



Juvenile Huntington's Disease and the School Experience:

Education and the Child Affected by Juvenile Onset HD



Huntington's Disease
Society of America



Juvenile Huntington's Disease and the School Experience:

Education and the Child Affected by Juvenile Onset HD

Martha Nance, M.D., Medical Editor

Debra Lovecky (HDSA), Editor

Karen Tarapata, Editor/Interviewer



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A Message from HDSA

Dear Reader:

If you are using these materials, it is because you have a child affected by juvenile onset HD in your home, classroom or school system. Welcome. We hope that these new resources, which were made possible by a generous grant from the American Legion Child Welfare Foundation, will provide you with the information you need as you work toward helping the child affected by juvenile onset HD make the most of his academic experience.

Approximately 10% of the US Huntington's Disease population is affected by juvenile onset HD which strikes very young children, as early as the age of 2 and before the age of 18-20 (hence the name juvenile HD). The disease course for JHD is more severe and accelerates at a faster pace than adult onset HD and thus these children become symptomatic before they have the opportunity to reach adulthood.

Research has demonstrated that children maintain independence and feel less isolated and "different" when they are able to remain in school while battling a long term or fatal disease. Friends are important to children and making provisions and accommodations that allow the student with JHD to maintain friendships is invaluable while teaching classmates tolerance and acceptance to those who may be "different".

Yet the vast majority of school systems and educators have no knowledge or experience with HD. Classmates do not understand that HD is a disease and the symptoms being exhibited by their friend or classmate are the result of brain cells dying. They only recognize that their friend is acting differently; may walk with a lurch; suddenly stiffen; strike out or be increasingly hard to understand. School plays a vital role in teaching children to accept differences and embrace diversity.

The purpose of this project is to create educational materials for school administrators, teachers, aides, classmates and parents so each of you can help the child with JHD have a fulfilling school experience. We hope that these materials will give you a better understanding of the inevitable changes that will occur and thus allow you to make the accommodations that are needed to afford the child with HD the best chance to remain in school surrounded by their peers and friends.

We also hope that these materials will help to teach children the importance of retaining friendships with these students so they can continue to be an active and vital part of the school community.

Though the child with JHD may face a decrease in their abilities, both mental and physical, over time, and sometimes, even within the course of a semester, schools can accommodate and adapt to meet the new challenges faced by these "special needs" children.

Please let us know how these resources have helped you to develop a fulfilling school experience for your child affected by juvenile onset HD.



Table of Contents

Message from HDSA 2

Questions and Answers for School Staff and Administrators.....7

Questions and Answers for Teachers, Students and Parents 41

Meeting the Challenges of JHD: Best Practices for the School Environment 63

Disclaimer

- This presentation was created to increase the understanding of JHD in the educational professionals who are involved in the schooling of a student with JHD.
- It contains “best practices” as suggested by people in the field who have worked successfully with JHD students.
- Nothing in this presentation claims to diagnose any condition, prescribe any specific treatment, or to take the place of consultation with qualified professionals.

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Juvenile Huntington's Disease in the School: Understanding JHD

Questions and Answers for School Staff and Administrators

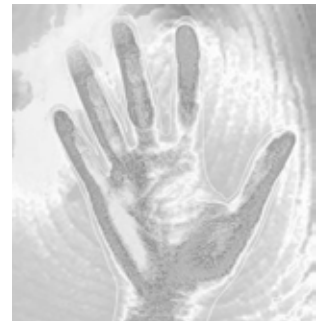
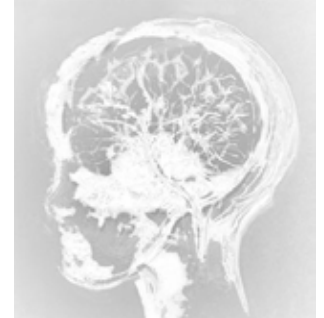
Special Thanks



**HDSA wishes to thank
the American Legion
Child Welfare Foundation
for their continued
support of the HDSA's
Juvenile HD Program.**

What is JHD and how do you get it?

- Juvenile Huntington's Disease (JHD) is a hereditary brain disease.
- Over time, this rare disorder causes increasingly severe disabling symptoms.
- No one can "get" JHD.
 - *It is an inherited genetic disease.*
 - *Only a person who is born with the defective gene can ever get the illness.*
 - *It is not contagious.*



What does JHD do?

- JHD causes the progressive loss of nerve cells in the brain.
- This affects:
 - *Movement*
 - *Cognition*
 - *Emotions and Behavior*



Is there a cure for JHD?

- There are currently no treatments that slow or stop the disease, although there are medications which may help with some of the symptoms.



JHD in school

- A diagnosis of JHD does not prevent a student from having a successful educational experience.
- However, a student with JHD will need a wide range of assistance to thrive in school.



The Connected Effects of JHD

- The multiple disabilities of JHD combine to affect the entire person.

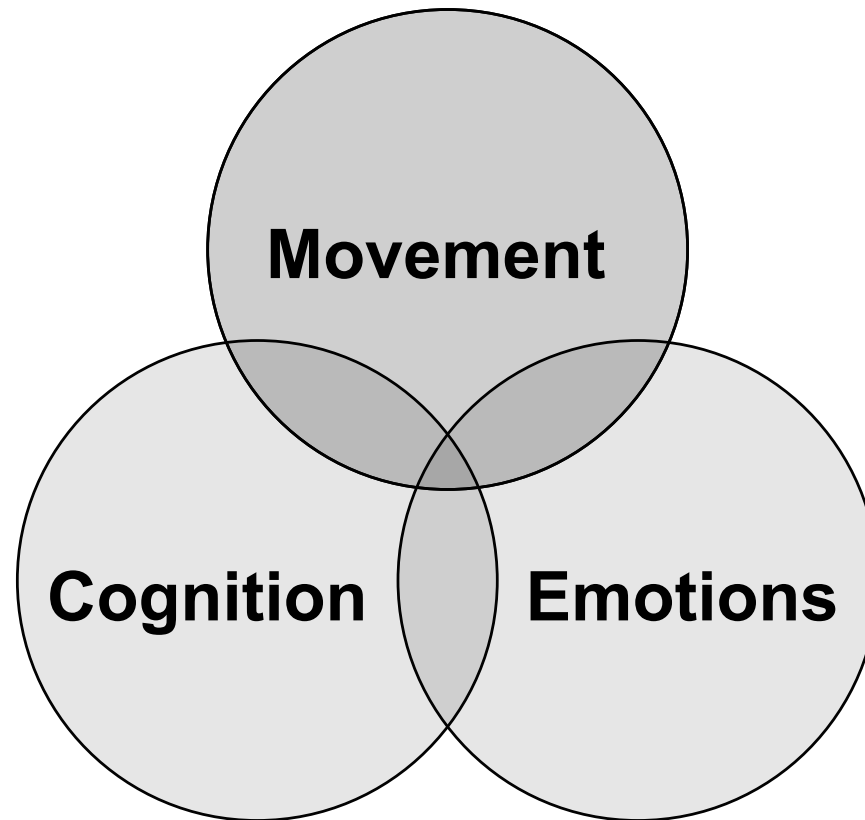
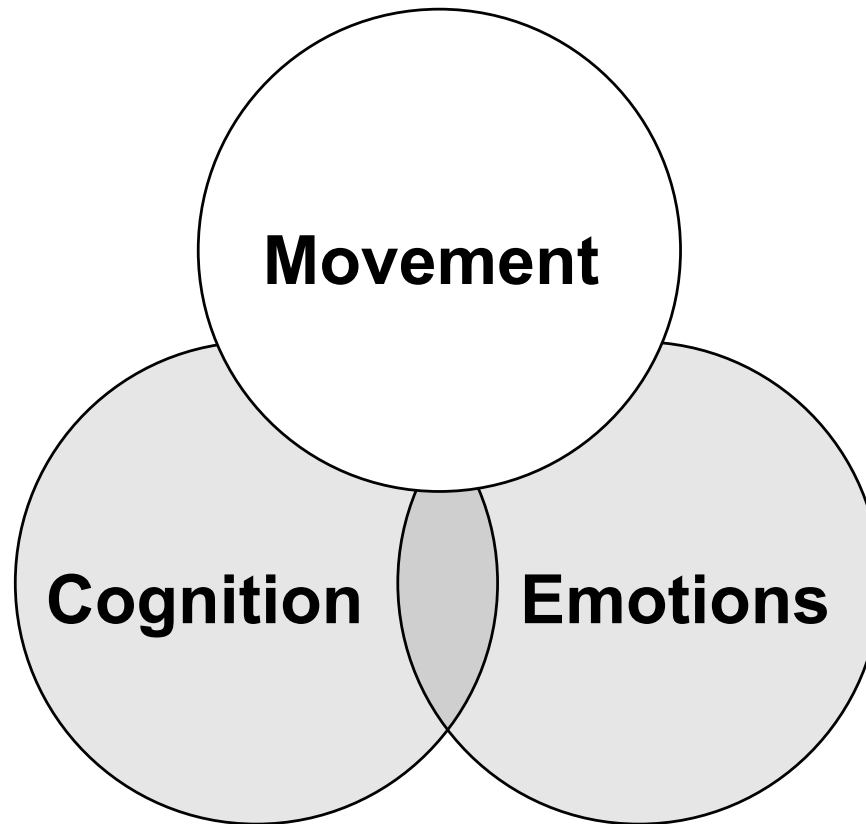


Diagram based on the work of Jane Paulsen, Ph.D. as found in "Understanding Behavior in Huntington's Disease".

