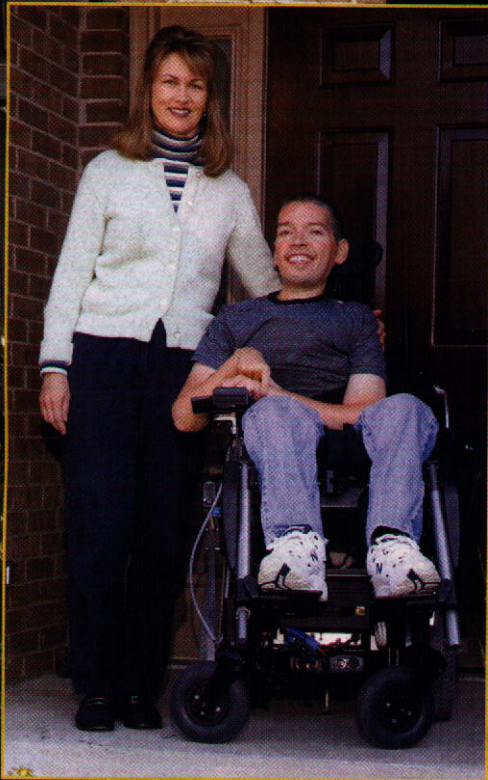


QUEST

Muscular Dystrophy Association

December 2002 • Vol. 9 No. 6



**BUILDING YOUR
DREAM HOME**

Cognitive Disabilities

Dental Care

QUEST is a quarterly publication of the Muscular Dystrophy Association. For more information please contact our toll-free line at 1-888-688-8888.

BEYOND THE BOOKS:

Parents become education experts and advocates

by Tara Wood

If your child has both cognitive and physical disabilities caused by a neuromuscular disease, an Individualized Education Plan (IEP) can make all the difference in getting the best possible school experience for your child. The law requires that the IEP provide for the necessary supports to give your child a complete, appropriate education (see "Glossary," page 20, and "Resources," page 28).

But parents have found that making sure this happens is their responsibility, not one to be left up to the school.

In addition to physical accommodations, the IEP should include educational goals and adaptations that best suit the child's specific learning abilities. Services such as physical and occupational therapy, speech therapy and counseling, if geared to a child's particular cognitive or sensory disabilities, can help make the school experience more productive both educationally and socially.

When disabilities are both physical and cognitive, the *individualized* part of the IEP is especially important.

IEPs are put together by the school staff, parents, physicians and anyone else the parents choose to involve in the process. Remember, you have to sign off on the IEP, so it isn't done until you're satisfied.

Homework for Mom, Dad and Teacher

While doctors and therapists may be experts in the physical or cognitive aspects of a child's neuromuscular disease, parents may ultimately be the only ones who have a clear understanding of both, and can see the "big picture" where their child is concerned.

That means parents should expect not only to consult with doctors who are experts in their child's neuromuscular disease, but also with therapists, specialists and teachers, and then to help build bridges over the gaps between them.

In Duchenne MD, neuropsychologist Veronica Hinton emphasizes tailoring the child's educational program to his strengths. For example, Hinton has found that boys with DMD are generally good at rote learning but have difficulty with phonetic approaches to reading, especially in the early years. (See "When Neuromuscular Disease Affects the Brain," page 16.)

That holds true for 12-year-old twins Aryn and Erik Brodsky, who have DMD and attend school in Ithaca, N.Y. The boys' learning delays mean they function more at the level of 7-year-olds, says their mother, Stephanie Brodsky.

Brodsky has noted unique strengths and weaknesses in each boy's learning abilities: Aryn learned to read just last year but is strong in math, while Eric has less difficulty with reading but has problems with memory. Repetitiveness seems to work well for both boys, as does being in smaller classes.

Brodsky finds that keeping on top of the boys' physical needs allows them to get the most out of their school day. For instance, she works to keep a good rapport with the physical therapists who make sure the boys' aides do special stretches to keep them comfortable, and therefore more receptive to learning.

Hinton has counseled a few families to delay a child with DMD from start-

ing first grade for a year and to wait a little longer than usual to teach phonetic reading methods. These recommendations have worked out well, she says.

Brodsky always gives teachers a copy of MDA's "A Teacher's Guide to Duchenne Muscular Dystrophy," to help make them aware of her sons' potential despite the disease.

