THE FAMILY GUIDE SERIES

# Juvenile Huntington's Disease

**Edited by:**

**Martha Nance, M.D.**
**Randi Jones, Ph.D.**
**Suzanne Imbriglio, P.T.**
**Betsey Gettig, M.S., C.G.C.**

**Huntington's Disease Society of America**
158 West 29th Street, 7th Floor
New York, New York 10001-5300
212-242-1968 • 1-800-345-HDSA • www.hdsa.org

*The Huntington's Disease Society of America is dedicated to eradicating Huntington's Disease by promoting and supporting HD research; to helping families cope with the problems presented by HD; and to educating the public and professionals about Huntington's Disease.*

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# Contents

# What is Juvenile Huntington's Disease?

Huntington's Disease (HD) is a genetic brain disorder that leads to abnormal movements, dementia, and behavioral disturbances. Individuals who develop HD have an abnormality in their HD gene from the moment of conception—years or decades before symptoms may begin. In the United States, HD occurs in about 1 in every 10,000 individuals, of almost every ethnic background. Fewer than ten percent of individuals with HD develop symptoms before age 20[1].

Juvenile-onset HD presents unique challenges to affected individuals, their caregivers, and the various professionals who are called upon to assist them.

This publication will describe how a physician makes a diagnosis of HD, the symptoms that are most commonly seen in juvenile HD, strategies for coping with juvenile HD and the current outlook for HD research.

# When to Consider HD

There is no symptom or group of symptoms that is absolutely required for the diagnosis of juvenile HD, but several features are common at the time of diagnosis.

### Typical initial symptoms of juvenile HD in children under the age of 10 are:

- Positive family history of HD, usually in the father
- Stiffness of the legs
- Clumsiness of arms and legs
- Decline in mental ability
- Changes in behavior
- Seizures
- Swallowing or speech problems.

1 Peter S. Harper, Huntington's Disease, NY: W.B. Saunders, 1996.

The dance-like or twisting movements (chorea) often seen in adults with HD is uncommon in children who develop HD before age 10, but may be one of the first symptoms a teenager exhibits. Behavioral disturbances are sometimes the first symptom in an adolescent.

## Family History

HD is an inherited disease. One parent usually has the disorder. For genetic reasons, children with a very early onset of HD are far more likely to have an affected father than an affected mother. If neither parent shows symptoms of the disease, it may be due to:

- The death of a parent before HD symptoms were evident
- Misdiagnosis or lack of diagnosis in the parent
- A biological father who is not the same as the apparent father
- Onset of symptoms in the child before the parent's onset
- The child was adopted and family history is unknown

If none of these seem to be the case, the child's physician should consider a diagnosis other than HD.

If the child was adopted, it may be possible to obtain the family medical history from the birth parents through the adoption agency or local social services department, once the serious nature of HD and its hereditary pattern are communicated.



# Seeing the Physician

Diagnosing juvenile HD is difficult. A parent should understand that the diagnosis of juvenile HD is unlikely to be made immediately at the first visit, and should be prepared to work with the physician to find the cause of the symptoms.

The parent and the physician should not assume that HD is causing a child's symptoms. Children in HD families can have developmental delay, attention deficit disorder, mental retardation, depression, or other medical or neurological conditions entirely unrelated to HD. Both parents and physicians should consider all possibilities as they go through the diagnostic process. Genetic testing is not the first step to take.

To begin the diagnostic process, the physician will take a medical and neurological history, a family history, a developmental history, and perform a neurological examination and neuropsychological assessment (tests of memory, developmental skills, and intelligence) to serve as a baseline for comparison later. The physician may order brain imaging or blood tests to rule out other conditions that may cause the child's symptoms. It is helpful for the parent to bring records of any previous neurological examinations, psychological evaluations and school testing.

### Steps in the Diagnosis of Juvenile HD

- History of a change in motor, behavioral, and cognitive function
- Family history of HD
- Abnormal neurological examination
- Abnormal neuropsychological test results
- Progression of symptoms despite appropriate treatment and psychosocial support
- Genetic test confirming the presence of the HD gene

Based on the child's behavior and school performance, the physician may ask physical, occupational, and speech therapists to assess the child. The physician may also make referrals for individual or family counseling, school-based programs, or social services.

