In this case, they will be asked to sign the *"Consent to Make a Referral for At Risk Tracking, if eligible"* and will be given the corresponding materials for this option.
16. At the conclusion after each Initial, Annual or Addendum to the IFSP the SC will also ensure that the family is informed of their procedural rights and obtains the signature of the family on a Parent's Rights Agreement.

Confidentiality

1. All families will be given notices of their right to confidentiality.
2. Service coordination will give each family a Civil Rights And Nondiscrimination notice – includes families rights, nondiscrimination policies, and a list of agencies to contact if families believe their rights have been violated or if they feel they have been discriminated against.
3. Service coordination and provider agencies will give each family HIPPA notice that describes how families' protected health information may be used and disclosed and how families can obtain access to their protected health information. Families are given this notice and are asked to sign for their receipt of this information. The SC and/or provider may sign as witness for the family.

4. All staff and independent contractors for the ongoing provider agencies will be oriented as to the agency's Confidentiality policies and FERPA guidelines.
5. Each service provider will insure that appropriate releases and/or consents are obtained before any information is shared about the child and family outside of the child's early intervention service delivery team.
6. Each agency's confidentiality policy will include guidelines for the storage and handling of case files and who will have access to them. Records will be retained for 4 years and will be destroyed in a manner that protects confidentiality.

FERPA (Family Education Rights and Privacy Act)

1. Service coordination will give each family information about the Family Education Rights and privacy Act of 1974 and Procedural Safeguards for Children in Early Intervention Services (FERPA) notice. This includes excerpts of the law and families' rights regarding their child's records, types of agencies who are authorized to view the records, conflict resolution procedures regarding the records; as well as other places where families can find additional protections.
2. Each Provider agency will inform the Parents that they serve of the FERPA guidelines and the procedures followed by at the agency. This will most often be outlined in the agency 'Welcome Letter' give to all parents when an agency is authorized to deliver a service on the IFSP.

Parent Request to Review Records

Access

1. Parents have the opportunity to inspect and review all EI records about the child and family.
2. The County will comply with a parent's request to inspect and review records without delay and no more than 10 days after the request has been made. This includes:
 - a) Response to requests for explanations and interpretations of the EI records;
 - b) Response to a request to provide copies of the EI records containing the information if failure to provide those copies would effectively prevent the parent from exercising the right to inspect and review the records; and
 - c) Responses to a request to have a representative of the parent inspect and review the EI records.
3. Family's review should be before any meeting regarding an IFSP, or any due process hearing procedure.
4. If more than one child is mentioned in a record, family will review only their child's information
5. Programs shall presume that the parent has authority to inspect and review records relating to his or her child unless the agency has been provided documentation that the parent does not have the authority under applicable State laws.
6. No cost will be assessed to families for requested copies of their child's record for:
 - a) the search or retrieval of information from a child's EI record.
 - b) a copy of each evaluation, assessment of the child, family assessment, and IFSP as soon as possible after each IFSP meeting.
 - c) an initial request for a copy of the child's entire EI record.

Amending Records:

1. Parent may request that the County amend information in their child's record if they believe the information is inaccurate.
2. County must "Amend" documents if content is inaccurate as per the family
3. County shall decide within a reasonable period of time, 10 business days, of receipt of request whether to amend the information.
4. If County refuses, parent shall be informed of the refusal and their right to a due process hearing or review by BEIS.
5. If BEIS decides information is inaccurate, BEIS will inform parent in writing and County shall amend information. County shall inform parent in writing when information is amended.
6. If BEIS decides information is not inaccurate, BEIS will inform parents of their right to include statement in child's record indicating reasons for disagreeing with decision of the County. County must maintain statement as part of EI Record of the child as long as the record or contested portion is maintained. If EI Record of the child or the contested portion is disclosed to any party, the explanation must also be disclosed to the party.