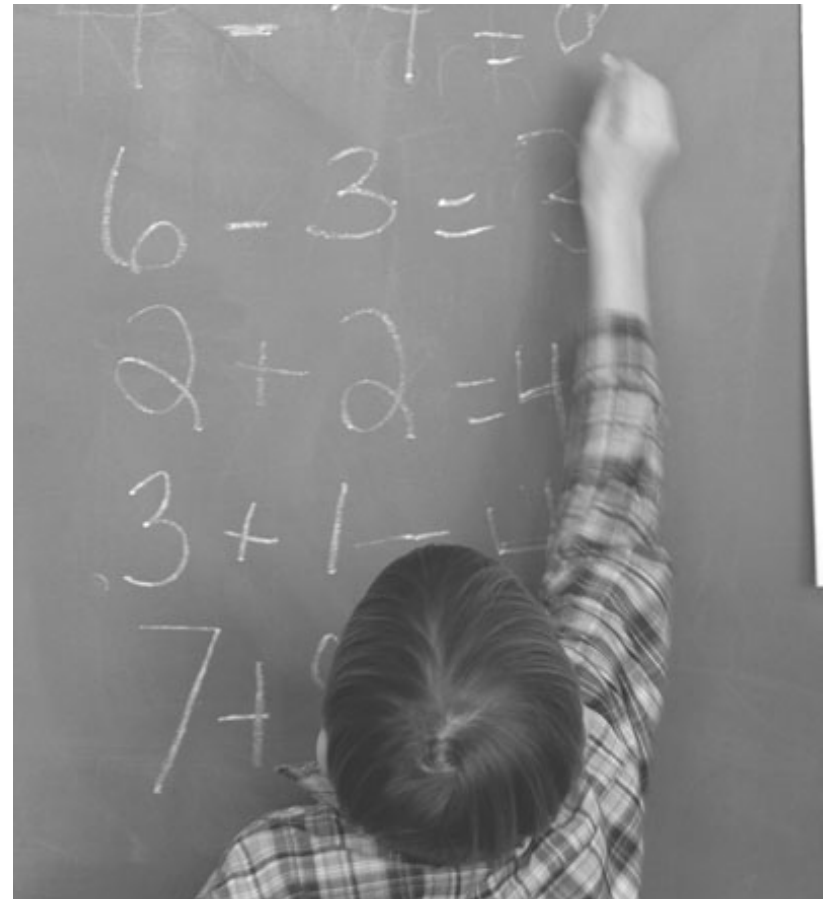
The Connected Effects of JHD

1. Movement disorders



Movement

- Movement disorders caused by JHD may include:
 - *Abnormal balance*
 - *Loss of muscle control*
 - *Rigidity*
 - *Spasticity*



Movement

- JHD causes changes in motor skills and coordination.
- Over time, a young person with JHD will lose skill and ability in:
 - *Walking and running*
 - *Playing sports*
 - *Writing and keyboarding*
 - *Using tools and utensils*



Movement

- JHD also reduces oral motor control thus causing:
 - *Indistinct speech*
 - *Drooling*
 - *Choking and difficulty eating*



Movement

- A student can overcome the movement disorders caused by JHD and continue their education with help from the school in the areas of:
 - *Physical Therapy*
 - *Occupational Therapy*
 - *Speech Therapy*
 - *Assistive Devices*
 - *Adaptive Physical Education classes*
- More information is included in the “Best Practices” section of the disc.

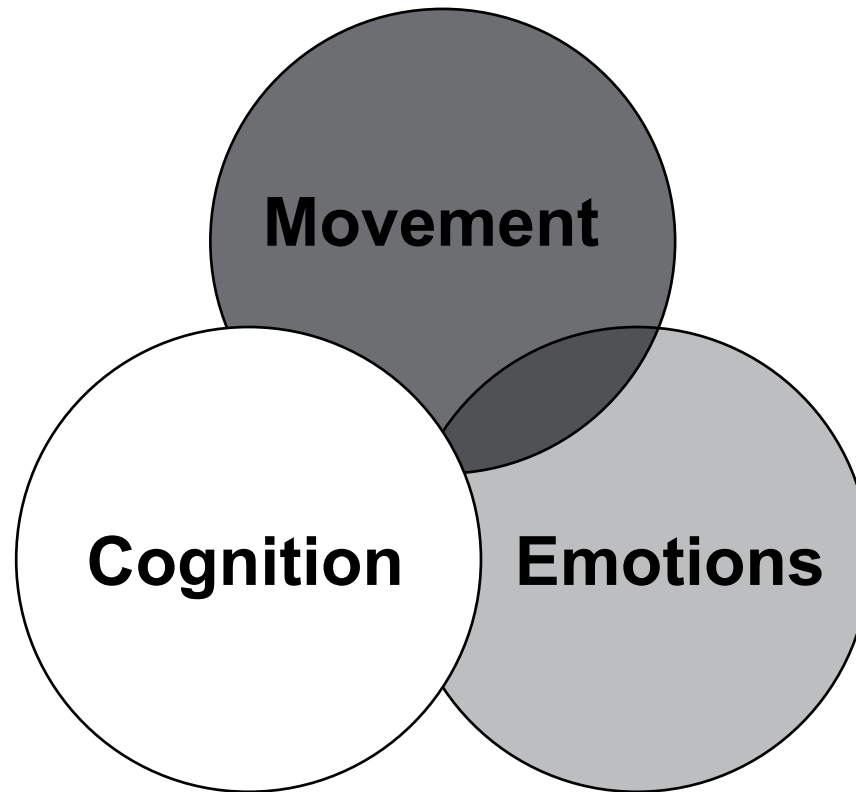


“Early detection and intervention will help the child maintain the ability to function and communicate.”

- Physical therapist

The Connected Effects of JHD

1. Cognitive disorders



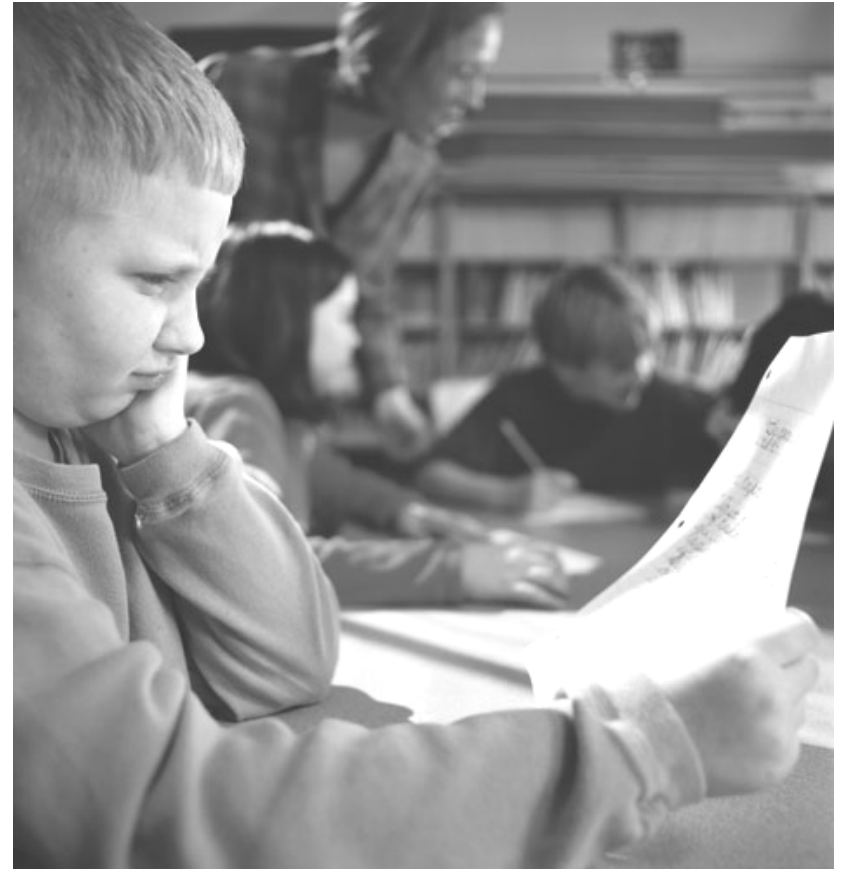
How does JHD affect cognition?

- JHD causes the progressive loss of nerve cells in the brain.
- This loss affects the ability of the brain to understand, organize and retain information.



Cognition

- Changes in cognition may be an initial indicator of JHD.
- Symptoms may include:
 - *Lack of attention/concentration*
 - *Loss of previously learned skills*
 - *Declining ability to learn new material*



Cognition

- JHD also causes the progressive loss of “executive functions” such as:
 - *Organizing and prioritizing*
 - *Controlling impulses*
 - *Beginning and ending activities*
 - *Creative thinking*
 - *Problem solving*



Cognition

- A student with JHD can continue his/her education with help from the school.
- For example, the cognitive disabilities in early stage JHD can often be mitigated with simple strategies using:
 - *Familiar routines*
 - *Breakdown of tasks*
 - *Temporary reduction of stimulus/distractions*
 - *Patience and a little extra time*
- More information is included in the “Best Practices” section of the disc.

