



The
**Ehlers
Danlos**
Society™

AN EDUCATOR'S GUIDE

Meeting the Needs of
the Ehlers-Danlos Child

A PARENT'S GUIDE

Helping Your Child
Succeed at School

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The material in this guide has been prepared to help educators better understand and provide for the needs of the Ehlers-Danlos student. Each person with Ehlers-Danlos syndrome is affected differently; therefore, the needs will be different for every student. The information has been compiled from a variety of resources including parents, administrators, teachers, guidance counselors and special education teachers. My sincere thanks to those who helped in this effort by sharing and providing personal and professional information.

Peggy Rocha Snuggs, November 2003

Peggy Rocha Snuggs served as Director at Large for Children’s Projects & Education, Board of Directors, Ehlers-Danlos National Foundation. She is an educator in the public school system in Tampa, Florida, and the mother of an EDS child.

The information contained in this educational guide is intended primarily for educators, teachers, and parents of children affected by Ehlers-Danlos syndrome (EDS). The proposed guidelines are not fixed protocols that must be followed, but rather are intended for consideration. The information contained in the guide does not constitute medical advice, nor is it a substitute for medical advice. The Ehlers-Danlos Society, its Board of Directors, and its Medical & Scientific Board does not make any express or implied warranties, representations, or endorsements whatsoever with regard to information provided. The Ehlers-Danlos Society does not warrant the accuracy, completeness or correctness, timeliness, or usefulness of any opinions, advice or other information provided in the guide. In no event will The Ehlers-Danlos Society assume the responsibility to the reader or anyone else for any decision made or action taken by the reader or anyone else in reliance upon the information provided through the guide.



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AN EDUCATOR'S GUIDE

Many teachers and schools have contacted The Ehlers-Danlos Society with questions about EDS, ranging from basic concerns for the safety of the student to questions about accommodations to meet the needs of the EDS child. This booklet was prepared to answer some of the questions asked most commonly by school personnel. Additional information on medical aspects of this syndrome is available from The Ehlers-Danlos Society at ehlers-danlos.com.

What Is Ehlers-Danlos Syndrome (EDS)?

The Ehlers-Danlos syndromes (EDS) are a collection of heritable connective tissue disorders affecting men and women of all ethnic backgrounds. EDS is named for two physicians (Edvard Ehlers and Henri Danlos) who described the forms of the condition in the early 1900s. At least six forms of Ehlers-Danlos Syndrome have been described, which are not graduations in severity, but represent distinct disorders which “run true” in a family.

Either directly or indirectly, Ehlers-Danlos syndrome is known or thought to alter the biology of collagen in the body (the most abundant protein), which can lead to multi-systemic symptoms. Each type has certain physical traits and with notable exception to the most common form, the hypermobile type of Ehlers-Danlos syndrome, most types have a known disease-causing gene.

There are physical characteristics that are common to all types of Ehlers-Danlos syndrome, including hypermobile joints (joints that move in greater amounts than expected) and skin involvement, such as any of the following: soft, stretchy, saggy, too thin, easy bruising, easy wounding, poor wound healing, atrophic scarring.

Each type is a distinct entity and may have very specific and unique features. It is highly improbable to have more than one type of Ehlers-Danlos syndrome, but as they have features and ‘biology’ in common, each type may appear to have variable features of other types.

What Medical Problems Are Associated With Ehlers-Danlos Syndrome?

Due to the different types of EDS and the varying degree of symptoms and severity between individuals with EDS, it is difficult to generalize. However, most often, the manifestations are related to skin and joints and may include:

Skin: soft velvet-like skin; variable hyperextensibility (stretchiness); fragile skin that tears or bruises easily (bruising may be severe); severe scarring; slow and poor wound healing; and fleshy lesions (molluscoid pseudotumors) associated with scars over pressure areas.

Joints: joint hypermobility; loose/unstable joints which are prone to frequent dislocations and/or subluxations; joint pain; hyperextensive joints (they move beyond the joint's normal range); early onset of osteoarthritis and chronic joint pain.

Miscellaneous: chronic, early onset, debilitating musculoskeletal pain; arterial/intestinal/uterine fragility or rupture (usually associated with Vascular Type of EDS); scoliosis; poor muscle tone; mitral valve prolapse; gum disease and vision problems.