## Genetic Testing

If the child's evaluation is suggestive of HD, a genetic test may be considered, though the genetic test is not a shortcut to diagnosis. It is possible that a gene test will show a result associated with adult-onset HD, not juvenile-onset HD, leaving the child's current symptoms unexplained. Only children who clearly have clinical symptoms and a course that is consistent with HD should undergo genetic testing. A genetic counselor should consult with the family before and after testing.

**Risks of premature testing for HD include:**

- Incorrect assignment of symptoms to HD
- Potential insurance or employment discrimination
- Psychological/social effects on the child

In most situations, before a genetic test is performed, the child should be evaluated twice, six to twelve months apart, to determine whether the symptoms have progressed despite initial treatments. As there is currently no cure for HD, there are many reasons to wait on testing.

The genetic test for HD is performed on a blood sample, which is examined chemically to detect certain changes in the length of the gene. The gene test is close to 100% accurate. If the test shows two normal HD genes, the child will never develop HD and is not at risk for passing HD on to future generations. If the test shows an abnormal HD gene, the child will someday develop HD. The gene test, however, cannot predict when symptoms will begin.



## Testing Children Who Do Not Have Symptoms

When one child has been diagnosed with HD, worried parents may want to have their other children tested as well. At this time there is no medical advantage to knowing that one carries the HD gene—treatments that prevent or delay the disease have not yet been developed. Because there is no benefit to testing a healthy child, and many possible social and psychological risks, "predictive testing" of children who do not have HD symptoms is not usually performed in North America. Adolescents in adult situations, such as an "emancipated minor" or a married teenager, may be exceptions to this rule.

In the United States, children who are eligible for adoption are not usually given predictive HD tests because of the potential for social, financial, educational, insurance, and employment discrimination based on the test results. Other countries may have different practices.

# After the Diagnosis

## The Expected Course

HD progresses over a number of years. Generally, the younger the child is when the symptoms start, the faster the disease will progress. As HD progresses, the child gradually loses the ability to walk, speak clearly, dress, eat, or bathe without assistance. Eventually, affected individuals require 24-hour supervision and care. Physicians cannot predict which child is likely to have a longer or shorter course of the disease.

A child with HD will need the services of many different medical specialists. Although juvenile HD is rare, the individual symptoms of HD are familiar to most health care professionals. At present, there is no cure and no medication known to slow down the progression of the disease. Treatment is directed at easing the individual's symptoms.

### Juvenile HD multidisciplinary team:

- Family doctor or pediatrician
- Psychologist or psychiatrist
- Neurologist
- Physical, occupational, and speech therapist
- Dentist
- Social worker, genetic counselor
- Dietician

The Huntington's Disease Society of America (HDSA) has established regional Centers of Excellence for Family Services and Research to provide the full range of services needed by HD families in one location. For those parents and physicians beyond the reach of an HDSA Center of Excellence, the National Office can assist with information and resources.

## Emotional Support

Parents should not expect to cope with a child's HD alone. Drawing emotional support from friends, family members, mental health professionals or a religious institution is vital to the well being of the parents and through them, the child.

Children are often more aware of problems than the parents realize and deserve honest answers. Children of almost any age can be told that their sibling has HD, that HD is not the same thing as AIDS or cancer, that it is not contagious, and that having HD does not mean that the sibling is dying soon.

An important part of your explanation of HD to a child who is diagnosed is that the affected parent did not pass on the gene deliberately.



HD is truly a family disease, affecting parents, siblings and the extended family. Professional counseling is important for any family member who feels overwhelmed, depressed or out of control. Many families find it helpful to schedule regular visits with a family counselor. School counselors should be made aware that all the children in a family facing HD are susceptible to depression and stress and may need special attention.

The Huntington's Disease Society of America assists HD families through literature, support groups, newsletters, an annual convention, and a website (www.hdsa.org). HDSA helps HD families to connect with one another and to obtain accurate and up-to-date information.

