

Education Issues

Parent of children with osteogenesis imperfecta (OI) need to become familiar with the federal and state services that are available to provide a free and appropriate education designed specifically to meet their child's needs. Parents will need to be aware of and take an active role in obtaining these services, which are available from birth through age 21.

Background

The federal law that supports special education and related service programming for children and youth with disabilities is called the **Individuals with Disabilities Education Act (IDEA)**. This law was enacted in 1975 and amended in 1986.

The IDEA is a federal law and, as such, provides minimum requirements that states must meet to receive federal funds to assist in providing special education and related services. Each state has its own laws and regulations. Parents can learn about the specifics by contacting their local public school system's central office and/or their state's Department of Education, Office of Special Education.

Early Intervention Services

Early intervention services for infants and toddlers are designed to identify and treat a problem as early as possible. These services are offered through a public or private agency and are provided in different settings, such as the home, a clinic, a neighborhood daycare center, hospital, or the local health department. Often, they are provided at no cost to the family. Good sources of information include the child's pediatrician and the local public school system's office of special education.

Obtaining Special Education Services for Your School-Age Child

The first step in obtaining special education services for your school-age child is to contact the school districts' office on special education and learn about which programs are offered and the process for obtaining services. Public and private schools typically offer different services depending on the state's laws. Each child is evaluated by school personnel and then recommended for an Individualized Education Program (IEP) or a 504 plan. Each type of plan offers different levels of service. The main issue for a child who has OI is ensuring a safe learning environment that meets his/her needs as a child, a student and a person with a physical disability.

As the child progresses through school, the need for services will be re-assessed yearly. Significant changes often occur at the move to middle school and again high school. The age of the child, the size of the student body and the size of the school building are all significant factors.

Tips for Parents

There are a number of things you can do to ease your child's transition into the classroom.

- Start the process early. Do not wait until a few days before the first day of school.
- Well before school opens, meet with the teachers to explain OI and provide pamphlets and brochures from the OI Foundation.
- Explain that fractures may occur and when they do, no one—including the teachers and other children—should feel that they are at fault. Emphasize that the benefits gained by the child's participation in a regular school program far outweigh the risk of a fracture, which could occur wherever the child may be. Provide a telephone number should an emergency arise, along with other instructions should a fracture occur.
- Decide together whether a parent, the teacher or the OI child will explain OI to the other children
- Explain to the teachers that it is best for your child to be treated the same as the other students, equally and without special favor or attention. It is most beneficial if the teachers understand the child's strengths and limitations and know that they have the full support of the parents.

- Arrange for an ambulatory child with OI to change classes a few minutes before the bell rings to prevent unnecessary physical contact in crowded halls.
- Keep a separate set of books at home for the student to use to avoid the need to carry heavy books for homework. Many older children use electronic text books.
- Modifications can be made in the curriculum so that a child can participate in regular programs, including gym, to the fullest extent possible.
- Many schools hire a full-time aide to assist a child using a wheelchair to get around. However, once a child has reached second grade, other classmates can sometimes be enlisted to assist the student in getting around or with other activities, when appropriate.
- If your child uses special equipment to accomplish a necessary activity, you can offer to provide the same equipment for use in school.

After High School

Most children who have OI can expect to live a nearly average life span so planning for an adult life and a career is important. Parents and young people are advised to begin working with school counselors at an early age.

Many young people who have OI attend college or participate in other education and training programs. In most cases, the only deterrents facing the student with OI in choosing a college is optimum accessibility of both the learning and living facilities and access to medical care. Many colleges and universities have support services to assist in the accommodation of students with disabilities. Personnel providing these services can often be helpful in providing information to help prospective students determine whether the college will meet their needs. A visit to any college being considered is imperative to judge the degree of accessibility.