



Navigating IEPs & 504s

A Guide for Hypophosphatasia (HPP) Parents

As a parent of a child with hypophosphatasia (HPP), navigating the Special Education (SPED) system can be overwhelming and challenging. **Soft Bones is committed to empowering parents with the knowledge, skills, and resources needed to advocate for their child's educational needs.** This Parent Advocacy Toolkit is designed to provide parents with the tools and support necessary to ensure that their child with HPP receives the support they need at home and at school.



Understanding Your Rights

As a parent of a child with HPP, it is essential to understand your rights under the *Individuals with Disabilities Education Act (IDEA)* and Section 504 of the Rehabilitation Act of 1973. Here are some key things to know:

- IDEA requires that schools provide a **free and appropriate public education (FAPE) to children with disabilities, including those with HPP.**
- Section 504 requires that schools provide reasonable accommodations to ensure that children with disabilities have equal access to education.
- **You have the right to request an evaluation for Special Education services** if you suspect that your child may have a disability.
- **You have the right to participate in the development of your child's Individualized Education Program (IEP) or 504 Plan.**



IEP and 504 Plan: What's the Difference?

An IEP and a 504 Plan are **both documents that outline the educational support and accommodations that will be provided to a child with a disability**. However, they are different in terms of their purpose, eligibility criteria, and the services and accommodations they provide.



IEP (Individualized Education Program)

An IEP is a written document that outlines the special education and related services that a child with a disability will receive. It is developed by a team of professionals, including parents, teachers, and other specialists, and is tailored to the child's unique needs.

To be eligible for an IEP, **a child must have a disability that affects their ability to learn or participate in educational activities**. The IEP team will assess the child's needs and develop a plan that includes:

- Annual goals and objectives
- Special education and related services, such as speech therapy or occupational therapy
- Accommodations and modifications to the curriculum or instructional methods
- Progress monitoring and evaluation



504 Plan

A 504 Plan is a written document that outlines the accommodations and modifications that a child with a disability will receive to ensure equal access to education. It is developed by a team of professionals, including parents, teachers, and other specialists.

To be eligible for a 504 Plan, **a child must have a disability that substantially limits one or more major life activities**. The 504 team will assess the child's needs and develop a plan that includes:

- Accommodations and modifications to the curriculum or instructional methods
- Related services, such as counseling or assistive technology
- Progress monitoring and evaluation

IEP

IEPs are available to children with disabilities that affect their ability to learn or participate in educational activities

IEPs provide special education and related services

IEPs provide more intensive support and services

504 Plan

504 Plans are available to children with disabilities that substantially limit one or more major life activities

504 Plans provide accommodations and modifications to ensure equal access to education

504 Plans provide less intensive support and services



Navigating IEPs and 504 Plans

As a parent, it is essential to understand the IEP and 504 Plan processes and to be actively involved in the development of your child's plan. Here are some tips for navigating the IEP and 504 Plan processes:

- 1. Understand the evaluation process:** The evaluation process involves assessing your child's needs and determining their eligibility for Special Education services or accommodations under Section 504.
- 2. Develop a plan that meets your child's needs:** Work with the IEP or 504 team to develop a plan that meets your child's unique needs. This may involve identifying accommodations and modifications, related services, and progress monitoring and evaluation.
- 3. Participate in the IEP or 504 meeting:** Attend the IEP or 504 meeting and participate in the development of the plan. Be prepared to ask questions and provide input on your child's needs.



Effective Communication Strategies

Effective communication is critical when advocating for your child's educational needs. Here are some strategies to help you communicate effectively with teachers, school administrators, and other professionals:

- 1. Prepare for meetings:** Before meeting with school staff, prepare by:
 - Writing down your concerns and questions
 - Gathering relevant documentation or information about your child's disability
 - Bringing a support person or advocate with you to the meeting
- 2. Use clear and concise language:** Avoid using technical or medical jargon that may be unfamiliar to school staff. Instead, use clear and concise language to explain your child's needs and concerns.
- 3. Listen actively:** Pay attention to what school staff are saying and show that you are engaged in the conversation.
- 4. Ask questions:** Don't be afraid to ask questions if you don't understand something. This will help ensure that you have a clear understanding of your child's educational plan.





Sample Letter and Template

Here is a sample letter and template that you can use to request an evaluation for Special Education services or to request a meeting to discuss your child's IEP or 504 Plan:

Sample Letter:

[Your Name] [Your Address] [City, State, ZIP] [Email Address] [Phone Number] [Date]

[School Administrator's Name] [School Name] [School Address] [City, State, ZIP]

Dear [School Administrator's Name],

I am writing to request an evaluation for Special Education services for my child, [Child's Name], who is a student at [School Name]. I believe that [Child's Name] may be eligible for Special Education services due to their diagnosis of Hypophosphatasia (HPP).