# Specific Medical Issues

## The Movement Disorder

Neurologists classify HD as a "movement disorder." Children who show HD symptoms before age 10 often develop stiff or rigid muscles. Some adolescents with HD develop involuntary, fidgety movements. As the disease progresses, clumsiness, stiffness and abnormal movements impact the ability to dress, bathe, or perform other activities of daily living.

### Symptoms of movement disorder include:

- Walking on the toes
- Losing balance when running, hopping, or bicycling
- Developing a scissoring or stiff-legged gait
- Slurred speech
- Difficulty swallowing
- Drooling
- Clumsiness
- Lost ability to write, throw a ball, or ride a bicycle
- Difficulty performing a series of movements in the right order

## Therapies for Children with HD

There is no medicine that can cure HD or even slow the onset of symptoms. Information about drugs that can be used to reduce rigidity, muscle spasms or chorea are available through HDSA Centers of Excellence.

Physical, occupational and speech therapists can suggest ways to help the child continue to perform daily tasks. A program of exercises may help to maintain range of motion. Special seating may be recommended for the classroom. Strategies to reduce falls can be taught. Assistive devices to help with dressing, walking, and feeding may be introduced. Problems with speaking and swallowing may be addressed with oral exercises and other individualized strategies. A county public health nurse can come to the home to assess and assist the family with appropriate safety measures and devices.

## The Cognitive Disorder

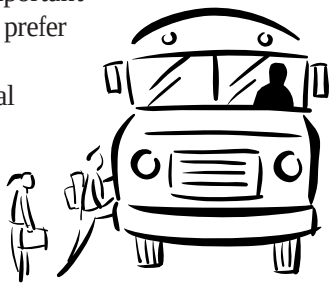
Huntington's Disease leads to a progressive loss of mental ability. Attention, concentration and judgement problems are also common. A general slowing of the speed of thought is typical. A common early symptom of juvenile HD is difficulty starting or finishing a task, or doing all the steps of a task in the right order. As these can also be common symptoms of ordinary adolescence, parents, teachers, and physicians must look beyond single symptoms for a pattern of change that suggests HD.

There are currently no medications that improve mental function. In fact, many of the medications used to treat mood disturbance, aggressive behavior, or other aspects of HD can have side effects that interfere with alertness. The parent and physician must carefully balance the need for these and any medications with their side effects.



## The School Environment

As HD progresses, children become less able to learn new information due to memory impairment, reduced ability to concentrate, and difficulty starting and completing complex actions. Behavioral problems may occur when a child is frustrated by material that is too difficult or presented too quickly. While remaining in a class with familiar classmates may be important to some children, others may prefer or need the individualized attention available in a special education program. All children with HD should have individual education programs, with new goals set each year.



## The Home Environment

Establishing routines early in the course of the disease will help as the child develops memory problems. Gently introducing wheelchairs, helmets, communication boards and other assistive devices, before they are absolutely needed, allows the child time to become familiar with them.

# Behavioral and Psychiatric Issues

## Depression

Depression is the most common mood change in children with HD. It may show itself in sad moods and tears, a significant change in sleep habits (either too much or too little), change in appetite or weight (in either direction), lack of interest in previously enjoyable activities, or poor performance at school or work.

Sometimes an excessively elevated mood alternates with a depressed mood. This is called a "bipolar disorder." In the times of an elevated mood, a child may require very little sleep, may be buzzing with activity (although often getting little accomplished), and may be easily excitable, or irritable. This condition may be brought on or made worse by the use of stimulant drugs such as cocaine or amphetamines. Information about medications used to treat depression or bipolar disorder in individuals with HD is available through HDSA Centers of Excellence.

## Aggression, Impulsiveness and Obsession

Behavior often presents the greatest management problem in children with HD. Changes in the brain, caused by HD, increase impulsive behavior as they reduce the ability to use previously learned social rules. Not all adolescents undergo these changes. However, adolescents with HD sometimes become dangerous, violent, or suicidal. Parents may find that certain situations act as triggers. Problems may consistently occur at mealtime, bedtime, or only in the presence of a certain care provider. There may be an obsession with soda, a certain food, sex or cigarettes. Some problems may be reduced through compromise, with rewards given for appropriate behavior. Sometimes a change of caregiver helps. Therapy with a skilled counselor or child psychiatrist can help both the family and the child to understand and control the behavior problems.