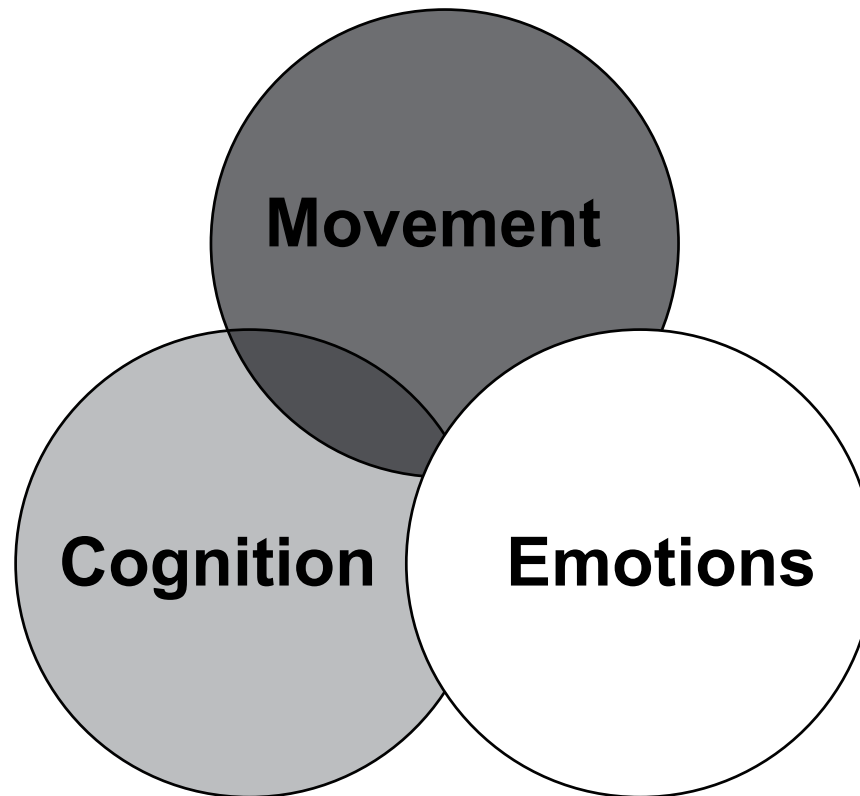


“JHD is not just physical, it is the whole package. Until I realized that, I thought it was not that big of a deal.”

- School psychologist

The Connected Effects of JHD

1. Emotional/behavioral disorders



How does JHD affect emotions?

- Among other things, JHD causes progressive damage to the nerve cells in the brain that regulate thoughts and feelings.
- Unregulated emotions may cause overreactions to everyday events:
 - *A minor annoyance triggers anger*
 - *Simple concerns become obsessions*
 - *Ordinary stimulation is overwhelming*



Emotions/Behavior

- Changes in behavior may be an initial indicator of the onset of JHD.
- Symptoms may include:
 - *Depression*
 - *Impulsive behavior*
 - *Aggression*
 - *ADD/Hyperactivity*
 - *Obsessive thinking*



Emotions/Behavior

- Sometimes, the unregulated emotions and behavior caused by JHD can be addressed with:
 - *Simple rules and goals*
 - *A quiet place for the student to withdraw*
 - *Separating the student from “trigger” individuals and situations*
 - *Medications*
- Apparent behavior problems may also be caused when the student is tired or confused.

Emotions/Behavior

- A student with emotional or behavioral disabilities caused by JHD can continue their education with help from the school.
- The student's neurologist and the school psychologist are valuable team members in monitoring and addressing the behavior issues triggered by JHD.
- More information is included in the "Best Practices" section of the disc.

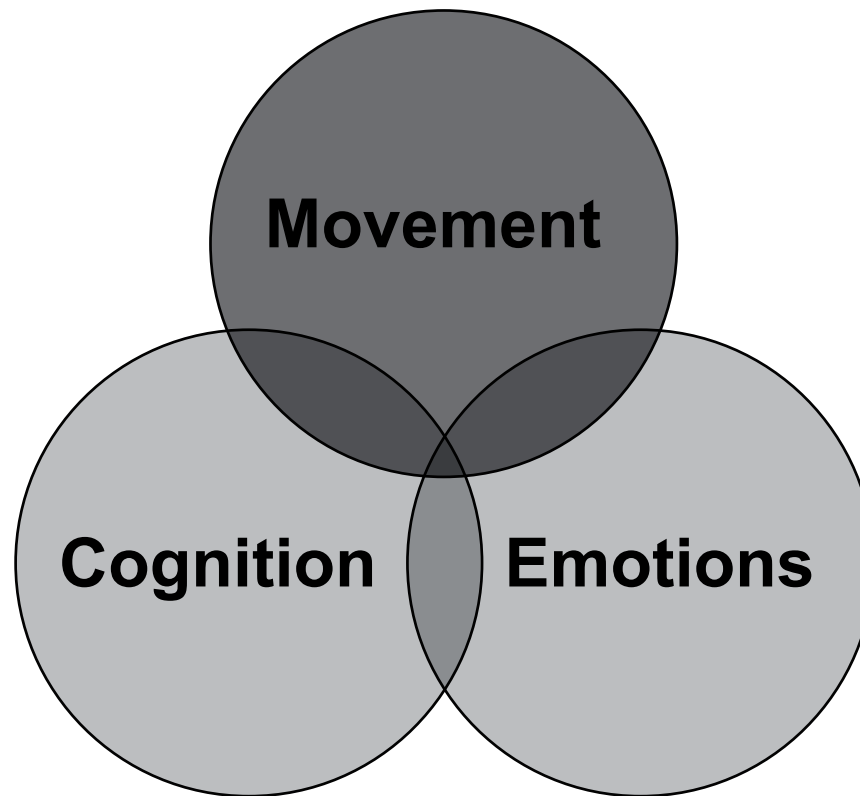


“High functioning kids with JHD can have the most problems because they don’t look ‘sick’. People think they’re just acting out.”

- Mother of JHD teenager

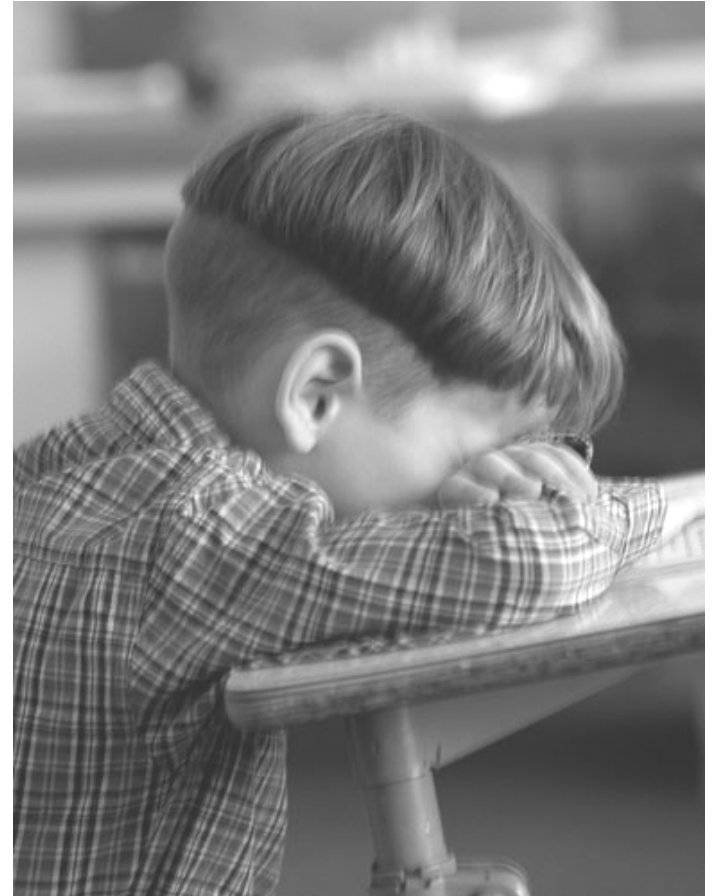
The Connected Effects of JHD

- The multiple disabilities of JHD combine to affect the entire person.



The Student with JHD

- In JHD, the various disabilities affect each other.
- For example:
 - *Difficulty speaking can make it hard to participate or ask a question*
 - *Hyperactivity may create a behavior problem*
 - *Depression can make it more difficult to organize a project*
 - *Loss of motor control will make test taking slow and confusing*



Social isolation and inclusion

- Social isolation is a common problem in JHD.
- Lack of knowledge and empathy can lead students and even teachers to misunderstand the symptoms of JHD and exclude or overlook the young person.
- Students with JHD should be included in important school activities and social events, especially as their condition will not improve over time.
- Like all students, young people with JHD deserve good memories of their time at school.

The IEP and JHD

- JHD is a disease that progresses at an uneven rate.
 - *Disabilities may increase slowly or rapidly.*
 - *JHD is unusual in the range and severity of symptoms it presents.*
- The Individual Education Plan (IEP) for a student with JHD may have to be amended during a single school year if the disease progresses.



“Standardized tests are not an adequate measure for JHD, because there is so much individual variation.”

- Speech therapist

Stages of JHD Functional Scale

	3 points	2 points	1 point	0 points
A. School Attendance	No special assistance needed	Some regular classes, some special or modified	No regular classes	Does not attend school
B. Academic/ Developmental Performance	Reading, writing and math age appropriate	Mild decrease, still able to take a test	Unable to write legibly; able to communicate orally	Unable to read/write/ communicate orally
C. Assigned Tasks		Age appropriate	Occasionally assists	Unable to participate
D. Activities of Daily Living	Age appropriate	Requires some assistance	Assists others in self-care	Unable to assist
E. Resides		Home with only family assistance	Home/group home with non/family assistance	Long-term care facility

11 - 13 points = Stage 1

7 - 10 points = Stage 2

3 - 6 points = Stage 3

Think about it...

- Young people with JHD face many challenges.
- The disease affects motion, cognition and emotions.
- JHD can make it difficult to walk, talk and think clearly.
- It can cause a person to feel depressed, anxious or angry.
- JHD can leave a young person socially isolated.



