

CHILD AND FAMILY CONNECTIONS NOTICE OF CONFIDENTIALITY PRACTICES

When your child receives Early Intervention (EI) services, EI will compile personal and health information about your child. This information is usually collected by Child and Family Connections (CFC) on behalf of EI. Information regarding suspected developmental delay or related medical conditions may be collected at intake or at other times while your child is enrolled in EI. This may include your child's past, present or future physical, medical or mental health conditions. EI may also compile information about you (such as information about your pregnancy). Information may be collected from you or your child's primary care physician, specialists, EI providers, and any other person or entity who has relevant information related to the developmental needs of your child. You will be asked to provide written informed consent before EI gathers information from any person or entity related to your child.

EI is required by law to maintain the privacy of you and your child's personal and health information and to inform you of its legal obligations and privacy practices. This notice describes some of the ways in which EI may use or disclose this information, and the rights you have concerning you and your child's personal and health information.

Personally Identifiable Information

The CFC shall ensure the confidentiality of all Personally Identifiable Information (PII) collected or maintained pursuant to Part C in accordance with the Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. 1232 (g), 34 CFR part 99, and 89 Illinois Administrative Code 500. The confidentiality procedures described in this policy apply to PII of a child and the child's family that is contained in EI records collected, used or maintained under Part C from the point in time when the child is referred for EI services until records are no longer required to be maintained under applicable Federal and State law.

Disclosures of Records

EI will obtain your consent for disclosures of PII for the following purposes:

- **Treatment:** EI will obtain your consent before disclosing you or your child's PII to a provider for treatment. For example, EI will obtain your consent before providing your child's occupational therapist with the results of your child's medical diagnostic evaluation.
- **Payment:** EI will obtain your consent before disclosing you or your child's PII for purposes of payment. For example, if you consent to use private health insurance, EI will obtain your consent to send PII to your health insurance company prior to sending the information. If your child is eligible for a government benefit program such as AllKids, and you consent to the use of AllKids to cover the cost of the EI services, EI will obtain your consent prior to sending PII to the Illinois Department of Health and Family Services, the entity which processes AllKids claims.

EI may disclose information without your consent for the following purposes:

- **When Required by Law:** EI may disclose you or your child's PII when require by federal, state or local laws. For example, EI may disclose information pursuant to a Federal Grand Jury subpoena.
- **Federal Oversight and Monitoring:** EI may disclose you or your child's PII to an office or agency of the federal government in connection with the federal government's oversight or monitoring information. For example, EI may disclose information to the Office of the Special Education Programs in connection with periodic program audits. In most cases, the information disclosed for this purpose will not identify the individual.
- **Illinois Department of Human Services:** Information collected from the CFC may be shared with the Illinois Department of Human Services, EI Program, the State Agency responsible for administering and overseeing the Illinois EI program.
- **In An Emergency:** EI may disclose you or your child's PII to medical or law enforcement personnel if the information is needed to prevent immediate harm to you or your child.

Right to Inspect and Copy EI Records

Parents have the right to inspect and review any EI records, including records related to evaluations, assessments, screenings, eligibility determinations, development and implementation of your child's Individualized Family Service Plan (IFSP), provision of EI services, individual complaints involving the child, or any part of the child's EI record. The CFC must reply with a request without unnecessary delay, and in all cases within 10 calendar days after the request has been made. The right to inspect and review includes: (1) the right to a response from the CFC to reasonable requests for explanations and interpretations of the EI records; (2) the right to request copies; and (3) the right to have you or your child's representative inspect and review the EI records.

Copy Charges

You shall be provided at no cost a copy of each initial evaluation, assessment and family assessment and IFSP as soon as possible after the initial IFSP and a copy of each evaluation, assessment of the child and IFSP as soon as possible after each update or annual IFSP meeting. The CFC may charge a reasonable fee for additional copies of EI records as long as the fee does not effectively prevent you from exercising your right to inspect and review the records. The CFC may not charge a search fee to retrieve information.

Right to List of Types and Locations of Records

You have the right to request the CFC to provide a list of the types and locations of personal and health information about you or your child collected, used or maintained by EI.

Amendment of Records at Parent's Request

If you believe that information in the EI records are inaccurate, misleading or violates the privacy or other rights of the child or parent, you may request that the CFC amend the information. The CFC must decide whether to amend the information within five business days of the request.

If the CFC denies the request to amend the records, the CFC must inform you of your right to an informal hearing. The date of your informal hearing will be set within seven days from the date the CFC denies the request for amendment. You will be given the opportunity to present evidence and may, at your expense, be assisted or represented by one or more individuals, including an attorney. A decision will be issued in writing within ten business days of the completion of the hearing. The decision must be based solely on the evidence presented at the hearing, and must include a summary of the evidence and the reasons for the decisions.

If the outcome of the hearing is that the record must be amended, the information shall be amended and you shall be informed in writing that the record was amended. If the outcome of the hearing is the record does not need to be amended, you will be notified that you have the right to place in the EI record a statement commenting on the information and setting forth any reasons for disagreeing with the decision. The statement must be maintained as part as the EI record as long as the record is maintained by the CFC and if the records are disclosed to any party, the statement also shall be disclosed to the party.

Right to Receive an Accounting of Disclosures

You have the right to request a list of each time EI has disclosed PII for reasons other than access by parents, authorized representatives of parents, the Illinois Department of Human Services, the CFC, EI treatment providers, or certain other reasons as provided by law. You must submit your request in writing to your local CFC. The CFC shall disclose: (1) the name of the party; (2) the date access was given; (3) and the purpose for which the party is authorized to access the EI records.

Access to Records

Each CFC must maintain, for public inspection, a current list of those employees within the agency who may have access to PII. The list shall detail the specific type of information each person has access to. The list shall be kept current.

Safeguarding Information

All paper records maintained at the CFC regarding you or your child shall be secured with a locking mechanism. Only authorized personnel shall have access to such records. Email communications between you, any other individual designated by you, and/or the CFC shall be encrypted and password protected unless you sign a consent to allow communication via a public internet system.

Retention of Records

Records shall be maintained for a period of 6 years, unless legal action is pending. If legal action is pending, the records shall be maintained in compliance with instructions from the Administrator of the EI Program.

Destruction of Records

At intake, the CFC shall inform the parent that records must be maintained for a period of 6 (six) years. If the parent would like the records destroyed at the end of the 6 (six) year period, the CFC shall destroy the records. This means the records will be physically destroyed or all personal identifiers are removed from the record so that the record is no longer personally identifiable. However, a permanent record of a child's name, date of birth, parent contact information (including address and phone number), names of service coordinator(s) and provider(s), exit data (including year and age upon exit, and any programs entered into upon exiting) may be maintained without time limitation. The records shall not be destroyed if litigation is threatened or pending without written permission from the Administrator of the EI Program.

Records on More Than One Child

If an EI record includes information on more than one child, you only have the right to inspect and review the information relating to your child or to be informed of that specific information.

Enforcement

You may file a State Complaint for violations of any of these procedural safeguards.

Native Language

This notice is provided publicly in Spanish and English and is available, to every extent possible, in the native language normally used by the child/family. Contact your CFC Service Coordinator to request this notice in a language other than those publicly offered.

To receive additional information or to file a complaint with EI, please contact your CFC Program Manager.

Under the provisions of the Illinois Mental Health and Developmental Disabilities Confidentiality Act, the Family Educational Rights and Privacy Act, 20 USC 1232g, and the Health Insurance Portability and Accountability Act of 1996, information collected hereunder may not be redisclosed unless the person who consented to this disclosure specifically consents to such redisclosure or the redisclosure is allowed by law.