MEDICAL EMERGENCIES AT SCHOOL

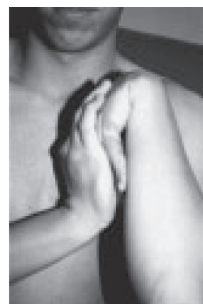
It is wise to make all school staff, including lunchroom supervisors, nurses, and office, aware that a medical emergency may occur and to outline a basic plan of action. It is important to have a prepared, parent-approved plan ahead on file. Current and updated parent contact information should be available at all times.

Dislocations/Subluxations: These often occur due to the loose ligaments and commonly affect the knees, shoulders and hips, but may affect the fingers and wrists or other joints as well. Activity may cause the joint to lock or overextend.

A physician may prescribe bracing to stabilize joints, or surgical repair of joints. Ice packs should be kept on hand. Occupational therapists and or physical therapists can help students learn how to strengthen their muscles and teach them how to properly use and preserve their joints.



Hands



Subluxations

Skin: Cuts/lacerations may occur and may vary from minor to major wounds. Gaping wounds should be handled with care. Scarring is not uncommon.

Proper repair of these wounds by a physician may be necessary. Excessive bleeding may occur with any cut. Severe bruising is also common.

Excessive sun exposure should be avoided and sunscreen is recommended for outdoor activities.



Scars



Hyper elastic skin

Vascular Type of EDS: Emergency information about Vascular EDS is always available from the red “Emergency” button at the top right on ehlers-danlos.com, or directly from ehlers-danlos.com/emergency/. For non-emergency use, there are the Vascular Type Medical Resource Guide and the Clinical Reference Manual: Vascular Type (always available from the ehlers-danlos.com/emergency/ page).

Abdominal Pain: Some children with EDS may complain of severe gastro pain and frequent stomach aches. A family plan, as well as a school plan for dealing with chronic stomach pain should be addressed with the parent and the teachers.

STEPS FOR ACADEMIC SUCCESS

Step 1: Providing A Safe Classroom/Physical Environment

Although each person is affected differently by Ehlers-Danlos syndrome, the need for a safe environment at school is important to avoid injury.

When possible, carpeted areas are preferable to slippery floors, and avoiding the use of stairs in favor of elevators. An evaluation of appropriate seating by a school based occupational therapist should be considered.

Step 2: Providing Appropriate Physical Education, Sports, and Elective Classes

It is important for emotional well-being that students with EDS try to lead as normal a life as possible. This includes playing with other children and participating as much as possible in physical activity. Students with EDS will have different needs or restrictions concerning physical education and sports. Where there is only mild hypermobility and the skin is not fragile, physical education and sports may be allowed with an adapted program. When guiding students to their choices of electives and activities, it is helpful to consider whether the activity could cause stress to joints or possible injury. Common

sense should prevail when designing sport programs. Contact sports or activities that require vigorous exertion, heavy lifting, blows to the head, or chest or excessive strain on joints and ligaments may not be the best choice. Sports such as swimming and golf may be a more logical alternative if done at an easy pace with opportunity for resting.

Certain musical instruments may stress some joints, where others may be more acceptable. Each activity should be accessed based on individual student abilities and restrictions.

Most students with EDS do not want to appear different. A student may experience all or some if the following which would affect their success in physical activities: impaired mobility, weak hand control, and/or poor coordination. Being forced to participate in physical education classes may cause the EDS child to become disheartened and embarrassed. Asking the child to sit on the sidelines and watch may cause the child to feel isolated and different. Ideally, alternative classes should be available if physical education classes are not recommended. Some schools allow health or related classes to be substituted for physical education credits, and some waive the credit altogether in favor of a more suitable elective.

Step 3: Cognitive Profiles and Providing Testing Accommodations

There is no evidence to indicate that EDS in itself causes learning difficulties. Premature birth is a complication associated with EDS and these children may experience the delays often associated with it. There are some speech and hearing and visual problems associated with EDS that medical specialist in the field can diagnose.