JHD in the school environment

- The school environment should be safe, welcoming and inclusive for the young person with JHD.
- While young people with JHD will get help from school specialists, they also need understanding from teachers and students.



Accommodating JHD in the school

- There are cost-effective strategies that can accommodate the student with JHD at school.
 - *See the “Best Practices” section of the disc.*
- Included are strategies for aiding:
 - *Locomotion, seating and transportation*
 - *Speech, communication and eating*
 - *Cognition management*
 - *Social Integration*
 - *Physical fitness and more*



“Our job is to keep life as normal as possible for as long as possible.”

- Speech Therapist



Juvenile Huntington's Disease in the School: Understanding JHD

Questions and Answers for Teachers, Students and Parents

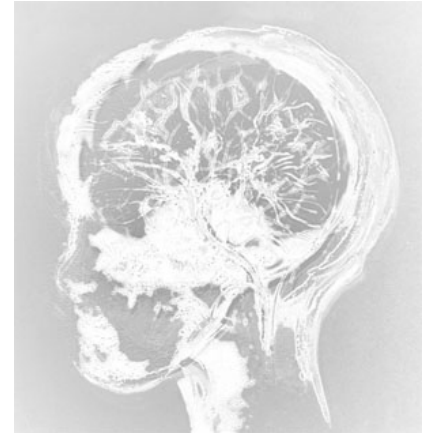
Special Thanks



**HDSA wishes to thank
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Juvenile HD Program.**

One of your classmates has Juvenile Huntington's Disease (JHD). What does that mean?

- JHD is a disease that affects the brain.
- JHD affects how a person moves, thinks and feels.
- JHD gradually gets worse over many years.
- Your classmate has an illness that will never go away.



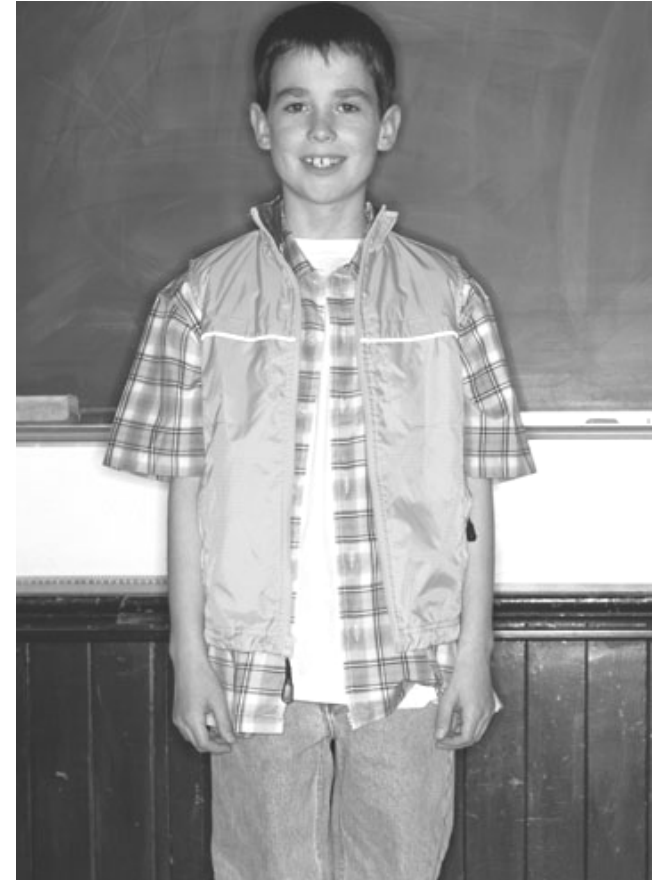
HD and JHD

- Juvenile Huntington's Disease (JHD) is a form of Huntington's Disease (HD).
- It is called Juvenile Huntington's Disease if symptoms begin when a person is under 18 years old.
- JHD causes some different symptoms and issues than HD that appears in adults.



How does someone get JHD?

- JHD is a genetic disease.
 - *It is not contagious.*
 - *You cannot “catch” JHD.*
- Your classmate did nothing to cause JHD.
 - *He or she was born with the disease.*
- A child with JHD may have brothers and sisters who do not have the defective gene and who will never get the disease.



How can you tell if someone has JHD?

- There is no one way to tell that someone has JHD.
 - *JHD causes different symptoms in different people.*
- Because JHD affects the way people move, think and feel, it has some symptoms you can see and others you cannot.
 - *For example, some children with JHD have trouble walking, which is easy to see.*
 - *But JHD can also make a person easily distracted and forgetful.*
 - *Forgetfulness is a symptom you cannot “see.”*

Is there a cure for JHD?

- There is no cure for JHD, but researchers are working hard to solve this problem.
 - *Doctors can use different medicines to make some of the symptoms better.*
 - *People with JHD have to live with the disease because there is currently no cure.*
 - *People with JHD deserve patience and understanding.*



What is it like living with JHD?

- JHD affects the brain.
 - *It can make simple things difficult.*
 - *For example, JHD can make it hard to walk, to write, even to talk and eat.*
- JHD affects thinking.
 - *It can make it hard to follow directions and learn new things.*
 - *People with JHD may forget things they used to know.*
- JHD affects emotions.
 - *It can make a person have a temper tantrum or get angry when they don't really mean to.*
 - *It is often the disease that is causing the problem.*

What can the school do for your classmate with JHD?

- Schools provide students with JHD the help they need to get an education.
 - *Some of the help comes right in the classroom. For example, the student may need extra time to take a test or a special chair to sit comfortably.*
- Some of the help may be done outside of regular class with special teachers trained to work with students who have disabilities.
- Schools provide JHD students with many kinds of support so that they can have a successful school experience.

What can teachers do for a student with JHD?

- Learn about the symptoms of JHD.
 - *Accept that the student with JHD is not lazy or “acting up” on purpose.*
- Be understanding when the student is forgetful.
- Be tolerant if the student needs more time to complete a task or needs the directions broken down.
- Look out for fatigue.
 - *Students with JHD tire easily and exhaustion can make their symptoms worse.*
- Remember that it is not possible for a JHD student to simply “try harder”.

What can classmates do?

- Don't make fun of your classmate with JHD.
 - *Treat them like everybody else.*
 - *They want to be included in classroom activities and school projects.*
- Be patient and kind.
 - *Remember that your classmate with JHD did nothing to get the disease.*
 - *He or she was born with the disease.*



What can classmates do?

- Be understanding if your classmate gets angry or frustrated.
 - *Because of JHD, sometimes they can't control their feelings.*
- Ask them to join you at lunch or at recess.
 - *It hurts to be "left out".*
 - *Be a friend and be there for them.*



Everyone has things they do well and other things they don't do as well.

- Over time, JHD will make it more difficult for your classmate to do things that they used to do well.
- They may not be able to do all their classwork or play sports the way they used to.
- Just because your classmate's abilities are changing shouldn't change the way you treat them.
 - *They are still your classmate and your friend.*
- Your classmate is learning to adapt to his or her changing abilities.
 - *You can adapt by not making a “big deal” out of it.*

What about brothers and sisters?

- Your classmate with JHD is part of a family.
 - *Their brothers and sisters need your support too.*
- Though your classmate has JHD, that doesn't mean their brothers and sisters have it too.
- Making fun of someone with JHD or of someone who has JHD in their family is hurtful and wrong.
 - *Imagine how hard it must be to see your brother or sister struggling with a serious disease like JHD.*
- Help the brothers and sisters of your classmate by treating them like everyone else.
 - *Be a friend and be there for them.*

Be a good friend

- Kids can be mean. Stick up for your classmate.
 - *If someone is making fun of your friend's disabilities, stand by them and let them know they are not alone.*
 - *If it gets bad, tell an adult.*
- If your classmate is moved to a special class where they can get more help, say “Hi” when you see them and treat them the way you always have.
- If your classmate with JHD is too sick to come to school, make them a card or call them on the phone.
 - *Don't stop being a friend just because they are not in school every day.*

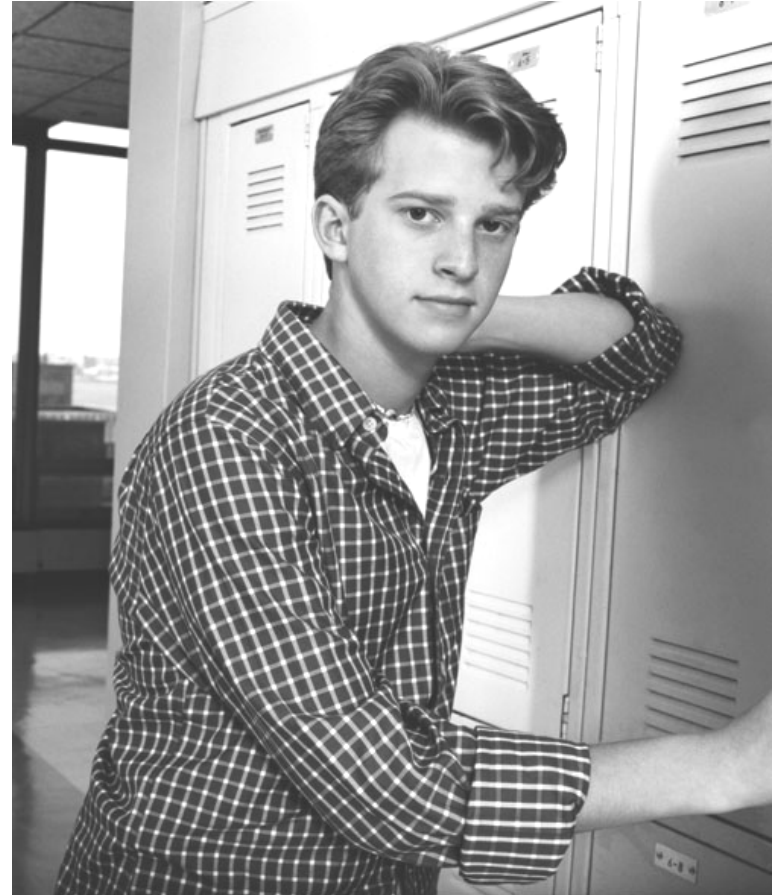
To older students...