If behavior problems cannot be controlled by changes in the environment or behavior modification strategies, medications may be necessary. Each of the most commonly used medications has potential side effects, and none is effective in all children with behavior problems. Families cannot rely on medications alone to control behavior. When behavior is chronically or unpredictably dangerous, particularly if other children are at risk for harm, psychiatric hospitalization may be needed.

In some children, problematic behavior is related to attention deficit hyperactivity disorder (ADHD) or an underlying depression. Treating ADHD or depression may help to decrease violent, angry, or aggressive behavior.

## Adolescence, Sexuality and HD

Teens with HD can be vulnerable to sexual or physical abuse, and to their own impulsive and aggressive behavior. Early attention to issues of sexuality is important, as many adolescents with HD are sexually promiscuous, but not fully aware of the potential consequences of their sexual activity. The school may be obligated to provide a personal care attendant if a boy or girl is judged to be particularly susceptible to teasing, physical threatening or sexual abuse by others in the school.

Impulsive or aggressive sexual behavior can be severe in adolescent boys with HD. A psychiatrist or counselor experienced in the treatment of sexual or conduct disorders may be needed. Medications can be used to curb aggressive sexual behavior, but should only be used as part of a larger treatment plan.

## Hallucinations

Hallucinations are uncommon in HD, but can occur. Hallucinations can be triggered by severe depression, by certain drugs, or in the late stages of the disease, by medical illness. Antipsychotic (neuroleptic) medications can be used to control hallucinations.

## Seizures

Epileptic seizures occur in about 25% of children with HD, but it should never be assumed that HD is the cause of the seizures until other possible causes have been ruled out by imaging studies, blood tests, and an electroencephalogram (EEG). Seizures may begin at any time during the disease, and range from mild or infrequent episodes to frequent and severe seizures. There are a number of anti-epileptic (seizure) medications, which can reduce the chances of having seizures; all medications must be used carefully to minimize their side effects. Referral to a pediatric epileptic specialist may be appropriate for some children.

# Swallowing, Speaking and Eating

## Choking

Choking, or dysphagia, is an expected complication of HD. While there are no medications that improve swallowing, a speech pathologist can often provide practical tips to minimize choking. Severe dysphagia can prevent children with HD from getting enough to eat which can lead to pneumonia and malnutrition. Feeding tubes may be recommended for those with severe dysphagia. While some parents may not want to use such “artificial” means of feeding, others feel that it allows their child to live comfortably without the discomfort or indignity of hunger and choking.

## Communication

A speech pathologist can also evaluate the child for communication problems. Communication boards or computerized devices may be prescribed as speech becomes more difficult. Each child must be assessed individually to determine which strategies and devices are most appropriate, based on age, cognitive skills, and motor skills.



## Nutrition

Most children with HD experience significant weight loss as the disease progresses. A child with HD needs high-quality foods with extra calories and protein and plenty of calcium and vitamins. A parent may add prepared supplements or protein/calorie additives such as Carnation Instant Breakfast‘ to the child’s diet, substitute cream for milk, offer ice cream for snacks, or serve high-carbohydrate foods such as pasta. As chewing and swallowing become more difficult, consultation with a dietitian may be helpful in order to arrange an easy-to-eat diet that includes ample calories, protein, and vitamins.

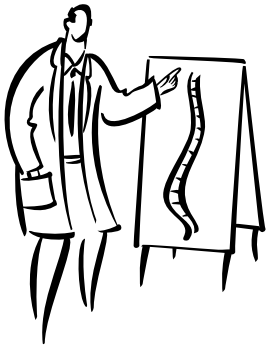
Many individuals with HD develop strong preferences, or even obsessions, for non-nutritious items such as soda or candy. For a child with HD, limiting snacks to nutritious foods can help manage this problem before it begins. Sometimes a prized food or snack item can be used as a reward for good behavior.

## General Medical and Dental Care

A child’s general health should not be neglected because of the special care related to HD. Immunizations should be given on time, and growth and maturation should be monitored as they would be for any other child.

