

# MISSOURI FIRST STEPS PARENTAL RIGHTS STATEMENT



The Missouri Department of Elementary and Secondary Education (DESE) makes sure the First Steps program follows Part C of the Individuals with Disabilities Education Act (IDEA), the law that allows for all eligible children to receive early intervention services regardless of race, culture, religion, or ability to pay. DESE contracts with ten System Point of Entry (SPOE) agencies to operate the First Steps program from regional offices.

In First Steps, parents have the right to:

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## **Prior Written Notice**

Parents must receive written notice a reasonable time before the SPOE proposes or refuses to start or change the identification (eligibility), evaluation, location or delivery of services to the child and the child’s family. The notice must inform the parent of the action being proposed or refused and the reason for the action. A copy of the Parental Rights Statement must be provided with the notice.

Notices must be written in a way that is understandable to the general public and in the native language of the family. Native language is the language or means of communication normally used by the parent. If a family uses another means of communication, such as sign language or Braille, they have the right to receive the notice in that way.

## **Consent**

Consent means the parent: is fully informed of all information related to the activity for which consent is requested, in the parent’s native language or other means of communication; understands and agrees in writing to the carrying out of the activity for which consent is requested; and, understands that the granting of consent is voluntary and may be taken back at any time. If the parent takes back consent it does not apply to an action that occurred before the consent was taken back.

Written parental consent must be obtained before:

- an evaluation and all assessment(s) of a child are conducted;
- services are provided to the child or family;
- public insurance (MOHealthNet/Medicaid) or private insurance is used; and,
- sharing with or requesting personally identifiable information from individuals outside of First Steps.

When a parent gives consent for an evaluation/initial assessment of the child, the evaluation is completed by at least two professionals who take the child’s history, gather information from other sources, review medical, educational and other records, administer an evaluation instrument and identify the child’s functioning in each developmental area: adaptive behavior, communication, cognition, physical (including vision and hearing) and social/emotional, unless medical or other records confirm eligibility. This consent also includes, for an eligible child, an initial assessment of the child to prepare for the Initial Individualized Family Service Plan (IFSP) and to identify the unique strengths and needs in each developmental area (adaptive

behavior, communication, cognition, physical and social/emotional), observations of the child and review the evaluation of the child, unless medical or other records confirm eligibility.

When a parent gives consent for an ongoing assessment of the child, the assessment is completed by at least two professionals who collect information in each developmental area (adaptive behavior, communication, cognition, physical (including vision and hearing) and social/emotional), including observations of the child and a review of the evaluation of the child, unless medical or other records confirmed eligibility.

The parents of a child with a disability can either accept or decline any services for the child or the family at any time. The parents may decline a service after first accepting it, without impacting other services.

If consent is not given, the SPOE must explain the evaluation and assessment or the services that would be available and help the parent understand that their child will not be able to receive the evaluation and assessment or services unless consent is given.

If consent is not given, the SPOE will not challenge the parent's decision. However, if the parent does not give consent and that is considered neglect under Missouri law, a report will be made to the proper authorities as required by state law.

### **Individualized Family Service Plan (IFSP)**

Within 45 days of the referral, a meeting must be held for each eligible child and family to develop an IFSP. The IFSP is written for a year and is reviewed at least every six months. The IFSP includes: the child's present levels of development; outcomes for the child and family; how progress is measured; services to be provided; payment arrangements for services; and discussions about transitions during the child's time in First Steps and upon exiting First Steps at age three.

### **Confidentiality**

The First Steps program collects child and family information and maintains a paper and electronic record on every child referred to the program. Information is gathered from the family, providers, and others identified by the parents as having knowledge about the child. This information is used in the referral, intake, eligibility determination and IFSP processes. The SPOE must protect the confidentiality of personally identifiable data, information and records at collection, maintenance, use, storage, disclosure, and destruction stages.