- JHD is going to affect your classmate's brain in many ways.
 - *It will change how they move, think and behave.*
 - *It will limit what they can do.*
- Accept your classmate for who they are inside and what they can do today.



To older students...

- School is a very important place for people with JHD.
 - *It is where they get to be with other kids and feel like everyone else for a while.*
- JHD can make a person impulsive, aggressive or willing to do risky things. Don't let your classmate do anything unsafe.
 - *They don't really want to. It is the disease that is making them act that way.*



To parents of classmates...

- Help your child to be a good friend to their classmate with JHD.
- School is the most important part of a child's life.
- Encourage your child to make school a positive experience for their classmate with JHD.
 - *Encourage them to treat their classmate with JHD just as they treat everyone else.*



To parents of classmates...

- JHD can leave a child isolated and depressed.
 - *If you are organizing an after-school activity, club or event, invite your child's classmate with JHD.*
- Your child's classmate is facing a difficult disease.
 - *As symptoms advance, they may not be able to remain in school.*
 - *Encourage your child to remain in contact with their classmate even when they are no longer in school.*



Think about it...

- Children with JHD face many challenges.
 - *The disease can make it difficult to walk, talk and think clearly.*
- Children with JHD get help from school specialists, but they also need help from teachers and students.
 - *To help a child with JHD, be patient and kind.*
- Understand that the disease may make simple things difficult for them.
- Everyone can help a child with JHD have a successful school experience.

Who can you ask if you have questions about JHD?

- The Huntington's Disease Society of America (HDSA) is an excellent place to get answers to your basic questions about JHD.
- They can also put you in touch with experts in your region, at the HDSA Centers of Excellence.
- HDSA can be contacted at 800-345-HDSA or www.hdsa.org



Meeting the Challenges of JHD

Best Practices for the School Environment

Special Thanks



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Index

Introduction

- What is Juvenile Huntington's Disease (JHD)?

Part 1:

- Cognitive Aspects of JHD

Part 2:

- Behavior Aspects of JHD

Part 3:

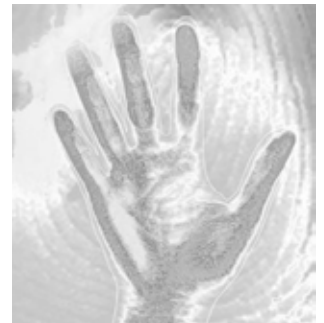
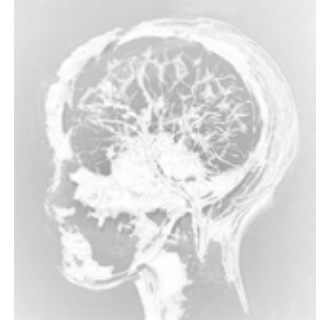
- Physical Aspects of JHD

Conclusions



Introduction: What is Juvenile HD?

- Juvenile Huntington's Disease (JHD) is a hereditary brain disease.
- Over time, this rare disorder causes increasingly severe disabling symptoms.
- No one can "get" JHD.
 - *It is an inherited genetic disease.*
 - *Only a person who is born with the defective gene can ever get the illness.*
 - *It is not contagious.*



Outlook for a Student with JHD

- JHD causes the progressive loss of nerve cells in the brain.
 - *This affects movement, cognition, emotions and behavior.*
- Currently, there are no treatments to halt the progression of the disease.
 - *The multiple disabling symptoms will become worse over time.*
- There are drugs and treatments which may help address some of the psychological, physical and emotional symptoms of the disease.

Important Facts about JHD

- As their disease progresses, young people with JHD face increasing difficulties with movement, cognition and emotional/behavioral issues.
- The symptoms of each young person with JHD will progress differently – some will show primarily physical symptoms and some will have cognitive or behavioral symptoms years before physical symptoms appear.
- JHD is a disease of many interrelated disabling symptoms.

Importance of the School Environment

- The school environment provides the majority of socialization for young people.
- A good school environment allows the young person with JHD to “fit in” and participate as part of the student population for as long as possible.
- Friendships made at school give the young person with JHD contacts and memories that will be increasingly important as the disease progresses.

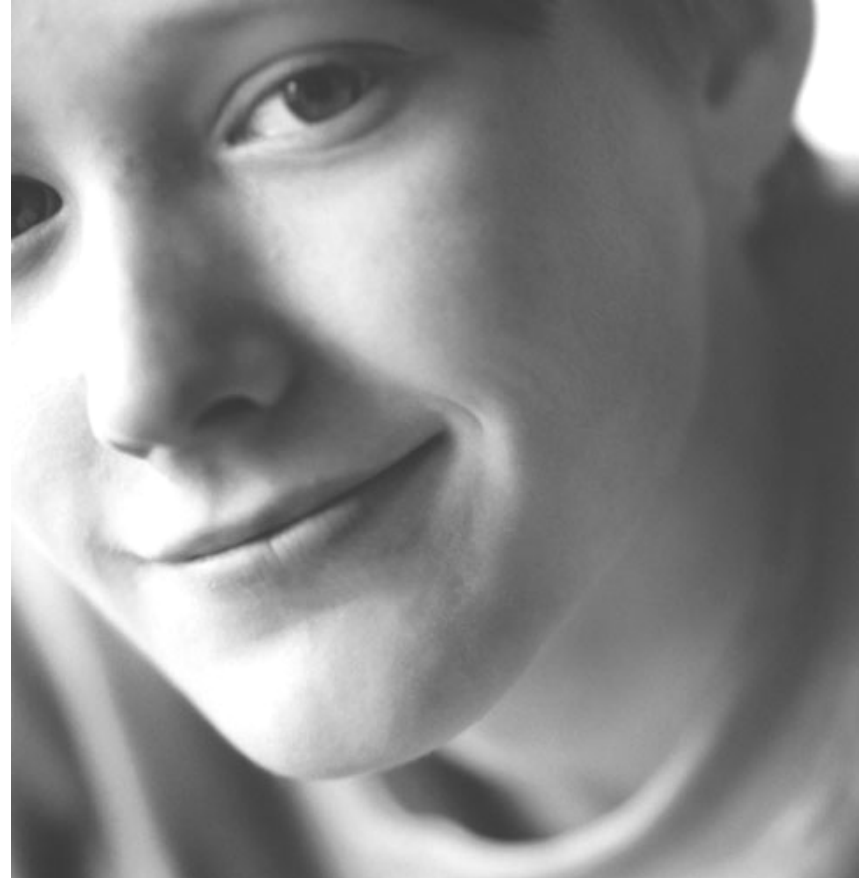
Each Young Person with JHD is Unique and will Present Unique Challenges to the School

- Over the years, experts in JHD have discovered methods and practices which can smooth and improve the school experience for the student and the school staff.
- Adopting these “best practices” can go a long way to maintaining the student’s ability to thrive at school, even as the disease progresses.



The Primary Goal: Establishing a Safe Learning Environment

- Creating a safe learning environment for a young person with JHD will take many forms.
- Issues to address are:
 - ***Cognitive management***
 - ***Behavior control***
 - ***Physical safety***





Part 1: Cognitive Aspects of JHD



Part 1: Cognitive Aspects of JHD

- Young people with JHD often experience changes in memory, judgment and problem solving (cognition).
- There may be a marked decline in schoolwork and the ability to learn new material or remember what they learned previously.
- Sometimes these problems start before physical symptoms of the disease appear.
- Cognition problems can be managed with sufficient understanding and patience.

Cognitive Management: Basic Strategies

- JHD causes degeneration of nerve cells in the brain.
- New information becomes difficult to learn and old information may be forgotten.
- The student cannot simply “try harder”.
 - *Keep information concise and simple.*
 - *Avoid multi-part, verbal requests.*
 - *Use calendars and checklists for required tasks.*
 - *As much as possible, maintain a structured environment with established daily routines.*

Best Practices: Case Study

- A JHD speech language pathologist in NYC has had success with the following:
 - *Give directions in writing.*
 - *Include examples for the student to follow.*
 - *Break assignments into steps.*
 - *See that each step is complete before assigning the next task.*