Formal IQ and performance testing can provide useful information. However, careful interpretation of formal evaluations should be made to assure that any occurrence of verbal-performance discrepancy, with performance scores being lower than verbal scores, is not due to motor problems instead of learning disability.

Teachers should be aware of potential difficulties due to hand-wrist hypermobility which are associated with reduced scores on performance tests. Students may need extra time or may require alternate forms of assessing performance that requires less motor input. Wrist or finger splints, large or padded pens or pencils or pencil grips may be helpful. Some students may need additional testing accommodations such as oral evaluations.

Step 4: Consideration for Chronic Absences

Due to frequent absences, the EDS child may need additional time, additional tutorials, and other child-specific accommodations. In some cases, at-home

instructions may need to be provided for long term recoveries.

Allowing special pupil assignment to a school closer to parent's home or work is a viable consideration.

Some schools post homework and class work assignments on a website for students who are absent. If the school has such a site, parents should be made aware of it.

Some schools offer incentive grade points or exam exemptions based on attendance. The EDS child should not be penalized for EDS-related absences.

Step 5: Providing Teacher Support in the Classroom

The inability to participate in some peer activities, the need for special accommodations, and the sense of "feeling different" may lead to frustration and isolation. Teachers can help the EDS child feel accepted, by addressing these issues in frequent discussions with the child about his or her feelings, identifying and encouraging development of other talents, and inclusion in activities that are not restricted. Many EDS children feel comfortable talking about EDS, and may be willing to discuss or report on EDS in class. Some however are embarrassed and choose not to discuss their condition.

Step 6: Meeting the Needs of the EDS Child

In making plans to meet the needs of the EDS child, a 504 Plan or ESE program should be addressed. A physical therapist and occupational therapist would be beneficial in evaluating and planning for accessibility and adaptation needs in the school.

Below is a list of some accommodation that other EDS students have found to be beneficial.

Physical education/sports needs:

- Modified physical education
- Alternative health related credit in lieu of PE
- Restrict contact sports
- Restrict weight bearing activities on arms, wrists (such as hand-stands, cartwheels, etc.)
- Limit exposure to the sun.

Hallway/classrooms needs:

- Allow storage of ice packs/gel packs
- Allow doctor note permitting use of non-prescription pain medications

- Rest periods in the middle of the day for fatigue
- Two sets of text books, one for home, one for school
- Priority seating
- Allow use of a chair instead of floor for circle time
- Adjusted chair /table height
- Use of elevators
- Allow passes for frequent bathroom breaks
- Book bag on wheels
- Help with note taking
- Extra time to get to and from class (leave before the bell) Stretching or walking to relieve stress
- Extended time for tests and assignments
- Extra time on timed/standardized tests
- Eliminate handwriting grade in favor of grades for content and effort
- Lockers – assign locker at eye level, allow digital lock instead of combination locks or alternative to standard locker such as a “safe” place to store belongings
- Copies of worksheets that allow fill in blanks or underlining in lieu of rewriting existing questions/sentences.

Assistive equipment:

- Chair with arms for upper body support Height adjustments on chairs/desks
- Pad for chair seat or back
- Pencil grips
- Pad for sitting on the floor
- Use of computers with ergonomic keyboards or Alpha Smart.

A PARENT'S GUIDE

Many parents have contacted The Ehlers-Danlos Society with questions about EDS, ranging from basic concerns for the safety of their child at school, to questions about accommodations for meeting the needs of the EDS child. This booklet was prepared to answer some of the questions asked most commonly by both parents and teachers. Additional information on medical aspects of this syndrome is available from The Ehlers-Danlos Society at ehlers-danlos.com.

Meeting the Needs of the EDS Child

It is wise to make all school staff, including lunchroom supervisors, nurses, and office, aware that a medical emergency may occur and to outline the basic plan of action. Although most children are accustomed to dealing with the problem and may give valuable advice at the time of the accident or injury, it is best to have a prepared parent-approved plan ahead of time. Keep parent contact information updated.

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School Site Interventions

You and your child have certain rights under the Section 504 of the Rehabilitation Act of 1973 (see Appendix 2). The rights described here and in the appendices apply to the United States; information for other countries is being gathered and will be included in future editions.