Written consent must be obtained before personally identifiable information is shared with anyone outside the First Steps system. The First Steps system includes SPOE staff, the child's Service Coordinator, the child's providers, the Central Finance Office, and DESE.

### **Destruction of Information**

The SPOE maintains a paper record and an electronic record for each child referred to First Steps. The child's paper record is kept at the SPOE for at least three years from the date the child no longer receives early intervention services and then the child's paper record is destroyed. The parent may request, in writing, the child's paper record be destroyed anytime after the record is no longer needed to provide services. However, the electronic record containing the child's name, date of birth, parent's address and phone number, names of Service Coordinators and providers, the child's IFSP, provider progress notes and exit data will be maintained by the First Steps program without time limits.

## **Review of Records**

The parents of children who have records in the First Steps program can review all records about the child and the child's family. This includes paper and electronic records of the evaluation, assessments, eligibility determination, IFSPs, provider progress notes, individual complaints involving the child, or anything else in the child's record.

The SPOE must answer a parent request to access records, without delay, before any IFSP meeting or any hearing, and in no case more than ten calendar days after the request has been made.

Parents have a right to:

- an answer from the SPOE when requesting an explanation of the child's record;
- request that the SPOE provide copies of the child's record; and,
- have a person selected by the parent review the child's record.

If a document in the child's early intervention record includes information on more than one child, parents accessing the record have the right to inspect and review only the information relating to their child.

The SPOE may assume that the parent has authority to review records relating to the child unless the SPOE has been provided documentation that the parent does not have the authority under laws governing such matters as custody, foster care, guardianship, separation, and divorce.

The SPOE must document who accesses the paper record, except access by those in the First Steps system, including the name of the person, the date access was given, and the purpose for accessing the record. The parent may receive, upon request, a list of the types and locations of records used by First Steps.

The SPOE may charge for copies of records, but only if the fee does not prevent the parents from reviewing those records. The SPOE may not charge a fee to search for or to collect information. The SPOE must provide at no cost to parents, a copy of each evaluation, assessment of the child, and IFSP as soon as possible after each IFSP meeting.

A parent who believes information in the child's record is inaccurate, misleading, or violates the confidentiality or other rights of the child or parent may make a written request that the SPOE change the information. The SPOE must decide whether to change the information within a reasonable period of time after receiving the request. If the SPOE refuses to change the information the SPOE must inform the parent of the refusal and inform the parent of the right to a hearing.

DESE must, on request, provide parents with the opportunity for a hearing to challenge information in the child's records to make sure that it is accurate and does not violate the confidentiality or other rights of the child or parent. A parent may request a due process hearing by contacting DESE.

If as a result of the hearing, the information is found to be inaccurate or in violation of the confidentiality or other rights of the child, the SPOE must change the information and inform the parents in writing.

If, as a result of the hearing, it is found that the information is accurate and does not violate the confidentiality or other rights of the child, DESE must inform the parent of the right to place in the records a statement of any reasons for disagreeing with the hearing decision. Any statement placed in the child's records must be kept by the SPOE as part of the child's records as long as the record is kept. If the child's records or the challenged part of the record is shared by the SPOE, the statement must also be shared.

## **Mediation**

The parent and DESE, the SPOE or provider will be offered the opportunity to use mediation to settle disagreements at any time. Parents interested in mediation should file a request with DESE.

The written mediation request must include:

- The name and contact information for the person requesting mediation;
- The name and address of the child;
- An indication whether the mediation involves a child complaint or due process;
- A description of the problem; and,
- A proposed solution for the problem.

Mediation is:

- voluntary on the part of all parties;
- not used to deny or delay a parent's right to a due process hearing, or to deny any other rights under Part C of the IDEA; and,
- carried out by a qualified and impartial mediator who is trained in effective mediation techniques. The impartial mediator may not be an employee of DESE, the SPOE or a provider who provides services to the child; and must not have a conflict of interest. The person selected as mediator is not an employee of DESE just because he or she is paid by DESE to be a mediator.