Cognitive Management: Testing

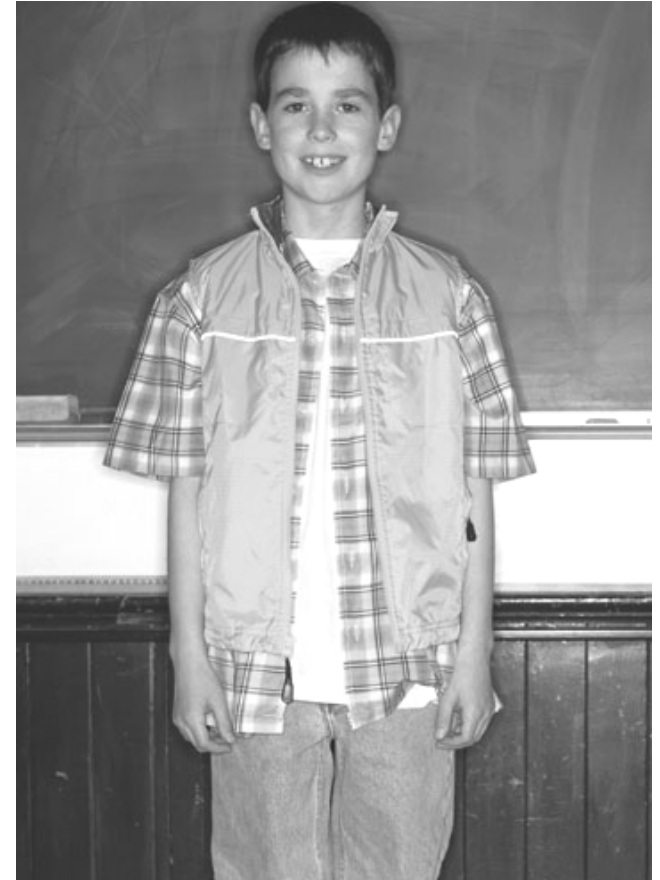
- Successfully testing a student with JHD may present challenges.
- The disabling symptoms of JHD may make it difficult for the student to prioritize tasks and remember data.
 - *Allow the student to take tests in a quiet place and give them more time to complete the test.*
 - *Keep the directions simple.*
 - *Look for ways to “lighten the load”. For example, reduce the number of math problems the student is required to complete.*
 - *Consider eliminating academic tests as the disease progresses.*

Testing and the IEP

- Symptoms of JHD can progress during a single school year.
- It may be necessary to re-assess the student more than once during the school year.
- Reassessment adjusts academic goals to bring them in line with the changing needs of the student while allowing him or her to continue to participate in the classroom.

Best Practices: Case Study

- JHD makes it difficult to learn new information.
- Things previously learned may be forgotten.
 - *As one boy's disease progressed, his Wisconsin school began to grade him more on behavior than on academics.*
 - *The school directed their focus to reading and spelling for communication purposes.*



Best Practices: Case Study

- A JHD student in a Michigan elementary school can only attend school part time.
 - *The school provides a folder of work for her to do at home.*
 - *The student continues to feel a part of the school community because she has homework like every other student.*



Assistive Aids and Technology

- JHD causes multiple disabling symptoms, some of which may be mitigated with assistive aids and technology.
- Because there is a decline in the ability of young people with JHD to learn new information and form new memories, it is critical to introduce assistive aids before they are absolutely necessary.
- While assistive aids need to be introduced early, every attempt should be made to maintain the highest possible functioning of the student.

Assistive Aids and Technology Strategies

- Assistive aids may include:
 - *Computer programs for instruction and respite.*
 - *Special seating, wheelchairs and strollers.*
 - *Picture or communication boards.*
 - *Augmentative and alternative communication devices (AAC) to improve communication.*
 - *A personal aide (considered an assistive aid) who makes it possible for the JHD student to remain in school.*

Best Practices: Case Study

- Schools in Southwest Wisconsin share a pool of communication devices, such as GoTalk 20+ or Dynavox, which are loaned to a student on the recommendation of a school speech therapist.
 - *The devices are introduced while the student is still able to communicate orally.*
 - *The device will enable a student to continue to communicate in school.*



Best Practices: Case Study

- One school district in Michigan found a tutor and personal aide through Americorps, a program of the Corporation for National and Community Service.
 - *The Americorps member replaced a group of volunteers coordinated by the school.*
 - *The student had not responded well to a changing group of volunteers, due to cognitive problems.*
 - *Providing a trained Americorps member was found to be a successful and cost-effective solution.*





Part 2: Behavior Aspects of JHD



Part 2: Behavior Control

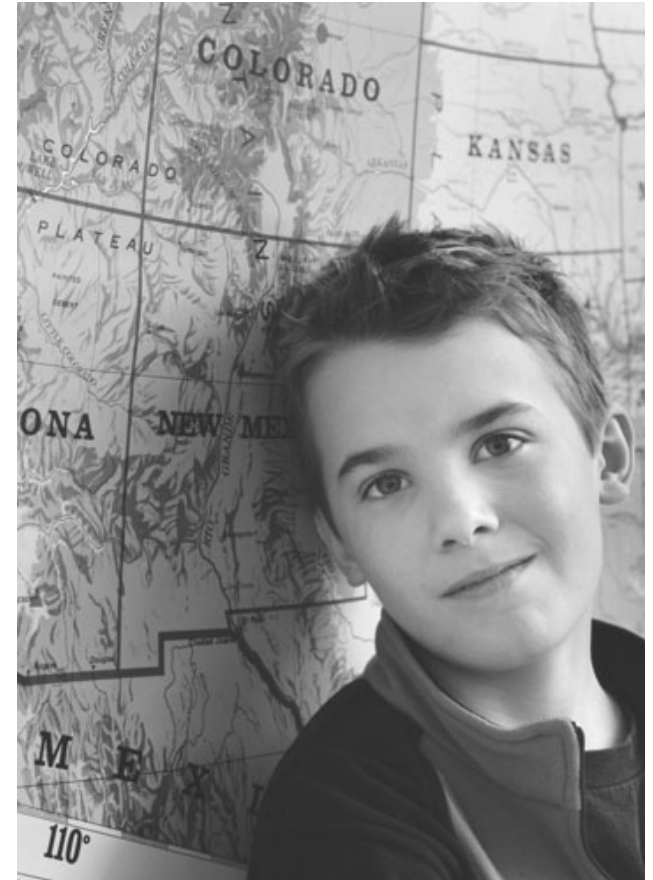
- Young people with JHD may lack emotional or behavioral control.
- This can compromise their safety.
 - *Acknowledge “trigger” individuals and situations.*
 - *There may be identifiable situations that consistently trigger outbursts which may be controlled or eliminated.*
 - *Be aware that they may be “picked on” or targeted by bullies.*
 - *Be aware that they may be easily influenced to take risks.*

Behavior Control: Strategies for Obsessive Thinking

- Young people with JHD often have obsessive thoughts. They may, for example, talk about cars or horses when the topic is American History.
 - *Successful treatment for obsessive thinking may include both Cognitive-behavioral psychotherapy (CBT) and medication.*
 - *If possible, allow the student to make their statement, then lead the discussion back to the topic at hand.*
 - *Recognize that the young person is not speaking out of turn “on purpose”.*

Best Practices: Case Study

- A young Wisconsin student with an obsession with bull riding was allowed to incorporate his interest into his schoolwork.
 - *When the class did gingerbread men stories, he did a story about a gingerbread bull.*
 - *The teachers found that the student could be very creative and engaged.*
 - *The student's personal aide helped keep him on track.*



Behavior Control: Strategies for Stimulus Control

- Because JHD makes it difficult to regulate and prioritize stimuli, it can make a young person easily “worked up” and distracted, causing them to act out or shut down.
 - *Put the student’s desk near the front of the room where they can focus on the teacher.*
 - *Maintain daily routines as much as possible.*
 - *Designate a quiet place, such as the resource room or library, where the student can calm down.*

Best Practices: Case Study

- The Assistive Technology specialist in a Colorado middle school selected educational computer programs for her JHD student.
- The programs provide:
 - *A quiet refuge when the student is agitated.*
 - *Step by step instructions in educational topics that can be repeated as needed.*
 - *An outlet for the obsessive thoughts that can accompany JHD.*



Best Practices: Case Study

- A middle school student in Colorado has a 5-minute routine for sensory calming using “brush therapy”.
 - *In this OT technique, the student uses a small soft “baby” brush to perform long strokes with good pressure along arms, legs, hands and feet and the torso.*
 - *The school found it best for the student to perform this in the staff lounge.*



Best Practices: Case Study

- To address disorientation when changing classes, a social worker in Michigan created a visual schedule for her JHD student.
 - *A picture was created for each class period with:*
 - *A photo of the classroom*
 - *A label identifying what class it is*
 - *A picture of an analog clock with the start time and stop time of the class*
 - *The student wears an analog watch for comparison.*



Social Inclusion Issues

- Lack of social inclusion can cause depression in the student with JHD and may lead to inappropriate behavior.
- There are several factors that affect social inclusion:
 - *The age of the student.*
 - *The stage of the disease.*
 - *The willingness of the other students – an attitude typically set by the classroom teacher.*
- There is a role for both teachers and student leaders in the social inclusion of a student with JHD.

Strategies for Social Inclusion

- School activities, such as pageants or the drama club, may involve activities that are appropriate for the student with JHD.
 - *The school's occupational therapist can suggest tasks that the student with JHD can successfully perform.*
- Like all students, young people with JHD love to receive printed awards or small rewards for jobs well done.
 - *Every child has a strength worth acknowledging.*

Best Practices: Case Study

- JHD is a disease that can rob a young person of life's typical milestones.
 - *A high school in Michigan designated an elementary school student with JHD as their "Homecoming Princess" and invited her to their event, where she was the crown bearer to the Homecoming Queen.*



Stress and JHD

- Students with JHD often feel tremendous stress.
 - *They often blame themselves for things that are really symptoms of the disease.*
- The attitude of the teacher will have a tremendous effect on the stress level of the JHD student.
- Changes in routine can cause stress in JHD students.
- The student with JHD may also have obsessive thoughts or irrational fears that create stress.
- Sensitivity and positive reinforcement from teachers can reduce classroom stress and improve results.

Stress Strategies

- Foster collaboration among the student's support team. (i.e. teacher, OT, PT, SLP and school nurse)
- Decide on strategies before the start of the school year or between semesters.
- Maintain the student's routine as much as possible.
- Educate all staff on the symptoms of JHD and establish an understanding environment.



