

---

## What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome (EDS) is a condition that is as black and white as the zebra ribbon that symbolizes the condition. Individuals with the condition are considered medical zebras because of how the condition mimics other conditions. At one time, EDS was considered to be rare; however, now it is considered to be underdiagnosed. Due to awareness and ongoing professional programs, recognition of EDS is improving.

EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes. Not all mutations have been identified for all the subtypes of EDS.

Individuals who are affected by this genetic connective tissue disorder can exhibit many signs such as joint hypermobility, fragile or soft skin, elastic skin, chronic fatigue and pain, spinal issues, neuropathic pain, joint instability, tendon ruptures, easy or unexplained bruising, chronic headaches, arterial dissection, easy bleeding, unexplained fractures and dislocations, and more. Because of these symptoms, this genetic disorder can be a life altering or deadly condition.

Not all who have EDS are affected the same way, which causes it to be misunderstood and underdiagnosed.

© CEDSA 2014 rev. date: 9/14

## About CEDSA

---

Center for Ehlers-Danlos Syndrome Alliance (CEDSA) is founded on the principals that children are our future and individuals with EDS need a strong supportive voice to improve their medical care, education, rights, and overall quality of life.

CEDSA works to help parents understand issues and treatment options for their children with EDS. We work with schools to find resolutions to education issues.

CEDSA advocates are driven to ensure justice for parents who have been wrongfully accused of child abuse and educate agencies as to how EDS can be mistaken for child abuse.

CEDSA's Board of Directors believes that all of our volunteers, medical and professional advisors, and associate consultants work as a team. The wonderful volunteers are the hub of the team! They truly make a difference by providing the coping and success tools to improve life with EDS.

As a non-profit organization, CEDSA relies on the generosity of others and fundraising awareness events in order to provide the multitude of programs that help individuals with EDS and other co-morbid conditions. See our website for the complete list of programs and services that CEDSA offers.

### *Center for Ehlers Danlos Syndrome Alliance*

4805 Hospital Dr. Cass City MI 48726  
Telephone: (989) 872-3372  
staff@cedsa.org www.CEDSA.org  
www.facebook.com/CEDSAorg

# Resolution options for complaints of IEPs and Sec. 504 Plans

---

## Center for Ehlers Danlos Syndrome Alliance Inc.

---



[www.CEDSA.org](http://www.CEDSA.org)

---

## IEP Resolution Process

---

Students with an IEP are afforded many options/forms of resolution to any grievances that cannot be resolved with the school.

**Tip:** Document everything in a notebook and never tear out a page or erase anything.

To start the complaint process, you must place your concerns in writing with the following information: Complaint, when, by whom, and the requested resolution. This is called a Child Complaint.

You must send a copy to the school and to the state Department of Education Special Education Compliance Office. Shortly after, the state receiving your complaint, you will ask you questions, along with your desired resolution method. They are as follows:

- **Mediation:** You and the school meet with a mediator to resolve your issues. No lawyers can be present; however, advocates are allowed.
- **State Investigation of the child complaint:** An investigator reviews the documents and complaint, then issues a finding.
- **Due process hearing:** This is a court case and loser must pay the costs. Both parties can have lawyers present.

---

## Independent Education Evaluations

---

When a parent is not satisfied with the testing or results of testing completed for evaluation of your child, or when a school refuses to evaluate your child, you may request an Independent Education Evaluation (IEE).

Requesting an IEE is not a difficult process. All that is needed is a written request (preferred method) or a meeting where the request is documented. The school is required to supply you their policy as to what they will financially pay for. We recommend that you review your states law on IEE before making this request, as laws vary by state.

---

## How far back can a complaint cover?

---

Section 504 investigation can go back 180 days, unless you obtain a waiver, which will allow you to file a complaint dating back for a period of 1 year.

IEP investigation can go back 1 year on any complaint.

In both types of complaints, investigators can go further back if they feel it warrants such action.

---

## Section 504 Resolution Process

---

The Americans with Disabilities Act (ADA) requires the US Dept. of Ed Office of Civil Rights (OCR) to investigate Sec. 504 complaints and occasionally select issues concerning IEPs.

Filing an OCR complaint resembles the process for filing a child complaint for an IEP in terms of the necessary documentation, but the form is online.

<http://www2.ed.gov/about/offices/list/ocr/complaintintro.html>

The complaint process is more informal in that the investigator will listen to your complaint, review the records, and interview the school. After they are done, they will make an official finding on your complaint. OCR complaints are usually final and can force a school to be compliant much like the state.

---

## For additional information

---

**READ** the Procedural and Safeguard Handbook given to you at the REED meeting, annual meetings, or at another time in the year. This handbook has valuable information about your rights in your state. Some states afford you more rights than federal IDEA or ADA laws.