I would appreciate it if you could provide me with information about the evaluation process and the steps that I need to take to initiate the process. I would also like to request a meeting to discuss [Child's Name]'s educational needs and to develop a plan that meets their unique needs.

Thank you for your time and assistance.

Sincerely,

[Your Name]

Template

You can use the following template to create your own letter:

- Start by stating your purpose and the reason for your request
- Provide information about your child's diagnosis and their educational needs
- Request a meeting to discuss your child's needs and to develop a plan
- Include your contact information and a statement of your willingness to work with the school to develop a plan that meets your child's needs



Keywords and Phrases

When writing an Individualized Education Program (IEP) or 504 Plan, language matters—especially when you're advocating for services or accommodations. **The right keywords can highlight the child's needs clearly and persuasively while aligning with legal and educational standards.** Here's a breakdown of strong, strategic keywords and phrases you can use, grouped by purpose:

To Emphasize the Child's Needs or Challenges

These phrases help underscore why services or supports are necessary:

- "Significant impact on academic performance"
- "Adversely affects educational access"
- "Interferes with daily functioning in the classroom"
- "Substantial limitation in one or more major life activities" (important for 504s)
- "Not making adequate progress despite interventions"
- "Inconsistent performance related to disability"
- "Chronic and ongoing challenges"
- "Demonstrates difficulty with..." (e.g., focus, transitions, written expression)





Keywords and Phrases (continued)



To Request Specific Services or Accommodations

Use these when asking for support, modifications, or tools:

- “Specialized instruction in...”
- “Direct support from [special education teacher/speech therapist/etc.]”
- “Preferential seating”
- “Extended time for assignments and tests”
- “Small group instruction”
- “Behavioral intervention plan (BIP)”
- “Sensory breaks”
- “Assistive technology as needed”
- “Visual supports”
- “Modified curriculum”



To Describe Executive Function or Behavioral Needs

Helpful if the child struggles with organization, focus, or behavior:

- “Difficulty with task initiation and completion”
- “Needs prompts to sustain attention”
- “Struggles with impulse control and self-regulation”
- “Requires structured environment and clear expectations”
- “Frequent redirection needed”
- “Demonstrates anxiety that interferes with participation”



To Justify Evaluations or Further Testing

When trying to get assessments or reevaluations approved:

- “Data indicates a pattern of underperformance”
- “Concerns noted across multiple settings”
- “Discrepancy between potential and performance”
- “Multi-tiered support efforts have not yielded progress”
- “Requires comprehensive evaluation to determine eligibility”



To Address Legal & Access Language

Helpful for 504 eligibility and support justification:

- “Disability substantially limits major life activity”
- “Equal access to learning environment”
- “Reasonable accommodations required for access”
- “Leveling the playing field with peers”
- “Non-discriminatory educational experience”



Sample Phrases in Context

- “The student demonstrates significant difficulty with attention and task completion, which adversely affects academic performance and social interaction in the general education classroom.”
- “Due to a substantial limitation in executive functioning, the student requires frequent check-ins and extended time to complete grade-level assignments.”
- “Specialized instruction in reading comprehension is required to address ongoing deficits that have not responded to Tier II interventions.”



Additional Resources

1. **Soft Bones Online Community:** Join our online community to connect with other parents of children with HPP, ask questions, and share experiences.
2. **HPP Educational Resources:** Access a list of HPP-specific educational resources, including articles, videos, and webinars.



Additional Support Experts

If you need additional support or guidance, consider reaching out to the following experts:

1. **Special Education Attorneys:** Special education attorneys can provide guidance on the IEP and 504 Plan processes and help you navigate any disputes or issues that may arise.
2. **Educational Consultants:** Educational consultants can provide guidance on educational strategies and accommodations that can help your child succeed in school.
3. **Disability Advocates:** Disability advocates can provide guidance on disability rights and help you navigate the Special Education system.

Some organizations that provide additional support and resources include:

1. **National Center for Learning Disabilities (NCLD):** NCLD provides resources and support for parents of children with learning disabilities, including HPP.
2. **Wrightslaw:** Wrightslaw is a website that provides information and resources on special education law and advocacy.
3. **Understood.org:** Understood.org is a website that provides resources and support for parents of children with learning disabilities, including HPP.

For more information, please contact the Soft Bones Foundation

☎ (866) 827-9937 – Toll Free ☎ (973) 453-3093 – Direct Line

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