Mediation services are provided at no cost to the parent. The parent and DESE must agree to use mediation and use an impartial mediator selected from a list of qualified mediators kept by DESE.

Mediation must be scheduled within 15 days of selecting a mediator and at a location the parent and DESE, the SPOE or provider agree upon. Discussions that occur during the mediation process are confidential and may not be used as evidence in any other due process hearing or civil proceeding of any federal court or state court. Mediation must be completed within 30 days of the decision to mediate.

No more than three people can come with the parent or other party to mediation unless both parties agree to allow more. Attorneys are not allowed to participate or attend the mediation session. The parent may be accompanied by an advocate.

Any agreement reached by the parties in the mediation process must be set forth in a written mediation agreement that is legally binding. The agreement will state that discussions held during the mediation are confidential and cannot be used later in a due process hearing or civil action. The agreement is signed by both the parent and a representative of DESE, the SPOE or provider who can bind the agency. The agreement is enforceable in any state court of competent jurisdiction or in a district court of the United States.

## **Child Complaint**

If any person or organization believes DESE, the SPOE or provider has violated any State or federal law or regulation in Part C of the IDEA, they can file a signed, written child complaint with DESE.

The written child complaint must include:

- A statement that DESE, the SPOE, or provider has violated a requirement of Part C of the IDEA;
- The facts on which the statement is based; and,
- The signature and contact information for the person filing the complaint.

If the complaint concerns a specific child, the written child complaint must also include:

- The name and address of the child;
- The name of the provider serving the child;
- A description of the problem, including facts relating to the problem; and,
- A proposed solution for the problem.

The complaint must be about a violation that occurred not more than one year prior to the date that the complaint is received.

The person filing the complaint must send a copy of the complaint to the SPOE or provider serving the child at the same time the complaint is filed with DESE. The person filing the complaint will have the opportunity to submit additional information, either verbally or in writing, about the complaint.

DESE, the SPOE or a provider will have an opportunity to respond to the complaint, and there will be an opportunity for the parent and DESE, the SPOE, or provider to voluntarily participate in mediation.

The complaint will be investigated through a review of all related information which may include interviewing parents, providers or other persons with information. An onsite investigation will take place if DESE determines this necessary. A written decision with findings of fact, conclusions and the reasons for DESE's final decision as to whether DESE, the SPOE or provider has violated Part C of IDEA will be sent to all those involved in the complaint within 60 calendar days of the filing of the complaint. The 60 calendar day timeline will be extended only if special circumstances exist or if the parent and DESE, the SPOE or provider involved agree to extend the time to participate in mediation.

If DESE, the SPOE or provider is found in violation, DESE must address how to correct the violation, including, as appropriate, making up missed services, financial reimbursement, or other actions that meet the needs of the child and future delivery of services for all families of children with disabilities.

If a written complaint is received that is also the subject of a due process hearing, or contains multiple issues that are a part of that hearing, DESE will not investigate the part of the complaint that is being addressed in the due process hearing until the conclusion of the hearing. However, any issue in the complaint that is not a part of the due process hearing must be investigated within the 60 calendar day timeline.

If an issue in a child complaint has already been decided in a due process hearing involving

the same people, the hearing decision controls that issue and DESE must inform the person filing the complaint of that decision. A complaint claiming DESE, the SPOE or provider failed to follow through with a due process decision must be investigated by DESE.

### **Due Process Hearing**

Parents and DESE have the right to work out disagreements through a procedure called a due process hearing. To begin a due process hearing, a written request with a description of the problem must be submitted to DESE.

The written due process request must include:

- The name and contact information for the person requesting due process hearing;
- The name and address of the child;
- A description of the disagreement; and,
- A proposed solution for the disagreement.

The request for a due process hearing must include a disagreement that occurred not more than one year before the date of the request.

The due process hearing must be carried out at a time and place that is convenient to the parents. DESE must make sure that, not later than 30 days after receiving a parent's due process request, the due process hearing is completed and a written decision mailed to each of the parties. A hearing officer may extend the time beyond the 30 days at the request of either party.

