

WHAT TO KNOW ABOUT YOUR CHILD'S RIGHTS IN SCHOOL

Federal laws mandate that public schools in the U.S. provide free appropriate public education to school-age children with disabilities, including rare diseases like hypophosphatasia (HPP). The information outlined below provides an overview of education laws and services that are available for children with disabilities. Navigating these programs in the schools can be confusing and draining. We're here to help. For more information, consult one of the [Resources](#) or reach out to info@softbones.org with questions.

Overview of School-Based Services for Children with Disabilities

There are essentially two types of services a child with a disability—defined as a physical or mental impairment—can receive in school to ensure their needs are met: Individualized Education Programs (IEPs) and 504 Educational Plans. The main difference is **IEPs are special education services** that modify education, whereas **504 plans are accommodations** that help kids who don't qualify for IEPs but need extra services to succeed academically. Both are described in detail below. There may be other differences in terms of services that fall under each that vary by state. Your child's school can help clarify and determine which plan may be best suited for your child.

What is an IEP?

An Individualized Education Program (IEP) is part of the Individuals with Disabilities Education Act (IDEA), the federal law that ensures eligible children with disabilities receive a free appropriate education. It provides a plan for the student to help them succeed in school with special education and related services. An IEP outlines all of the instructional objectives, goals, benchmarks and accommodations that will help each student learn and progress academically. Services that may be provided in an IEP include:

- Transportation
- Speech, occupational or physical therapy
- Counseling
- Medical services
- Classroom accommodations
- An aide in the classroom or specialized instruction
- Modified classes
- Accommodations for extracurricular activities

A team of educators is assembled to put together the IEP for your child, coordinated by a team leader who will be your main point of contact for the plan. The team may include a school psychologist, special educator, speech, language, physical or occupational therapist, school nurse, and others depending on the child's needs. IEP plans are based on formal assessments that are conducted using standardized measures of the child's academic and functional performance.

IEPs are reviewed annually and modified as needs change. Parents can request an IEP meeting any time if they have concerns or issues they want to discuss.

What is a 504 Plan?

A 504 plan falls under the American with Disabilities Act, a federal civil rights law, that requires schools to assist students with disabilities so they can perform at the same level as other students. 504 plans are not special education services. Rather, they allow students to succeed in the general education classroom. 504 plans are intended to empower students to perform at the same level as their peers.

For example, a 504 plan might allow a student with diabetes to perform blood sugar monitoring at specified times during the day, provide a special seating area for a child with a peanut allergy, or provide educational aids or tools like electronic note takers to a student with attention deficit disorder.

For a student with HPP, a 504 plan might include:

- Modified or extra textbooks for home use
- Technology tools and aids
- Extended time for tests and assignments
- Extra time to get from one classroom to another
- Preferential seating in the classroom
- Reduced homework
- Pre-approved visits to the school nurse's office

Getting Your Child an IEP or 504 Plan

To inquire about either plan or to request an evaluation, parents should contact their child's teacher or the school they attend or will attend. An IEP or 504 plan can be put in place at any point during the school year. What's important to remember is the sooner you start the process, the sooner your child can start receiving services or accommodations that will help them succeed at school. Early intervention is key, so try not to delay the process. For either plan, the school will need to conduct an evaluation to determine eligibility and the best supports for each child.

Know Your Rights

- Your school district should provide you with a written copy of your rights.
- Parents must sign a permission form to have their child evaluated. The form should provide detailed information about who is conducting the testing, what types of tests are being used, and what functional areas are being assessed.
- You should take an active role in developing the plan and ensuring that it meets your child's needs.
- Parents should be able to review an IEP that is in progress.
- If you disagree with the report, you have the right to speak up and work with the school to modify the plan.
- An IEP can be changed or updated over time. Keep track of your child's progress and be sure to contact your child's team leader if you feel something isn't working or your child needs additional support.
- These federal laws establish educational rights for children in public schools. Private schools do not fall under the same mandate.

General Tips for Parents with School-Age Children with HPP

- Establish a consistent routine at home for homework. Even with accommodations, it's important that your child keep up with their peers.
- Encourage your child to be proactive with teachers and speak to them directly if they're having trouble keeping up or need more time to complete assignments.
- Talk to your child's teachers about their HPP—chances are they won't understand what it is and how it impacts your child. It's up to you to educate them.
- If there are changes in your child's condition, such as new symptoms, be sure to notify the school so they are aware.

General Tips for Parents with School-Age Children with HPP (cont'd)

- Some families feel that supplemental services outside of school, such as private tutors or therapists, are helpful. However, you must incur the costs for these services.
- If your child needs to be out of school for an extended time, talk to their teachers or IEP coordinator about how to best transition them back to the school setting and ensure they have the best supports in place for when they return.
- You are your child's best advocate. Stay close to your child's progress, review the reports, ask questions, and always voice your concerns.

HPP and Developmental & Behavioral Health—Special Considerations

HPP can impact social, emotional and behavioral health as well as physical health. Although the connection between HPP and developmental and behavioral health is not yet well understood, a recent study showed HPP can affect sleep, focus, mood and cognitive functioning in certain school-age children and adolescents. Some children may have symptoms of depression, anxiety or attention deficit hyperactivity disorder (ADHD) that can affect their performance at school or ability to socialize with peers.

If parents observe any of these symptoms, be sure to inform your child's teachers and IEP or 504 plan coordinator that these are features of HPP and appropriate modifications, such as extra check-ins with the teacher or school counselor, could be helpful.

In addition, if these are areas of concern for you, when your student is undergoing an evaluation for school services, be sure a neuropsychological evaluation is part of the testing. You can also consider getting an outside evaluation by a trained professional, which can be included in the school's report.

Resources

The following organizations provide information and resources for parents on special education services. You can also refer to your individual state's Department or Agency of Education.

U.S. Department of Education

- The U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website can be found here: <https://sites.ed.gov/idea/>
- Protecting Students With Disabilities and Frequently Asked Questions About Section 504 and the Education of Children with Disabilities can be found here: <https://www2.ed.gov/about/offices/list/ocr/504faq.html>

National PTA

- Special Education Toolkit for Parents: Resources – Provides information and links for parents on a range of programs, services for children with disabilities.
- <https://www.pta.org/home/family-resources/Special-Education-Toolkit/Special-Education-Toolkit-Resources>

The Nemours Foundation

- Provides doctor-reviewed articles, information and tools for parents and kids via [KidsHealth.org](https://kidshealth.org).
- Special Education: Getting Help for Your Child can be found here: <https://kidshealth.org/en/parents/special-ed-support.html>