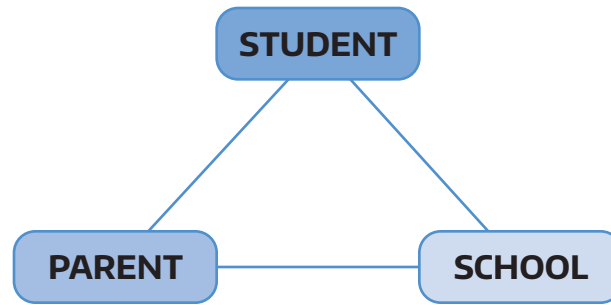
All students who are considered exceptional under the Individuals with Disabilities Act (IDEA) are also considered disabled under section 504. However, all 504 disabled students are **not** considered exceptional under IDEA. (See Appendix 3 for explanation of differences).

In most districts, those children considered disabled under the IDEA will have goals and objectives written in an Individual Education Plan (IEP). These often are written to include accommodations. A 504 plan is different than an IEP, as it addresses the accommodations needed instead of long and short term goals.

Each school district handles these plans a little differently as far as referral method or request for services. Generally, it is the guidance department who manages these cases.

Knowing your rights is important, but having a good working relationship with school personnel and teachers is often more important. Go into all meetings with an attitude of

cooperation. Being combative, intimidating, or demanding is not productive. Litigation takes a long time and your child's needs are immediate. The ideal situation is one where parents, teachers, and schools are working together, not pulling apart. Solving your child's individual problems may require a new or unique approach. If the plan as written does not meet your child's needs, or if the needs change over time, you may request additional meetings to change the 504 plan or the IEP.



You are your child's advocate, which means you are their voice. Ask your child what they need most. Include them in the plans. During meetings and discussions about your child's needs, keep your child as the center of discussion. If the topic sways to other focuses, draw the conversation back to the child and meeting their needs. Stick to the facts as you discuss EDS. Discuss options, and be open to new ideas for meeting your child's needs. When discussion is finished, ask for action.

Below are helpful suggestions from parents who have already been where you are going. Be aware that asking the school for special considerations does not mean they must provide all the items you are requesting. For example, if the school allows your child to use a rolling backpack or to store therapeutic ice packs in the refrigerator, you will most likely be providing the items.

- Check with your school system to see what programs are already in place at your school or in your system.
- Ask your doctor to provide a letter of diagnosis and suggestions for the school.
- Ask about 504 plans at your school, as well as occupational and physical therapy and evaluations.
- Make appointments with the school guidance counselor, school nurse and the individual teachers **before** problems arise. Make a plan for emergencies to be posted with the nurse/teacher.
- Try to educate the school ahead of time about EDS. Provide information on EDS for inclusion in the Cumulative Record.
- Do not assume that teachers know about your child's needs. You should be sure they are aware of the information each year.
- If you or your child are comfortable presenting information, ask to do so for the teachers/faculty or students.
- Make a list of the problems your child is having. What are some of the solutions you believe might help?
- Be clear about the things your child should and should not do.

- Be a creative problem solver. Think of ways to “make it happen”.
- Bring a list of possible suggestions with you to your meetings. Prioritize those that are important “all of the time”, and those that “may” be needed some of the time. This list and plan can be revised at your request anytime during the year or as needs change.

Be prepared to discuss:

- Accident/emergency plan
- Physical Therapy needs
- Assistive devices / braces/ wheelchair needs
- Assistive technology needs
- Occupational Therapy needs
- Speech/Language needs
- Class modifications and interventions/accommodations needs
- Physical needs in room/hallways
- Assignments/class work needs
- Organization needs
- Special considerations

Appendix 1

DEFINITIONS AND TERMS

The following are definitions or words often used by people who work with exceptional children. The definitions are meant to help or guide you and are simplified for easier understanding and use. Different school districts and educators may use these words in somewhat different ways. You should feel free to ask for definitions of words and abbreviations being used when discussing or describing your child. Each state has specific Boards of Education rules and requirements for eligibility for services and programs.

Academic - Having to do with school subjects such as reading, writing, math, social studies, and science.

Accommodation - Learning to do things differently from other students because of a handicap, impairment, or disability.

Assessment - A way of collecting information about a student's special learning needs, strengths, and interests. This could include observing the student, looking at records, or performing evaluations and tests.