The hearing will be conducted by an impartial hearing officer paid by DESE. This hearing officer must know about early intervention services, the Part C requirements and the needs of eligible children and their families, and must not be an employee of DESE, the SPOE or provider who delivers services to the child. Hearing officers must not have a conflict of interest that would affect the hearing officer's ability to make an impartial decision. The hearing officer shall not be an employee of any agency involved in the care of the child. A hearing officer is not an employee of DESE just because the hearing officer is paid by DESE to hold the due process hearing. The hearing officer will listen to the presentation of the parties involved, review the information presented, make a decision on the issues and provide a written decision.

Any parent involved in a due process hearing has the right to:

- have an attorney represent them and have individuals with special knowledge or training in early intervention services for children with disabilities participate in the hearing;
- present evidence and confront, cross-examine, and require the attendance of witnesses;
- exclude evidence that has not been shared with the parent at least five days prior to the hearing;
- obtain a free written or electronic word for word record of the hearing; and,
- obtain a free copy of the final decision which includes written findings of fact.

If the due process complaint involves the child's ongoing services, unless otherwise agreed to by the parent and DESE, the SPOE or provider, the child will continue to receive the services in their IFSP that were being provided at the time the parent requested the due process hearing.

If the due process complaint involves initial services, the child must receive those services that are not in disagreement.

If the parent or the DESE disagrees with the final due process decision, either party has the right to appeal to a state or federal district court.

### **Educational Surrogate Services**

A child has the right to an Educational Surrogate if they are a ward of the State or do not have a parent that can be identified or found. An Educational Surrogate will represent the child in the evaluation and assessment of the child, the development and review of the IFSP, the ongoing delivery of services and any other rights established under the IDEA.

The SPOE must determine if an Educational Surrogate is needed for a child and submit a request for an Educational Surrogate to DESE. Appointment of an Educational Surrogate shall be made by DESE from a group of approved surrogates who live near the child. DESE must make reasonable efforts to make sure an Educational Surrogate is assigned not more than 30 days after a SPOE determines the child needs an Educational Surrogate.

For children who are wards of the State or placed in foster care, the SPOE must talk with the agency that has been assigned care of the child. In the case of a child who is a ward of the State, the Educational Surrogate may be chosen by the judge handling the child's case.

The Educational Surrogate selected must have no conflict with the interests of the child he or she represents and must have knowledge and skills to represent the child. The Educational Surrogate may not be an employee of any State agency and may not be a provider who delivers services, education, or care to the child or any family member of the child. A person who is qualified to be an Educational Surrogate is not an employee of DESE just because he or she is paid by DESE to be an Educational Surrogate. The Educational Surrogate has the same rights as a parent for all purposes under Part C of IDEA.

**To find out more about the First Steps program, visit the First Steps website at:**

<http://dese.mo.gov/special-education/first-steps>.

**For more information about First Steps parental rights:**

Contact your Service Coordinator

Call the SPOE office toll-free at:

**1-866-583-2392**

Contact the DESE office at:

**Office of Special Education**

**P.O. Box 480**

**Jefferson City, MO 65102-0480**

**(573) 751-5739; RELAY in Missouri 1-800-735-2966 TDD**

The Department of Elementary and Secondary Education does not discriminate on the basis of race, color, religion, gender, national origin, age, or disability in its programs and activities. Inquiries related to Department programs and to the location of services, activities, and facilities that are accessible by persons with disabilities may be directed to the Jefferson State Office Building, Office of the General Counsel, Coordinator – Civil Rights Compliance (Title VI/Title IX/504/ADA/Age Act), 6<sup>th</sup> Floor, 205 Jefferson Street, P.O. Box 480, Jefferson City, MO 65102-0480; telephone number 573-526-4757 or TTY 800-735-2966; email [civilrights@dese.mo.gov](mailto:civilrights@dese.mo.gov).