

A School Survival Guide for Parents of Children with Ichthyosis

Stephen G. Pickford

Assistant Principal, Sandy Run Middle School

If you are a parent with a child who has ichthyosis, there are many things to consider ensuring a successful school year for your child. If your child will be entering a school system for the first time this fall, these thoughts can be quite confusing and downright intimidating. This article will offer some suggestions on how to set your child up for success at school this year, whether it is your first foray into the educational system or your child is already attending school.

As a parent, you already know the strengths and weaknesses of your child when it comes to his or her readiness for attending school for the first time. If your child has previously been enrolled in a school system, you have celebrated your child's successes and wondered how to help with his or her areas of weakness. There are some practical steps you can take that apply to both situations.

Ichthyosis affects each individual differently. Depending on the severity of the symptoms exhibited by an individual, this may or may not have an effect on the child's ability to perform at a level consistent with his or her age group peers. If a child does exhibit some developmental delays in cognitive functioning because of how the disease has affected his or her physical and/or mental growth, these are warning signs the child will need some special accommodations in a school setting. If the child is progressing with his or her age-appropriate peers, other accommodations can be made in terms of the health issues surrounding the treatment of his or her particular variety of ichthyosis.

Communicate with teachers regarding involvement in the educational progress: such as special equipment, medication, medical problems, activities or events that might affect performance, student work and grades. Ask how to support or build upon school activities and learning at home. Volunteer to help in the classroom or school, and encouraging behavior that leads to success at school because success at school for your child is the bottom line. It is also a good idea to schedule a meeting with the principal, guidance counselor, and nurse prior to the beginning of school. Discuss your child's special interests and skills, medical treatments and privacy during school hours, the side effects from medicines and or treatments, transportation issues, what your child excels at, strengths and weaknesses, seating arrangements, and other issues you feel are important to the success of your child at school.

Decide beforehand how to handle intrusive questions or ridicule. Do you want to present the information about ichthyosis to the class on the first day of school? How will this be handled? Who will be responsible for the special accommodations regarding overheating, medicines, and other issues? Your child may need some other special accommodations outside of the normal school rules. Clothing issues may arise from hats or sunglasses needed by your child that violate dress codes. Your child may require seating in cushioned chairs or seats away from windows and/or bright areas. Outdoor play and overheating should be discussed. Also frequent water breaks, sunscreen, cooling vests, temperature maximums and other restrictions for physical education participation without total exclusion from everyday school activities should also be reviewed prior to the start of the school year. These special accommodations can sometimes be provided under section 504 of the Rehabilitation Act of 1973. Section 504 makes it illegal for any group receiving federal money to be unfair to a person with a disability. It applies to any school that receives federal money. Section 504 is a civil rights law, which prohibits discrimination against individuals with disabilities. Section 504 ensures that the child with a disability has equal access to an education. The child may receive accommodations and modifications. Unlike IDEA, Section 504 does not require the school to provide an individualized educational program (IEP) that is designed to meet the child's unique needs and provides the child with educational benefit. Fewer procedural safeguards are available for disabled children and their parents under Section 504 than under IDEA.

If you believe your child will need some academic accommodations in school, schedule a meeting with the school guidance counselor and principal prior to the beginning of the school year. Find out about the special services and programs your school district offers to individuals with special needs. Learn more about the Individuals with Disabilities Education Act (IDEA). This federal law gives your child the right to receive special accommodations in an academic setting. This is instruction specifically designed to meet the unique needs of children with disabilities. Over five million children ages six to 21 receive special education and related services each year in the U.S. at no cost to parents. IDEA was designed to meet the child's unique needs that result from having a disability and to help the child learn the information and skills that other children are learning.

How do you know if your child is eligible for special services? IDEA provides a definition of a child with a disability. The disability must affect the child's educational performance. The child must fit into one of the 13 disability categories established by IDEA, and the disability must cause the child to need special education and related services.

The 13 disability categories established by IDEA are autism, deafness, deaf-blindness, hearing impairment, mental retardation,

multiple disabilities, orthopedic impairment, other health impairment, serious emotional disturbance, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

How can you be sure your child has a special need? Write to the school district's Director of Special Education or local principal requesting that your child be evaluated for special education services. Written notification will start the timelines for evaluation if the school district agrees to an evaluation. Always keep a copy for your records.

What happens during an evaluation? The school must evaluate your child in all the areas where your child may be affected by the possible disability: health, vision, hearing, social and emotional well-being, general intelligence, performance in school, and how well your child communicates with others and uses his or her body. The evaluation must be complete enough to identify all of your child's needs for special education and related services. An appropriate evaluation will give you and the school a lot of information about your child. This information will help you and the school to determine if your child has a disability and then design instruction based on your child's special needs.

The evaluation has been completed, now what? If your child is found not to be eligible for special education, it must be in writing, an explanation given, and you must be given information about what to do if you disagree with the evaluation and want to challenge district's decision. Most states also have a Parent Training and Information Center (PTI) you can access on the web for more specific answers to your questions. If your child is found eligible for an Individualized Education Plan (IEP), that plan must be developed within 30 days of that finding. An IEP sets reasonable learning goals for the student and also states the specific services the district will provide. Other information found in an IEP includes present levels of educational performance, annual goals, special education and related services to be provided, participation with non-disabled children, participation in state and district-wide assessments, transition services, and measuring progress.

Who develops the IEP for your youngster? The parents and child (when appropriate), the regular education teacher, a special education teacher, a district representative (LEA), the school psychologist to interpret the evaluation results, and other individuals such as a speech therapist or occupational therapist.

What happens during the IEP meeting? The child's strengths and needs are discussed by the IEP Team to decide the educational and other appropriate goals for your child, the type of special services your child needs, and the related services your child may require to benefit from his or her special education plan.

What are the "related services" for which your child may be eligible? Transportation, speech and language pathology, audiology services, physical therapy, occupational therapy, recreation, counseling services, orientation and mobility services, medical evaluation or diagnostic services, psychological services, parent counseling and training, and other related services. Each state will vary in the services offered to IEP students.

Infants and toddlers also can receive services under the IDEA umbrella. These services are called early intervention services for children up to 2 years old and preschool services for children ages 3-5. Contact your local state agency for more information.

Hopefully, this article has answered many of your questions about the special services your child may require in order to have a successful school year. I encourage you to contact your child's school to start to lay the groundwork for a rewarding, enriching, and exciting school year for you and your child.

Website Resources for Parents

www.nasponline.org/advocacy

www.usdoj.gov/crt/ada/adahom1.htm

www.ed.gov/index.jhtml

www.idonline.org/1d_indepth/special_education/

www.orangeusd.k12.ca.us

www.calvertnet.k12.md.us/departments/specialed/adaide504.asp

www.nod.org

www.asha.org/about/Legislation-Advocacy

lone-eagles.com/virginia.htm