Oral hygiene may be difficult for a child with HD. Tooth brushing requires small muscle coordination. Rigidity in the jaw muscles may make brushing difficult. An electric toothbrush may be helpful. The parent may need to seek out a dentist who treats children with disabilities.

## Alternative Therapies and Medications



Very little is known about the benefits of alternative therapies in treating HD. Alternative therapies might include vitamins, herbal preparations, homeopathic preparations, chiropractic manipulations, acupuncture and magnet therapy. Several clinical trials are underway to discover if certain vitamins or dietary supplements can help people with HD. Until more is known, the decision to use alternative therapies must be made by the individual or parent after considering the unknown benefits, the potential risks, and the financial cost.

# Daily Life

Parents of a child with HD will come into contact with many people who have no experience with the disease. They may have to inform doctors, teachers and other individuals that although juvenile HD is rare, many of the daily challenges are similar to those of children who have other disorders or disabilities.

## School

Public schools are required to provide education for children with handicaps of all types. As soon as a diagnosis of HD is made, the family should meet with school representatives to create an individual education plan (IEP) for the child. This plan must take into account not only the child's cognitive skills, but also the motor, behavioral, and social factors that can influence school performance. Because HD is a progressive disease, the educational plan must be reviewed frequently (at least once a year), to set new goals appropriate to the child's age and stage of disease. Teachers and other school officials must be helped to understand HD and how it affects the child's performance at school.



**Parents of children with HD may request assistance or adjustments in:**

- Academic classes
- Physical education
- Meals
- Seating and transportation
- Safety and hygiene
- Behavior control

## Other Schooling Options

The Americans with Disabilities Act (ADA) requires that public schools meet the needs of all individuals. If a local school is unable to meet a child's needs, it must provide an alternative for the family. One alternative that a school will frequently suggest is home-based tutoring. This may or may not be appropriate. Residential schools for handicapped children are another option. Local schools must fund residential placement when it is deemed "educationally necessary." For some families, residential placement greatly enhances the child's educational and social experience.

**Some behavior management options available to parents are:**

- Set simple goals
- Limit choices to those that are acceptable
- Avoid open-ended questions (i.e. "What do you want to eat?")
- Connect behavior with rewards (i.e. "Do you want peas or beans before your ice cream?")
- Change the environment or schedule to adapt to the child with HD

## Behavior

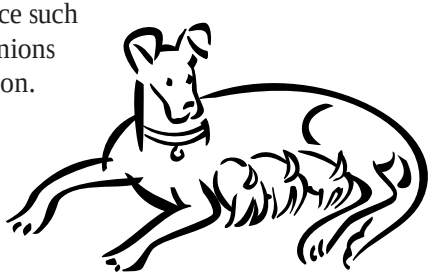
Managing behavior may become increasingly difficult as a child's ability to reason and communicate declines. When things get frustrating, parents and other caregivers should remember that it is rarely the child's desire to behave irritably or aggressively. It is HD that causes the problems.

## Activities

As HD progresses, the child will need a simpler schedule. Apparent behavior problems may be caused by fatigue or confusion. The emphasis should be on familiarity, comfort, and enjoyment. Activities involving small groups are often the most successful.

Ultimately, children with HD lose the ability to maintain friendships due to the decline in physical and cognitive skills. Severe behavior problems and impulsive actions may also limit social interactions. However, as the disease progresses, the child becomes unable to carry out previously problematic behaviors.

Animals may provide an emotional outlet for a child with HD. A pet can be a friend, an emergency alarm, and a physical therapy helper, among many other roles. Some animals are trained specially to assist individuals with disabilities. Families can contact a local veterinarian, the ASPCA or a service such as Canine Companions for more information.





# The Progression of Juvenile HD

## The Stages of HD

A functional scale to help parents and physicians judge where a child is in the progression of HD (based on the scale for adults devised by Drs. Ira Shoulson and Stanley Fahn) can be found on page 21. This scale rates motor and cognitive functions, but does not rate severe behavioral or psychiatric problems. Treatment of behavior problems may result in an increase in a child's score. Despite its limitations, this scale can help families to understand generally where the child is in the course of the disease, and may assist in the development of treatment plans for school or home.

