

Special Education Accommodations

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 a 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. This resource sheet is designed to inform those families affected with ichthyosis about the options available for special accommodations such as an Individualized Educational Plan (IEP), and a 504 Plan.

IEP Defined

The Individualized Educational Plan (IEP) is a plan or program developed to ensure that a child who has a disability identified under the law, and is attending an elementary or secondary educational institution, receives specialized instruction and related services.

IEP Eligibility

If you believe your child will need special 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. Each district has their own specific IEP policy.

How do you know if your child is eligible for special services? The Individuals with Disabilities Education Act (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 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 needs 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

The ABC's of Adaptations and Accommodations

- A**lphabet strip taped to student's desk.
- B**reak long-range assignments and projects into smaller ones.
- C**alculators, checklists, and computers.
- D**ictate work or assignments to students.
- E**xtended time for tests, projects, and assignments.
- F**lash cards.
- G**roup cooperatively, give cues, graphic organizers.
- H**ighlight main ideas or specific words.
- I**nstruction given orally and in print.
- J**ournal writing could be drawing pictures or scripted by another.
- K**ids use assignment books to organize their work.
- L**arge print or type for easier reading.
- M**anipulatives and models.
- N**umber lines, notebooks.
- O**ral reports in place of written ones.
- P**aired reading, peer tutors.
- Q**uiet space or work area.
- R**ead tests, directions, and assignments.
- S**horten assignments, smaller amounts, study guides.
- T**ape texts and stories, three-dimensional ruler.
- U**se a test format that requires little writing.
- V**erbal responses to questions and tests, vocabulary lists and visuals.
- W**orksheets and/or test written on a lower level.
- X**erox copies of assignments for home and provide examples of projects.
- Y**our tests could be open book or take home.
- Z**ero in on reinforcing concepts through hands-on activities and games.

local state agency for more information. We 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.

504 Plan Defined

Section 504 of the Rehabilitation Act of 1973, makes it illegal for any group receiving federal money to be unfair to a person with a disability. Section 504 is a civil rights law, which prohibits discrimination against individuals with disabilities and ensures that the child with a disability has equal access to an education. The child may receive special accommodations and modifications, specific to their needs. However, unlike IDEA, Section 504 does not require the school to provide an IEP. Section 504 has a broader definition, as outlined below, of a disability than IDEA. Therefore a child who doesn't qualify for an IEP, might still be able to get a 504 plan.

504 Eligibility

As defined by the 504 plan, an individual with a disability is any person who has a physical or mental impairment that substantially limits one or more major life activities. The term physical or mental impairment may include, but is not limited to, conditions such as visual or hearing impairment, mobility impairment, HIV infection, mental retardation, drug addiction (except current illegal use of or addiction to drugs), or mental illness. The term major life activity may include seeing, hearing, walking, breathing, performing manual tasks, caring for one's self, learning, speaking, or working. Section 504 also protects persons who have a record of such impairment, or are regarded as having such an impairment.

Preparing Your 504 Plan

A 504 plan spells out the modifications and accommodations that will be needed for students to have an opportunity to perform at the same level as their peers. It is beneficial to be as specific as possible when describing your child's special needs in the 504 plan. In the case of ichthyosis, some examples might be:

- Classroom needs air conditioning
- Allowing frequent visits the nurse's office to apply cream
- Access to a water bottle at all times
- Allowed to leave gym, or any other class, to go to the nurse's office to cool off, without being penalized for not completing the activity or leaving the class
- Hat allowed in school due to loss of hair
- Special transportation if necessary
- Accommodations for standardized testing such as frequent breaks (see more information below).

Educate School Personnel

Another item to be included on his 504 Plan is to educate all staff about ichthyosis. Staff includes teachers, custodians, secretaries, bus drivers, cafeteria workers, and anyone who will come in contact with the child. It is vital for them to know about ichthyosis and what to do in case a situation arises. Also, it is important to take time to educate classmates and their parents as well. Many tips and resources can be found on the FIRST Blog and website for how to successfully share information about ichthyosis in a classroom setting.

Standardized Tests and Your Child's 504

Be sure your child's 504 includes accommodations for standardized testing, such as breaks, extended test time, and any items needed for self-care (more outlined below). Also of note, the College Board does not honor 504 plans. It is not recognized when taking the tests for college, such as the PSAT, SAT, or AP tests, and possible scholarship money. **You must apply for special accommodations directly from the College Board.**

"When your child enters kindergarten, you will likely meet with administration to develop a 504 plan that will allow your child to complete their education and care for their skin at the same time. You tweak it and change it as they grow to ensure their educational and medical needs can continue to be met effectively. My first piece of advice would be that at no time should you let the administration convince you that your child doesn't need a 504 plan anymore, particularly when they reach high school.

In fact, the 504 plan follows them through college, (yes colleges honor your child's 504). Abby's elementary and middle school were full of wonderful teachers who would have done whatever she needed without the plan, but her high school is more rigid and many times I have found myself saying. "We have always done it this way" and, fortunately, the 504 plan was there to back me up.