Part 3: Physical Aspects of JHD



Part 3: Physical Aspects of JHD

- JHD affects:
 - *Balance and walking*
 - *Hand-eye coordination and depth perception*
 - *Eye tracking and saccade skills needed for reading*
 - *The ability to sit safely in a regular chair*
 - *Chewing and swallowing*
 - *The capacity to ride safely on a school bus*
 - *The ability to identify dangerous situations and control risk-taking behavior*

Physical Safety: Balance and Walking

- Among other things, JHD is a movement disorder.
 - *In teens, this may show up as “chorea” – involuntary jerky movements of the arms, legs, trunk, neck or face.*
- Younger children with JHD typically do not exhibit chorea.
 - *Instead, they develop stiffness – especially in the legs.*
- A young person with JHD may begin to walk on their toes or develop a stiff-legged gait.
 - *They may lose their balance easily.*

Walking and Balance Strategies

- No medications can improve control of voluntary movements, though some may help with rigidity and involuntary movements. (However, undesirable side effects may prevent their use.)
- Physical therapy can help with rigidity, spasticity or dystonia (a fixed position of a body part.)
 - *Daily exercises and stretching can help maintain range of motion and strength.*
- Braces and other devices can help keep the young person walking as long as possible.
- A stroller or wheelchair may be needed as muscle control declines.

Best Practices: Case Study

- A Michigan elementary school student with JHD wears knee and elbow pads to reduce bruises that occur in gym, on the playground and when sitting on the floor in class.
 - *Protective gear that curved around elbows and knees were found to stay on better and not slip off the students arms and legs.*
 - *Bruises and injuries from falls were significantly reduced.*



Physical Safety: Hand-Eye Coordination

- JHD affects hand-eye coordination.
 - *The young person will begin to lose their spatial sense and become clumsy.*
 - *They may drop things or bang into objects.*
- JHD affects all kinds of voluntary muscle control, such as the ability to throw a ball or use tools.
- Handwriting skills will also decline as the disease progresses.

Best Practices: Case Study

- Video games have been recommended by one HD neurologist for maintaining hand-eye coordination.
 - *The games can also be used as a recess or respite activity.*
- For younger children, “Lite Brite” light patterning sets are a recommended tool for maintaining hand-eye coordination.



Physical Safety: Seating

- As the disease progresses, loss of voluntary muscle control can make safe seating an issue in the classroom and the lunchroom.
- Loss of muscle tone and weight can also make hard seating extremely uncomfortable.
 - *Bruising can be a problem.*
- A special recliner chair or wheelchair may become necessary as the disease progresses.
 - *A PT or OT can make recommendations.*

Seating Strategies

- To prevent falls, the young person may benefit from practicing a simple “touch-turn-sit” maneuver to keep from missing the chair.
 - *This is helpful even for those with marked memory loss.*
 - *Your OT can help with this.*
- Seating can be modified with a pommel to keep the individual from sliding out of the chair.
- Simple padding can reduce bruising and make seating more comfortable.
- It is best to start the introduction of assistive devices such as strollers, reclining chairs and wheelchairs before they are absolutely necessary.
 - *Memory loss can make change difficult for the person with JHD.*

Physical Safety: Chewing and Swallowing, Lunchroom Issues

- Eating is an issue for young people with JHD.
 - *The multiple disabilities of JHD all impact on lunchtime at school.*
- Physically, choking is a constant concern.
 - *If their speech has become indistinct, they are likely to have difficulty swallowing as well.*
 - *They may have difficulty using utensils and getting enough nutrition in the allotted time.*
- Cognitively, the lunchroom may be overwhelming.
 - *They may get distracted and not eat.*
- Emotionally, young people with JHD can be very conscious of their clumsiness with utensils and vulnerability to teasing.

Lunchroom Strategies

- The student should be monitored at lunchtime if there are choking or seating concerns.
- Consider moving lunchtime to the resource room or other quiet place.
 - *Allow additional time for eating, if possible.*
- It may be helpful to utilize a straw or covered cup to minimize spills and limit the amount taken with each swallow.
- Thin liquids often cause choking.
 - *Soups or liquids can be thickened with protein powder.*
- Watch for obsessive interest in soda or sweets.

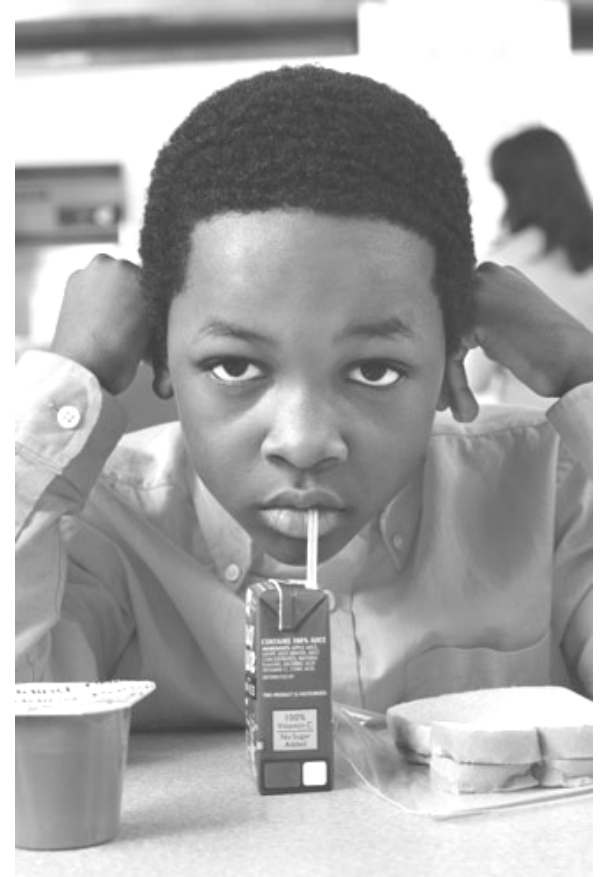
Best Practices: Case Study

- A speech therapist and occupational therapist in Colorado recommend the “Hand on the Shoulder” technique for eating.
 - *Light pressure on the shoulders seems to help with concentration and can reduce choking. Place a pair of rectangular “bean bags” on the shoulders of the young person with JHD once they are seated for lunch.*
 - *The bags must be the right size and texture not to slip off. Soft fleece may be a good choice.*



Best Practices: Case Study

- A school nurse in Michigan trained an Americorps volunteer as a lunchroom aide for a third grader with JHD.
 - *The aide supervised and assisted the JHD student at lunchtime.*
 - *With the volunteer’s help, the student adopted the “chin-tuck” maneuver when eating, reducing the risk of choking.*
 - *The school was able to provide a personal aide at reasonable cost.*



Nutrition: Supplemental Snacks

- As JHD progresses, the young person may experience significant weight loss.
 - *This is believed to be due to a combination of involuntary movements and difficulty in eating.*
- Weight loss and hunger contribute to exhaustion and emotional distress.
- People with JHD do not “self-regulate” well, so often they may not know when hunger or exhaustion are affecting them.

Supplemental Nourishment Strategies

- Consider allowing the student to bring in supplemental snacks to eat during the school day.
 - *Protein/calorie supplements such as “Ensure” or “Carnation Instant Breakfast”*
 - *Any high calorie/high carbohydrate food*
- Allow additional time for nutrition.
- Consider assigning a personal aide to help with feeding.

Physical Safety: Bus Transportation

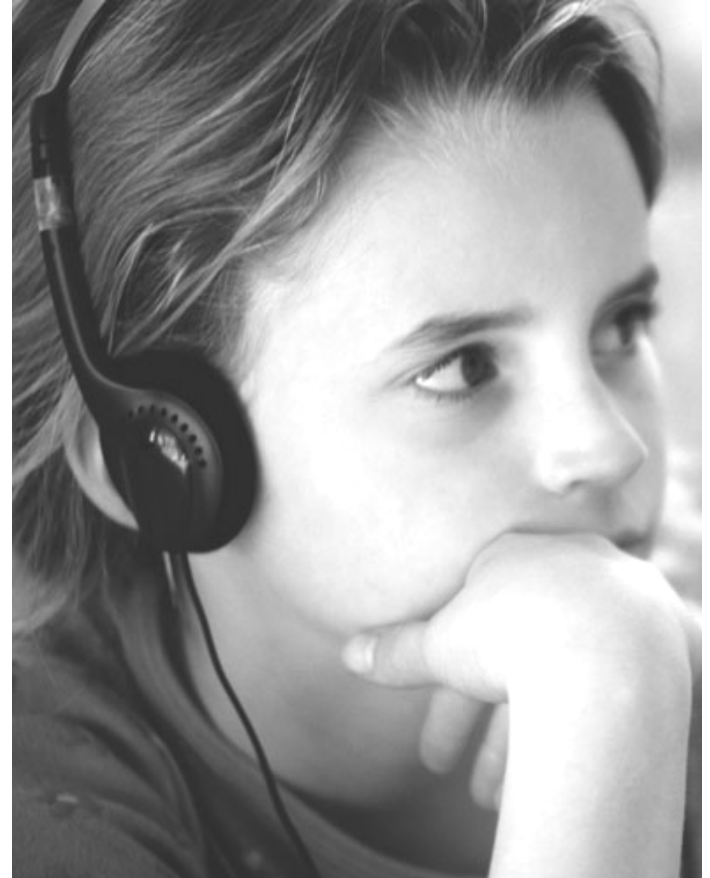
- Bus travel, whether to and from school or on a school trip presents challenges.
 - *Seating may be slippery and unsafe.*
 - *The young person may have difficulty getting up the steps to the bus.*
 - *They may have difficulty navigating the aisle.*
 - *As a disabled person, they may be open to teasing or harassment from other students.*
 - *Young people with JHD have reduced impulse control and may display impulsive or aggressive behavior on the bus.*
 - *Noise and activity on the bus may be overwhelming.*

Bus Transportation Strategies

- Reserve the front seat of the bus for the student with JHD so they can sit near the bus driver.
- Make certain a seatbelt is provided.
 - *Without a seatbelt, the student may wander.*
- Establish “zero tolerance” for taunting.
- Consider a “no-touching” rule on the bus.
- Special transportation will become necessary as disabilities increase.