## Preparing for Late Stage HD

Although it is difficult to think about the progression of symptoms and the late stages of the disease, it is important to do so. Before a crisis arises, families should discuss such issues as nursing home placement, end of life care limitations, tube feeding, tissue donation and autopsy.

In the late stages of HD, the child or young adult may not be able to participate in discussions regarding medical care or other wishes. Talking about these issues early on allows the child to make his/her wishes known and to have them recorded in the form of "Advance Directives." When an affected teen reaches the legal age of maturity, it is wise to designate a family member as a legal guardian who can make his or her medical care decisions on his or her behalf. These arrangements are usually made through the probate court of the county of residence.

## A functional scale for assessing juvenile-onset HD

**A. School attendance**

3—attends school, no special assistance needed

2—attends school, some regular classes, some special or modified classes

1—attends school, few or no regular classes

0—unable to attend school or work program

**B. Academic/developmental performance**

3—reading/writing/math skills appropriate to age

2—mild decrease in academic performance but still able to take a test or to write

1—unable to write legibly but able to communicate orally

0—unable to read/write/communicate orally

**C. Chores**

2—able to assist in age-appropriate manner with household chores

1—occasionally assists with chores

0—unable to participate in household chores

**D. Activities of daily living**

3—performs self-cares in an age-appropriate manner

2—requires some assistance for bathing, dressing, grooming, or feeding

1—assists others who bathe, dress, or feed him/her

0—unable to assist in self-care

**E. Residence**

2—at home with only family assistance

1—at home/group home/foster care with assistance from non-family members

0—living in a skilled nursing care facility

### Add the points to determine the stage of HD

11-13 points..... Stage 1

7-10 points..... Stage 2

3-6 points..... Stage 3

1-2 points..... Stage 4

0 points..... Stage 5



## Home Care and Nursing Homes

Parents of a child with HD should plan to ask for outside assistance in the late stages of the disease. Some families find enough volunteers to help care for the affected child and never require professional help. Other parents may hire someone to help with household chores. Still other parents need professional home health aides or certified nursing assistants for "custodial" tasks such as bathing, dressing, and feeding. A visiting nurse can work with the family to determine which services the aides or assistants will supply. Home health services are often administered by a hospital or county government agency.

Individuals with late-stage juvenile HD require 24-hour nursing care. Placement in a skilled nursing care facility may become necessary. While there are no facilities in the United States that specialize in the care of children with juvenile HD, there are several facilities that have specialized care units for adults or young adults with HD.

For young adults, who are not yet in the late stages of the disease, a number of different living situations are possible with varying amounts of care or supervision. These include adult foster homes, group homes, board and care facilities, assisted living facilities, and nursing homes.

## Hospice Care

Hospice care is a special kind of clinical care, which focuses on easing the transition between life and death for both the ill individual and the family. Hospice care is provided by nurses, social workers and pastoral counselors who have special training and experience in the problems and concerns that occur in the last few weeks of life. Hospice can be provided in the hospital, in the nursing home, or at home. Hospice nurses can answer questions about medical issues such as pain, nutrition, or infections and help the family prepare for the tasks that must be taken care of at the time of death.

# Financial, Legal and Social Service Issues

## Medical Consent

Parents are generally the ones who make medical decisions for their children until they reach the age where they are legally responsible for themselves (generally eighteen). In the case of a young adult with juvenile HD, a parent or grandparent may need to assume guardianship, which will allow them to consent to medical treatment for the young person with HD. This is a legal procedure handled within the probate court of most counties. The caregiver must file a petition, an independent evaluator and attorney for the proposed ward is assigned, and a hearing is held. If guardianship is granted, the caregiver will have the legal authority to make personal and financial decisions for the person with HD.

## Financial Options

### Supplemental Security Income

Supplemental Security Income (SSI) is a federal program of cash assistance to disabled needy individuals of any age, including children. Under SSI, children are considered disabled if they have a physical or mental condition which is so severe that it results in marked and severe functional limitation. The individual's condition must last or be expected to last at least twelve (12) months, or be expected to result in the child's death.