However, the College Board testing is entirely different (ie. SAT and PSAT tests). You have to apply to them directly for special accommodations. It can be a long, drawn out process, so my second piece of advice would be to apply as soon as possible."

– Rhayne Evans, mother of Abby Evans, affected with ARCI-lamellar type ichthyosis

Applying for College Board Testing Accommodations

Applying for accommodations can be done in two different ways:

Contact your high school guidance office. This is often a process that takes several months for a response, so you actually may want to apply at the end of middle school. Often schools encourage freshman to take the PSAT and you won't have enough time to get the necessary accommodations if you wait till they enter high school.

Apply directly yourself. You can go to [College Board's website](#) and/or call for guidance. The direct line to "Services for Students with Disabilities" is: 212.713.8333. This connects you to the voicemail prompts for this department. It's best to start early, as it takes 7 to 8 weeks for initial approval. If an accommodation is denied, it is an additional seven weeks for appeal from the day they receive extra documentation. Also you want to allow for general mistakes.

Some of the accommodations your child may need are listed below. However, your child may require additional accommodations:

Breaks as needed and extended breaks as needed. Request that the clock stops during breaks and restarts when they come back from a break. The breaks do not shorten the allowed test time, and it doesn't give them extra actual time while testing.

Extended testing time. This is to give your child extra actual test time if they can't complete the work in the allotted time. A general time extension is called +50%. This gives them time and a half to take the test. So a section that may allow one hour, would be extended to 90 minutes. (This is also a good reason to ask for multiple day testing).

Multiple day testing. This allows for two days to complete the test. This is helpful if your child has a medical emergency and can't complete the test in one day. It may not be needed, however, if there's an issue, it's helpful to have the 2nd day as a safety net.

Permission for food/medication. This allows your child to have a water bottle and their lotion with them in the testing room.

Testing in their home school during the school day. The above accommodations, if granted, make this one automatic, but ask for it in case they deny the other three. By having the test in your child's home school, during the school day, you are assured that a nurse is on the premises as there is no nurse on site during a Saturday test. There is also more control over the room temperature and condition and they will likely take the test either by themselves or in a small group with the SSD person for their school.

Ask for a scribe. If your child's hand contractures are so severe that it impedes their ability to write you can ask for a scribe to write what they dictate.

Preparing Documentation

Some tips for presenting a strong case within your documentation include:

Include information from the FIRST website, in addition to photographs. Highlight the parts that are pertinent to your child's type of ichthyosis and make notes on the printouts to help College Board better understand the condition.

Include letters from doctors. An allergist may write about environmental allergens and the need to be in a controlled environment. A dermatologist may write in regard to the need for access to lotions and medications, dehydration and overheating and the need for a nurse to be on the premises. A family doctor may write about the need for extended time and how, while the itching may not require a break, it would slow your child down and their ability to complete the test. If your child has a hearing impairment get a letter from your audiologist or ENT. Have them all include a line that in their professional opinion, (specific accommodation) is needed.

The more documentation you have the less likely College Board will deny you. Also be sure your form, from their website, is complete. They will not process an incomplete form.

Discuss teacher's survey with teacher prior to them filling it out. When you ask the teachers to fill out the Teacher Survey Form, send them an email outlining what accommodations you are asking College Board to grant. The teachers fill out the form to better suit your needs if they know what you are asking for. Remember most teachers are more than happy to work with you and will do whatever they can to help your child be successful. Don't be afraid to let them know what you need.

Include a copy of your child's most recent 504. This will show what accommodations your child currently receives. It is very important that your 504 matches the accommodations you are asking for as it sets a precedent. That's another reason to be sure your child's 504 reflects accommodations specific to standardized testing.

Finally, write a cover letter. Start with a brief description of your child's condition. Don't be afraid to provide some examples of instances when ichthyosis caused a medical emergency. Whatever information you can provide, will help illustrate the seriousness of your child's health condition. Also outline in your letter which accommodations you are asking for and why you are asking for them, and give examples of how your child's education has been modified in the past.

In summary, the "applying for accommodations" process requires thorough documentation and past precedents. It can be a timely process, so do not hesitate to get started once your child enters high school. In the process, always remember, there is no such thing as too much information.

Website Resources for Parents

WWW.NASPONLINE.ORG/ADVOCACY

WWW.ADA.GOV

WWW.ED.GOV/INDEX.JHTML

WWW.IDONLINE.ORG/1D_INDEPTH/SPECIAL_EDUCATION/

WWW.ORANGEUSD.K12.CA.US

WWW.CALVERTNET.K12.MD.US/DEPARTMENTS/SPECIAL/ADAIDE504.ASP

WWW.NOD.ORG

WWW.ASHA.SLP/SCHOOLS/SCHOOLS_RESOURCES_ADVOCACY

LONE-EAGLES.COM/VIRGINIA.HTM

This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.



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Improve lives and seek cures for those affected by ichthyosis and related skin types.