

SCHOOL AND DEVELOPMENTAL SERVICES FOR YOUR CHILD



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SCHOOL AND DEVELOPMENTAL SERVICES FOR YOUR CHILD WITH SPECIAL NEEDS

The services your child needs will depend on their age and the severity of their condition. The most common resources needed include therapies to maximize the child's development, special accommodations in school and financial support of the child.

DEVELOPMENTAL SUPPORT FOR INFANTS AND YOUNG CHILDREN

Children diagnosed with developmental delays who are younger than 3 years of age, are referred to programs that provide developmental assessment and intervention (often within the child's home). These programs vary from state to state in how they are funded and what specific services are available. In some states, they may be free; in others, the services may be billed to insurance; and in many states, the cost is dependent on the income of the family. Your health care provider may be able to assist you in obtaining these services by writing a letter describing your child's medical diagnosis and specific needs. Information for early childhood programs in Missouri and Illinois are listed below.

First Steps (Missouri)

1-800-583-2392

First Steps is Missouri's Early Intervention system that provides services to families with children, birth to 3 years of age, with disabilities or developmental delays. The program is designed to meet the needs of families related to enhancing their child's development, learning and participation in family and community life.

Child and Family Connections (Illinois)

1-847-377-8931

Children, age birth to 3 years of age, eligible for early intervention services, must be experiencing developmental delays in one or more of the following areas: cognitive development; physical development, including vision and hearing; language and speech development; psycho-social development; and self-help skills. Children may also be eligible due to diagnosed physical or mental conditions, such as cerebral palsy or Down syndrome, or certain family circumstances that put them at risk of having substantial delays.

SPECIAL NEEDS IN THE SCHOOL SYSTEM: THE IEP

Children with developmental disabilities 3 years of age and older are generally treated within the school system. Services offered vary from school district to school district, but each school should strive to support the child to maximize their development. Most schools evaluate and set goals for a student through the development of an Individualized Education Program (IEP). The IEP is the legal document



that defines a child's special education program. It is created following a formal evaluation of the child by therapists specializing in the treatment of children with special needs. An IEP includes the disability under which the child qualifies for Special Education Services (also known as a child's classification), the services the team has determined the school will provide, the child's yearly goals and objectives, and any accommodations that must be made to assist the child's learning. A school professional may ask that a child be evaluated to see if he or she has a disability requiring intervention. Parents may also contact the child's teacher or other school professional to ask that their child be evaluated.

This request may be verbal or in writing. Parental consent is needed before the child may be evaluated. Evaluation needs to be completed within a reasonable time after the parent gives consent. Once in place, the IEP should be revisited regularly (at least yearly) to determine if goals have been met and to set new goals for the next evaluation period. Parents should play an active role in this process by discussing their wishes and concerns for their child with the evaluation and treatment teams.

FINANCIAL SUPPORT: SOCIAL SECURITY

Children from birth up to age 18 may qualify for Supplemental Security Income (SSI) benefits. SSI can provide a monthly payment to families to support the care of a child with special needs. Most children who get SSI are also eligible for state insurance assistance such as Medicaid. To be eligible for SSI, they must be disabled and they must have little or no income and resources. In general, Social Security has a strict definition of disability for children.

- The child must have a physical or mental condition(s) that very seriously limits his or her activities; and
- The condition(s) must have lasted, or be expected to last, at least one year or result in death.

If you would like to apply for SSI on behalf of your child, contact the Social Security Administration (SSA) at 1-800-772-1213. They will ask for information from you, your child's health care providers and from the child's school. Sometimes the SSA office will arrange an examination or test for the child to determine eligibility. In general, this testing is paid for by the agency. After reviewing the information you provide, a state agency makes the disability decision. Many applications are denied after the initial evaluation and some families choose to reapply.

ADDITIONAL RESOURCES FOR FAMILIES: MPACT

MPACT's mission is to empower families of children with special needs to advocate for themselves – through support, training and education. They offer many helpful resources including printable information on school services, transition and dispute resolution. In addition, their website includes numerous fact sheets and sample letters (e.g. to request forms or services) and links to useful community resources. In Missouri, MPACT can be reached at 1-800-743-7634 or online at ptimpact.org.

A PARENT'S PERSPECTIVE ON IEP'S

Individualized education plans can be a stressful experience for many parents, but it doesn't have to be if you approach it with proper planning, communication and a positive outlook. Here is a glimpse of the prep work and resources I've used to make the meetings run smoothly and effectively:

- **Plan Ahead:** All IEP meetings have a component where parents have an opportunity to share their child's strengths, concerns and future goals. It's easier to brainstorm all of these questions over several days than to try to remember them quickly when you are under stress. To accomplish this I make a "Meet Katie" sheet that includes her picture to help them focus on and identify with your child. By creating these information sheets you'll feel confident that you won't forget anything and it will make the meeting shorter. I include sections on:
 - ~ strengths
 - ~ weaknesses
 - ~ what you want your child to accomplish over the next year and into the future
 - ~ favorite things
 - ~ concerns for her school day
- **Think about educational needs and care:** Although the majority of the IEP will be centered on learning goals, it's important to think about what aid your child will need day-to-day such as toilet training, fire drills, navigating around school and carrying lunch trays.
- **Bring educational resources about your child's medical diagnosis (if they have one):** Many conditions come with their own unique learning profile. Bring pamphlets and education guides to give the teachers and therapists.
- **Bring advocates:** Bring a second person who is familiar with your child's needs to the meeting. Even if they aren't active participants, having someone to listen impartially is important. I request a state advocate from the Department of Mental Health who is familiar in disability law to support me in this role.
- **Know your options:** If you feel your child needs special services, such as an aide, don't be afraid to ask for it but when you do, provide sound reasons why your child needs that support. School districts will want what is best for your child, but within limitations. Start with your largest priority and focus talk around safety and guaranteeing your child's participation in a least restricted environment.
- **Stay positive:** Accusations and threats are not received well by others. You should be confident and be an advocate but remain kind and professional. Keep your discussion child-centered. The

IEP is all about what is best for your child's success. When discussing goals and modifications, always evaluate if the goals are centered on what your child needs to be successful.

- **Follow up:** If you aren't happy with the results, say so. You are not required to sign right away and can call another meeting if you feel there is more to discuss. Once the IEP is in place, maintain contact with your child's educators and therapists. Share new information about your child's diagnosis as new research or articles are available. Diagnosis-specific family advocacy groups may offer web-based resources about ideal ways to approach speech, physical and occupational therapy and approaches issues specific to children with your child's diagnosis. Ask therapists to send home reports of exercises they are working on so you can reinforce them in your own home. If you work as a team with your child's educators you'll be amazed by the achievements your child will make!



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Resources/Quoted Materials:

Missouri First Steps Website www.mofirststeps.com

Illinois Child and Family Connections Website www.dhs.state.il.us

Social Security Administration Website www.ssa.gov

MPACT Website www.ptimpact.org

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