



Center for Ehlers-Danlos Syndrome Alliance (CEDSA)

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 by increasing their knowledge of EDS and the parents of about the education process.

CEDSA advocates are driven to insure justice for parents who have been wrongfully accused of child abuse and educate agencies as to why EDS is not 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 INC.

**4805 Hospital Dr,
Cass City, MI 48726**

P (989) 872-3372

F (989) 912-2203

E staff@cedsa.org

www.CEDSA.org

SAY NO TO BULLYING



Bullying A Student With Disability Violates Their Right To FAPE!

Standup, do your part by saying bullying is not allowed, and show students with disabilities YOU DO CARE!

What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome 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, but if your joints are very flexible or you have some of the above-mentioned symptoms, you might have Ehlers-Danlos Syndrome. EDS is underdiagnosed and under-recognized as it is considered an invisible illness/disease.

Bullying a Disabled Student

Center for Ehlers Danlos Syndrome Alliance (CEDSA), and the **United States Department of Education** is committed to making sure that all of our young people grow up free of fear, violence, and bullying. Unfortunately, we know that children with disabilities, including those with invisible illnesses like EDS, are disproportionately affected by this problem. Bullying not only threatens a student's physical and emotional safety at school, it also fosters a climate of fear and disrespect, creating conditions that negatively impact learning—undermining students' ability to achieve to their full potential.

The school districts' responsibilities to ensure that students with disabilities who are subject to bullying continue to receive Free Appropriate Public Education (FAPE) under the Individuals with Disabilities Education Act (IDEA). Under IDEA, States and school districts are obligated to ensure that students with disabilities receive FAPE in the Least Restrictive Environment (LRE). Bullying of a student with disabilities, which results in the student not receiving a meaningful educational benefit, is considered a denial of FAPE. Furthermore, it may require certain changes to an

educational program of a student with a disability (e.g., placement in a more restricted "protected" setting to avoid bullying behavior) to avoid a denial of FAPE in the LRE.

Schools have an obligation to ensure that a student with disabilities who is bullied, continues to receive FAPE as outlined in his or her Individualized Education Program (IEP). IEPs, as well as 504 plans, can be useful in outlining specialized approaches to prevent and respond to bullying, as well as provide additional supports and services to students with disabilities.

Sadly, students are not the only source of bullying. Teachers, parents and even medical professionals may inadvertently make statements to a student with a disability that can be construed as an act of bullying by the student and his or her parents. Students do not always understand what adults mean or have the coping skills to combat both their illness and the emotional impact of bullying. Sensitivity training helps staff understand words hurt even when they are not meant to be harmful!

What does bullying do to students with Ehlers-Danlos Syndrome?

- Increases anxiety issues.
- Decreases self-esteem that is currently compromised.
- Increases the risk of suicide.
- Disengages a student from learning.
- Increases the student's risk of depression.
- Increases the student's level of pain.
- Increases gastrointestinal problems.
- Causes student's to have risky behaviors that includes self-harm.

Do not be one of the "Oh, That school...." instead be the school the people say "they protect their students from bullying"!

Allowing a student with disability to be bullied can be worse than their disability. Do not be an enabler!

Is your school a true no Bully Zone? If not we want to help and make it a safe school for academic success!