Disability - A problem or condition which makes it hard for a student to learn or do things in the same ways as most other students. A disability may be short-term or permanent.

Exceptional Student - A student who has special learning needs as described in state and local school board rules. This includes students with handicaps, a disability, or impairment, as well as those who are gifted.

Exceptionality - A special learning need. Exceptionalities include handicaps, disabilities, or impairments. Gifted is also included as an exceptionality.

Free Appropriate Public Education - The words used in the federal law, the Education of the Handicapped Act, to describe an exceptional student's right to a special education which will meet his individual special learning needs, at no cost to his parents.

Handicap - A problem or condition which makes it hard for a student to learn or do things in the same ways as most of the students. A handicap may be short-term or permanent.

Homebound or **Hospitalized** - A kind of exceptional student education program for a student who must stay at home or in a hospital for a period of time because of a severe illness, injury, or health problem. In order to be eligible for such a program in most districts, a child must meet certain listed requirements to qualify.

Impairment - A problem or condition which makes it hard for a student to learn or do things in the same ways as most other students. An impairment may be short-term or permanent.

Individual Education Plan (IEP) - A written plan which describes an exceptional student's special individual learning needs and the exceptional education programs, and services which will be provided for the student under IDEAS.

Least Restrictive Environment - Part of the federal law and state law that deals with determining a handicapped child's placement. This includes that, to the maximum extent appropriate, handicapped children are educated with children who are not handicapped. It states that the removal of the child from the regular school environment occurs only when the handicap is such that the child cannot be satisfactorily educated in regular classes with the use of aids and services. In choosing a child's placement in the least restrictive environment, possible harmful effects of the child and the quality of services needed are considered.

Motor - Use of large and small muscles to move different parts of the body. Examples of motor skills are walking, holding and moving a pencil, or opening a door.

Occupational Therapy (OT) - Treatment for an exceptional student which helps them to develop mental or physical well-being in areas of daily living such as self-care and pre-vocational skills, etc. This treatment is given by a licensed occupational therapist. In order to be eligible for "occupational therapy" programs and services, a student usually must meet specific requirements.

Physically Impaired - The physically impaired student is one who has a severe illness, condition, or disability which makes it hard for him to learn in the same ways as other students his age. In order to be eligible for "physically impaired" programs and services, a student must meet certain specific requirements.

Physical Therapy (PT) - Treatment for an exceptional student which helps to maintain or improve his use of bones, joints, muscles, and nerves. This treatment is given by a licensed physical therapist. In order to be eligible for "physical therapy" programs and services, a student usually must meet certain requirements.

Sensory - Having to do with the use of the senses of hearing, seeing, touching (feeling), smelling, or tasting as a part of learning. An example of a sensory skill is being able to see the differences between letters of the alphabet.

Speech-Language - Having to do with a student's ability to speak (talk), write, listen, or read. This includes understanding others and making himself understood. An example of a speech-language skill is being able to put words together into a good sentence.

Speech-Language Impaired - The speech or language impaired student is one who has problems talking so that he can be understood, sharing ideas, expressing needs, or understanding what others are saying. In order to be eligible for "speech language" programs and services, a student usually must meet requirements.

Appendix 2

SECTION 504 OF THE REHABILITATION ACT OF 1973 (United States)

Section 504 of the Rehabilitation Act of 1973 is civil rights legislation in the United States that protects the civil and constitutional rights of persons with disabilities (information for other nations is being developed and will be included in future editions). The law states that "No otherwise qualified disabled individual in the United States...shall, solely by reason of his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Students determined qualified under Section 504 cannot be discriminated against based on their disability.

Students are considered disabled under Section 504 if they:

1. Have a physical or mental impairment that substantially limits one or more major life activities (learning or schooling is considered a major life activity);
2. Have a record of such an impairment; or
3. Are regarded as having such an impairment. All students who are considered exceptional under the Individuals with Disabilities Education Act (IDEA) are also considered disabled under Section 504. However, all 504 disabled students are **not** considered exceptional under IDEA.