An important component of this program is the fact that after an individual is determined eligible for SSI benefits he/she is automatically qualified to receive Medicaid benefits as well. The program provides monthly checks from the federal government of up to $530 (in 2001) for an individual. Some states provide an additional cash supplement. The exact amount of SSI for which a claimant is entitled depends on what the individual (or the parents in the case of a child) owns and how much income he or she has. Eligibility requirements and benefit payments for federal SSI benefits are identical throughout the 50 states and the District of Columbia. For more information, check the website for Social Security at http://www.ssa.gov or call (800) 772-1213.

A disability law attorney can also provide state-specific information and guidance in planning for eligibility for SSI benefits.

### Medicaid

Medicaid is a jointly funded and administered state and federal welfare program that pays the qualifying medical expenses for those individuals whose financial resources fall below the program's established minimums.

Medicaid may pay for such services as hospital and doctor bills not covered by insurance, home health care services, medical transportation, and nursing home care. Many states also have waiver programs under which an individual who is disabled but does not meet the financial criteria may still become eligible for benefits.

Because the eligibility criteria and available benefits vary greatly by state, one should contact the State or County department that administers the Medicaid program in his/her state (called Medi-Cal in California) or a disability law attorney for information specific to the individual's state.

Also ask a pediatric health care provider or medical social worker about the Children's Special Health Care Needs programs. This program exists in every U.S. state and territory, but it may be called "Crippled Children's Services" or "Children's Medical Services and Handicapped Children's Program." The program starts with medical eligibility and then considers income eligibility. These programs may provide "waivers" for families who do not meet the standard eligibility requirements for Medicaid.

## Other Financial and Placement Considerations

Many states do not have nursing home beds for people under sixteen years of age, with some very specific exceptions for short-term care. Because of this, there has been an increase in home-based services for people with severe and chronic illnesses and also in respite services for their caretakers. Respite care offers short-term care in order to give a break to the regular caregivers. Community Mental Health programs, which in many states cover virtually every corner of the state, are frequently involved with children deemed to be "developmentally disabled" and may be a source of information on respite programs.

The Tax Equity Fiscal Reform Act (TEFRA) is one special program for children without family health insurance, or for a child who has "topped out" the lifetime limits of the family insurance. TEFRA will help cover necessary treatment and support, often in a home setting.

Assistance may also come from the public education programs of the state. Under the Individuals with Disabilities Educational Act (IDEA), children with severe disabilities must be accommodated with services such as transportation, variable school hours as needed, and personal assistance to participate. An Individual Educational Plan Committee must be held to develop a learning plan for each child in special education. Services available to private schools and to charter schools may vary from jurisdiction to jurisdiction. States may add services to federally mandated programs, but they cannot detract.

Even experienced professionals may have to search for entry points for care and often have to follow up with phone calls and letters to clarify eligibility and to gather information. The rules can be complicated, but most professionals want to help a family with a disabled child obtain all appropriate benefits. Expect to make numerous phone calls and to keep logs of calls, correspondence and visits. Expect to be a bit discouraged by the necessary paperwork.



The HDSA Chapter Social Workers and the Center of Excellence Social Workers are very knowledgeable about the resources in their state and region. Social workers will help you get started with services, and then help with advocacy as needed.

# Hope for the Future

Now, more than ever before, there is reason to hope for improved treatments for HD. The discovery of the HD gene in 1993 has resulted in an explosion of experimental research and new findings and insights about the disease announced almost every month.

With the tools of modern molecular biology, it is possible to "cut and paste" genes and parts of genes and to create "HD models" in fruit flies, mice and other animals that can be used in experiments to understand different aspects of the gene, the HD protein, or the disease.

HD researchers are beginning to collaborate with researchers of other brain disorders, such as Parkinson's and Alzheimer's diseases. The dawn of a new century brings with it a great hope for new treatments for this difficult disease. With good reasons for optimism, we foresee the worldwide HD community of families, friends, clinicians and researchers working together to find the final pieces of the puzzle of HD, and to develop effective therapies for those facing this devastating disease.

# Resources

For more information—visit the HDSA website at www.hdsa.org or phone the HDSA National Office at 1-800-345-HDSA. HDSA can direct you to local chapters, HDSA Centers of Excellence for Family Services, and other sources of information.