

# **Parent Guide to 504, PEP, and IEP for K-12 kids with EDS**

## **from a Teacher and a Parent of 2 Zebras**

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If your child has just gotten an EDS diagnosis of any kind there are a few things that may help you get through the process of making sure they are well taken care of in public school. My hope is that this will help answer questions you may have about the process of getting a 504, PEP, and/or IEP for your student. I want to make sure that all Zebras get the best possible education and feel safe in their learning environment.

A 504 helps get accommodations for your child so that they can be successful in school. This can be something that says easy skin tearing, must clean wounds well, student can't write and needs to record what teacher is saying or have verbal exams, etc. As stated on the Dept of Education website "Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the U.S. Department of Education (ED). Section 504 provides: "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . ." This is for short term goals and is not the same as an IEP. You may ask for certain learning help devices like talk to write programs, a cushion to sit on, gatorade or water bottle to be on hand at all times, space pens, large grip pencils, etc. These devices do not and may not be paid by the school district. It will be your job to procure them and get them to school.

<https://www2.ed.gov/about/offices/list/ocr/504faq.html>

IEP stands for Individualized Education program and helps with anything that may affect a student's learning. Unlike a 504 that is only updated once a year an IEP and PEP can be reviewed and changed throughout the year.

PEP stands for Physical Education Program and helps with any physical differences your child may have. For instance, not being able to run, hang upside down, play contact sports, etc. This can help in any sport, PE, or outdoor time at school.

To begin, please know that you are not alone and it is not as hard or fearful as it may seem. Start by talking to your child about what you might say to the people he/she will be with every day. Ask them if they may want you to say anything to the education professionals and ask how they feel about it. It's very important that your child self advocates if possible so talking to them about it can be good for everyone involved. After the talk with your child, call the Homeroom teacher about the process of starting a 504 (before school starts if you can). Then, request to speak to the Principal, Assistant Principal, Guidance Counsellor, Nurse, Coach, and any teachers that will need to know your specific circumstances. There is absolutely no shame in getting a 504 because it is private. It will not be broadcast to other students and your child can self advocate by talking to their teachers in private. If your child(ren) have a substitute teacher then things may not go according to the 504 because they are not always allowed to see the forms. This is why it is so important for your child to speak up and learn about their uniqueness early on.

I have been on both sides of the table for a 504 and IEP/PEP meeting. As a teacher, I learned everything I could about the student and was always in open communication with the guardians. As a mother, I would talk to the teachers and as a parent I've had some professionals listen and some that really did not. Often times it really depends on the teacher so these formal pages will allow each teacher to know what your child needs. If, for some reason, they are not followed then you have documentation to make sure that your child's education team does what they need.

## **The Meeting**

At my 504/PEP meeting I made sure to write down all important things about my then 6 year old. the Assistant Principal, Two Teachers, and myself were included. Sometimes it can be emotional or overwhelming to tell someone about your child's health. It really helps to make a list of the things that are most important for you and your child before you go into any meeting. Make the top 5 your most important or have to happen rules for the teaching team. Also, bring a notepad or ask if you can record the conversation if you can't write. That way, you will remember what they need from you and you will have time to write down more questions.

You *DO NOT* need a diagnosis to have a 504 for any student but unfortunately you may be told this to avoid paperwork. It does help to have documentation from a Geneticist, Pediatrician, Allergist, (or any other specialist that your child needs) so that all persons involved can better understand the particular uniqueness of your child or children. For example, if your child has POTS and you would like them to have salt and water available when every they need it then have your cardiologist acknowledge it. If your child needs an EPIpen then you will need an allergy action plan to give to the nurse and teacher. Any OTC medicines they may need to take can be kept by the nurse so your student(s) can have safeaccess to them. It really depends on the school but some will allow the nurse to give them meds if you get a Doctor note and reasoning beforehand. Otherwise, your student may have to call home to have you bring the meds. They can not self administer or carry them to school because it can be a danger to their peers if somehow they get lost or stolen. In my experience, leave a first aid kit for everything your children need is essential. For example, bandages and coban they can use, benadryl and/or epi pen, salt sticks, easy cold packs, cleaners for any wounds (i.e. neosporin, alcohol wipes, salt water, etc) to leave in nurses office and for the classroom. You should always be able to communicate with education staff if anything goes wrong. I find email is a good way so that you have documented evidence. If you go to talk to a Teacher who may be less helpful, bring your partner or another family member so they can back you up if needed. As a parent and a Teacher I realize that some parents can go overboard but I also know that some education staff are Super hard to get through to. Everything you email will be documented so it is best to be diplomatic and try not to share too many angry feelings. If the teachers aren't responding then go up the ladder to get help. No one will be angry if your child is mistreated and you tell on the teacher. If the school doesn't listen the call the School District's SPED dept and aks for a meeting.

After the meeting, the forms will be drawn up for you to look over and sign. If something is wrong don't have to sign them and bring it up with the Assistant Principal or Principal. They can change the documents to make sure everything is covered. These documents are made to help and protect your Zebra.

## **Examples of 504**

- <https://www.understood.org/~media/121ad49382ad4b898be34f816d605d70.pdf>
- <https://www.gemssforschools.org/conditions/ehlers-danlos/default>

Below is a generic example of a 504. Most districts have their own format and I just added a few things that might be important for a student.

Sample 504 Plan

ACCOMMODATIONS AND/OR SERVICES			
Area of Educational Need	Accommodation or Service	Person(s) Responsible for Implementing	Frequency of Accommodation or Service
Physical play, PE, sports	Modify exercise Give different assignment. No contact sports	Teacher Home room, PE	Daily as needed
Main Classroom POTS	Water needed Salt available standing ok Blood pressure cuff	Head Teacher Student	Every Day Every Classroom
All Subjects	Ipads for recording notes. Special pens Verbal answers	Teacher Student	Daily Every day every class

NOTES

Student has low hand function and dislocates fingers frequently. Therefore writing is not optional and other forms of communication are necessary.  
P.O.T.S can cause dizziness, nausea, fainting, heart rate increase and lowered blood pressure. Salt & water is readily available in all classrooms  
No contact sports are and frequent breaks needed with physical activity of any kind

Date Approved: \_\_\_\_\_

Understood

## **Teaching about EDS**

I like to bring in the Education guide for EDS to the education team so that they can learn a little more about it. There are several other websites that can help with this, too, but [this one is for teachers and parents.](#)