Some examples of types of discrimination that 504 prohibits are:

1. Denial of opportunity to participate in or benefit from a service, educational program, or activity which is afforded to students who are not disabled;
2. Provisions of opportunity to participate in or to benefit from service, educational program, or activity which is not equal to that afforded to others;
3. Provision of aids, benefits or services that are not as effective as those provided to others;
4. Provision of different or separate benefits or services unless such action is necessary to be effective.
5. Selecting a site or location which effectively excludes persons with disabilities or subjects them to discrimination.

Appendix 3

DIFFERENCES BETWEEN IDEA DISABILITIES AND 504 HANDICAPS (United States)

In the United States most students are educated in regular, General Education. This is where students achieve through a general education program in the regular classroom.

504 Handicaps allow for education and achievement through a general education instructional program with modifications recorded in a 504 plan. IDEA Disabilities allow for education and achievement through Exceptional Student Education (ESE) instructional programs as documented in an Individual Education Plan (IEP). Below are some of the differences:

What is it?

IDEA - Individuals with Disabilities Act previously called Education for Handicapped Children Act or 94-142.

504 - Section 504 of the Rehabilitation Act of 1973.

Language Used:

IDEA - Disabilities (eligible).

504 - Handicaps (qualifies).

Who is protected?

IDEA - Students who meet qualifying conditions for 13 categories.

504 - Students who meet the definition of a physical, mental impairment which substantially limit a major life activity (including learning).

Educational Implication:

IDEA - Disabling condition results in a need for Exceptional Student Education.

504 - Handicapping condition requires an education as effective as that provided other non-handicapped students.

Duty to Provide a Free Appropriate Education. Both require the provision of a free appropriate education to students covered under them.

IDEA - Requires the district to develop IEPs. "Appropriate education" means a program designed to provide "educational benefit".

504 - Requires a district to develop a 504 Plan. "Appropriate" means an education comparable to the education provided to non handicapped students, requiring that reasonable modifications be made.

Funding:

IDEA - If a student is eligible under IDEA; the district receives additional funding (FTE) to provide special services.

504 - If a student qualifies under 504, the district receives no additional funds. 504 provides protection from discrimination, not special education services.

Evaluations: The regulations are very similar for IDEA and 504.

IDEA - Consent is required before an initial evaluation is conducted. Provides for independent evaluations. Re-evaluation must be conducted every so many years (usually three).

504 - Only notice, not consent, is required. Independent evaluations are not required. Requires periodic re-evaluations.

Appendix 4

RIGHTS OF STUDENTS WITH DISABILITIES (IDEA & 504 PLAN) TO ASSISTIVE TECHNOLOGY (United States)

The following is taken from the Advocacy Center for Persons with Disabilities fact sheet 11/97. This fact sheet is not intended as a substitute for legal advice, and applies to the United States. Other countries may have equivalent rights.

The 1997 Amendments to the IDEA (Individuals with Disabilities Education Act) require that the need for assistive technology be considered at the IEP meeting. By becoming familiar with the right to assistive technology, parents and student will be better prepared to advocate for needed assistive technology in the IEP, and also in the 504 Plan (equal access to all school programs), thereby promoting enhanced learning and functioning in inclusive environments.

What is Assistive Technology?

Assistive technology (AT) includes devices and services as well as training that help an individual to select and utilize a device or aid. AT devices are items, pieces of equipment, or systems (both off-the-shelf and customized) used to increase, maintain or improve the functional capabilities of students with disabilities.

Assistive technology services include evaluation, maintenance or repair and training for students, professionals or families. AT devices or aids include, but are not limited to the following:

- Augmentative communication devices, including talking computers'
- Assistive listening devices, including hearing aids, personal hearing aids,
- Personal FM units, closed-caption TYs, and teletype machines (TDDs);
- Specially adapted learning games, toys, and recreation equipment;
- Computer-assisted instruction, drawing software;
- Electronic tools (scanners with speech synthesizers, tape recorders, word processors);
- Curriculum and textbook adaptations (e.g. audio format, large print format, Braille);
- Copies of overheads, transparencies, and notes;
- Adaptation of the learning environment, such a special desks, modified learning stations, computer touch screens, or different computer keyboards;
- Adaptive mobility devices for driver's education;
- Orthotics such as hand braces to facilitate writing skills.