Best Practices: Case Study

- One Michigan student with JHD found that a CD player with headphones was useful.
 - *The music shut out the noise and distractions and made it possible for the student to continue to ride the regular school bus.*
 - *This solution also allowed the student to continue to participate in class outings.*



Physical Safety: Bullying

- Young people often taunt anyone who is different – out of fear or ignorance.
 - *Bullying a person with JHD is dangerous and destructive.*
- With disabilities that are cognitive and emotional as well as physical, young people with JHD are highly vulnerable to physical or psychological abuse.
- Bullying can cause depression in the young person with JHD.
 - *It can also trigger dangerous aggressive responses.*
- JHD makes a young person impulsive and willing to take risks, especially as they become adolescents.
 - *It can be easy to bully a person with JHD into dangerous or inappropriate behavior.*

Strategies to Prevent Bullying

- Educate other students on the basics of JHD.
 - *The disc includes a presentations on JHD for students and their parents.*
- Establish a team of student “mentors” or buddies for the student with JHD.
 - *They can accompany the JHD student during class changes, for example, and alert adults to bullying situations.*
- Consider hiring a personal aide to maintain the safety of the student with JHD.

Best Practices: Case Study

- To increase understanding of JHD, one Minnesota middle school hosts a fundraiser for HD research.
 - *Students and their families participate in a “Hoop-a-thon”, where sponsors donate a sum for each basket the students complete.*
 - *The event has created a positive image of JHD in the local media and has become a source of pride for the school.*



Best Practices: Case Study

- One Minnesota High School student with JHD remained in the classroom even in the late stages of her disease.
 - *Bullying was prevented by having the class participate in the student's care as much as possible.*
 - *Classmates included the student in their activities and avoided the social isolation that can lead to bullying.*



Physical Safety: Risk-taking

- Risk-taking can be a significant problem in JHD, because of reduced impulse control and obsessive thoughts.
- Adolescents with the disease may be susceptible to sexual promiscuity and aggressive behavior.
- The control of impulsive, aggressive or obsessive behavior requires a multi-faceted approach that may include medication and behavior modification techniques.

Strategies for Reducing Risk-Taking

- Teachers can keep a log of incidents to help identify persons, factors or situations that trigger inappropriate behavior so they can be avoided.
- A psychiatrist may suggest behavior modification techniques or medications that treat depression or symptoms of hyperactivity and attention deficit disorder (ADD).
- Reward good behavior with treats or activities the student favors.
- Form a safety plan for restraining the student, if necessary, before it is needed.

Best Practices: Case Study

- The behavior of a New York State student improved greatly when his depression and symptoms of Attention Deficit Disorder were treated medically.
 - *Treating the underlying depression led to fewer angry and aggressive behaviors.*
 - *Treating the symptoms of ADD made it possible for the student to remain more calm and focused.*



Physical Fitness

- Students with JHD will begin to lose coordination and balance.
 - *JHD can also cause involuntary movements and rigidity.*
- Students with JHD are frequently exhausted from the physical and cognitive changes caused by the disease.
- Even as coordination declines, it is important for the student to maintain physical fitness in the form of strength and flexibility.

Strategies for Physical Fitness

- Team sports and common gym activities may become inappropriate; lack of coordination can lead to teasing or social exclusion.
- An physical therapist can implement an appropriate exercise program to help reduce rigidity and maintain strength.
- Adaptive gym activities can keep the student involved as long as possible.

Best Practices: Case Study

- A Physical Therapist in Michigan created a set of exercises for a young student with JHD.
 - *Exercises were created for joint motion, muscle strength, balance and endurance.*
 - *Balance exercises helped improve the student's spatial awareness and reduced bruises and falls.*
 - *Exercise can help with depression and reduce the need for medication.*



Physical Safety: Seizures

- Seizures affect about 25% of young people with JHD.
 - *The ongoing tendency to have seizures is called epilepsy.*
- Medication may be used to reduce the occurrence of seizures.
 - *All seizure medications can have serious side effects that may worsen other JHD symptoms such as forgetfulness, exhaustion or problems with coordination.*
- It is critical that seizure medications be given consistently and at the time prescribed.

Seizure Management Strategies

- The school nurse is the “point person” in managing a student’s seizures at school.
- The school nurse will develop a student health plan that addresses the type of seizures the JHD student has and the interventions to be taken.
- The school nurse can also support school staff by:
 - *Educating classmates to decrease anxiety.*
 - *Educating school staff on seizure management.*

Physical Safety: Sexual Activity/Abuse

- The ordinary challenges of adolescent sexual development can cause significant problems in students with JHD.
- Normal sexual urges combined with reduced impulse control can lead to inappropriate or obsessive behavior.
- Some JHD students are overly trusting, which puts them at risk for sexual abuse by other students.
 - *Others may exhibit inappropriate sexual behavior in school.*

Strategies to Prevent Sexual Activity/Abuse

- Controlling the sexual urges and behavior of a student with JHD may require a combination of strategies.
 - *Reward the student for controlling inappropriate touching or comments in school.*
 - *Remember that they are not doing this “on purpose”.*
 - *Be alert to sexual abuse by other students.*
 - *Medications may be recommended to curb obsessive thoughts and aggressive or sexual behavior.*

Best Practices: Case Study

- Residential schooling was provided for an adolescent student with JHD in New York at a special needs facility.
 - *The student no longer disrupted the school with dangerous and inappropriate behavior.*
 - *The student's needs were better met in the residential school.*
 - *The student's outlook and behavior improved markedly.*



Conclusions: Best Practices for the School Environment

- Assemble the team of teacher, OT, PT, SLP and school nurse before the JHD student starts the school year.
 - *Decide on strategies and put them in place early.*
- Establish and maintain a safe learning environment.
- Promote an understanding attitude among teachers and students.
- Review the IEP more than once a year and be willing to make necessary changes.
- Introduce assistive aides before absolutely needed.

Spreading the Word

- While young people with JHD will get help from school specialists, they also need understanding from teachers and students.
- A tone of understanding and acceptance will improve the school experience of a JHD student.
- Above all else, a student with JHD is a young person who deserves to achieve the most they possibly can.

Resources

- The Huntington's Disease Society of America – www.hdsa.org, 800-345-HDSA
- “The Family Guide Series: Juvenile Huntington's Disease”, Martha Nance, M.D., editor. Available from HDSA.
- “The Juvenile HD Handbook: A Guide for Physicians, Neurologists and other Professionals”, Martha Nance, M.D., editor. Available from HDSA.
- JHD Caregivers Discussion Group:
<http://health.groups.yahoo.com/group/JHDCargivers/>

Additional Resources Primarily for Parents

These documents are provided in in Adobe Acrobat PDF format

- [Children With Disabilities: Understanding Sibling Issues](#)
- [Communicating With Your Child's School Through Letter Writing](#)
- [Evaluation - What Does It Mean For Your Child](#)
- [Functional Behavioral Assessment and Positive Interventions - What Parents Need To Know](#)
- [Helping Students Develop Their IEP's](#)
- [How Will I Know If My Child Is Making Progress](#)
- [IEP Goals and Objectives](#)
- [Parent Guide To Developing Your Child's IEP](#)
- [Planning to Move - Parent Guide to Mapping Your Strategy](#)
- [Planning Your Child's Individualized Education Program - Some Suggestions To Consider](#)
- [Related Services Required To Assist A Child Benefit From Special Education](#)
- [Special Education Re-Evaluation](#)
- [The Special Education Evaluation per IDEA](#)
- [Third Party Payments for IEP's](#)
- [Understanding The Special Education Process](#)
- [What You Need To Know About Transportation - Child With Disability](#)
- [When The School Must Give Special Notice](#)

Special thanks to Jean Miller for collecting these documents, which were produced by: the National Information Center for Children and Youth with Disabilities (NICHCY); Consortium for Appropriate Dispute Resolution in Special Education (CADRE); the Parent Advocacy Coalition for Education Rights (PACER); and the Families and Advocates Partnership for Education (FAPE) at the PACER Center. PACER Center materials Used with permission from PACER Center Inc., Minneapolis, MN, (952) 838-9000. www.pacer.org. All rights reserved.

Other Additional Resources

These documents are provided in in Adobe Acrobat PDF format

- [Adaptations and Accommodations for Students with Disabilities](#)
- [Educating Our Children Together - A Sourcebook for Effective Family-School-Community Partnerships](#)
- [Facts-on-Hand Acronyms and Special Education](#)
- [Facts-On-Hand Informed Parent Consent for Pre-School and School Aged Children With Disabilities](#)
- [Frequently Asked Questions \(FAQs\) on Mediation](#)
- [School Accommodations and Modifications](#)
- [Sexuality Education for Children & Youth with Disabilities](#)
- [Simple, Inexpensive Communication Devices](#)

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505 Eighth Avenue, Suite 902
New York, NY 10018
212-242-1968
1-800-345-HDSA
www.hdsa.org