First Impressions

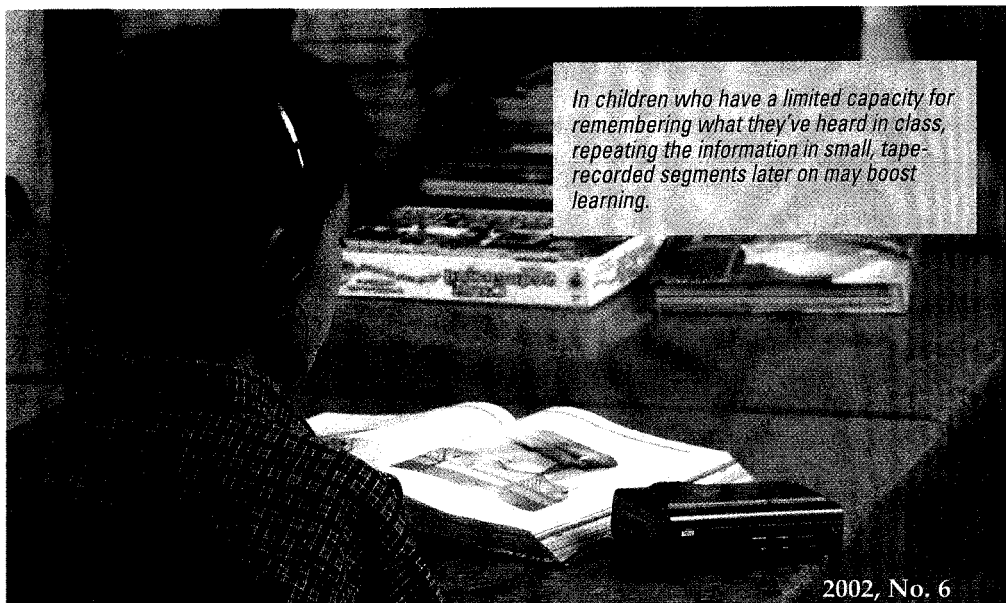
Parents should help teachers and school personnel understand other ways in which a neuromuscular disease might come into play at school.

In congenital myotonic muscular dystrophy, for example, neurologist Charles Thornton cautions that the facial weakness seen in the disease can confuse parents and teachers. Because of profound facial muscle weakness, children with congenital MMD often can't express emotions with their faces, have difficulty speaking clearly because of weak mouth muscles, and may drool.

These factors may make children appear less intelligent than they really are, and can even lead to social shunning. The result may be depression, further complicating the situation.

Thornton has found that speech therapy can be helpful in MMD. He also refers patients for hearing and vision assessments — all services that can be incorporated into an IEP.

Side effects of certain medications may affect a child's responsiveness in the classroom. Drugs for seizures (which may occur in some congenital MDs and mitochondrial diseases) may make a child drowsy or cause some digestive problems. Teachers may not



realize that a behavior or learning problem is a component of the neuromuscular disease rather than a separate learning or behavioral disorder.

Some parents of children with neuromuscular diseases have even incorporated social and emotional supports into their children's IEPs. If a child who uses a wheelchair is shy or withdrawn, having classmates take turns carrying the child's books may help in enhancing social skills, as can finding ways to include the child in playground activities.

Getting What You Need

Unfortunately, dealing with your child's school needs can become a combative experience. Parents of students with disabilities sometimes end up squaring off against the bureaucracy of teachers, administrators and experts, facing each other in a "ring" of meetings, discussions and even legal hearings.

Brodsky knows all about fighting for her kids. She's had to go to the mat to get Aryn and Erik supports ranging from basic accessibility to services that were promised but not delivered.

Brodsky acknowledges that most of the special education services her sons receive are great — "once you actually get them." But she's often been exasperated by the process.

"I have found that people with children with disabilities seem to have to fight more than a typical kid for some reason. We have to justify reasons why we want certain things for our kids, and it shouldn't be that way," Brodsky said.

Following Aryn's heel cord surgery in 1998, he was unable to walk up or down stairs. He would have had to go up and down six stairs to go to the bathroom and walk to the other end of the school for gym, lunch and other classes.

Brodsky suggested that his classroom be switched to another room in a different part of the building where stairs weren't a barrier. School officials suggested instead that he walk outside around the building, even in the winter, and that he use a portable toilet in the hallway with some dividers set up around it for privacy.

Brodsky considered the school's solution unacceptable, but found herself outnumbered and without backing

during a meeting that included top school administrators and special education officials. The next day, she contacted the superintendent of schools.

"I told him that my child was being discriminated against because he was handicapped," Brodsky said. "The next day, the super told them to move the room."

Another issue arose last fall. The boys' IEPs stated that Erik would have a one-on-one aide for part of the day, and that Aryn would have a floating aide in his room.

Although the IEP guidelines were set in October 2001, come January Erik still had no aide for his class.

Brodsky, who said not many children with disabilities have attended school in her area, "got the runaround" trying to solve the problem. She eventually contacted someone in the state Department of Education for help.

Good News and Bad

Unfortunately, Brodsky's experience isn't unique, according to an attorney who specializes in special education

The Original Rear-Entry Kneelvan.

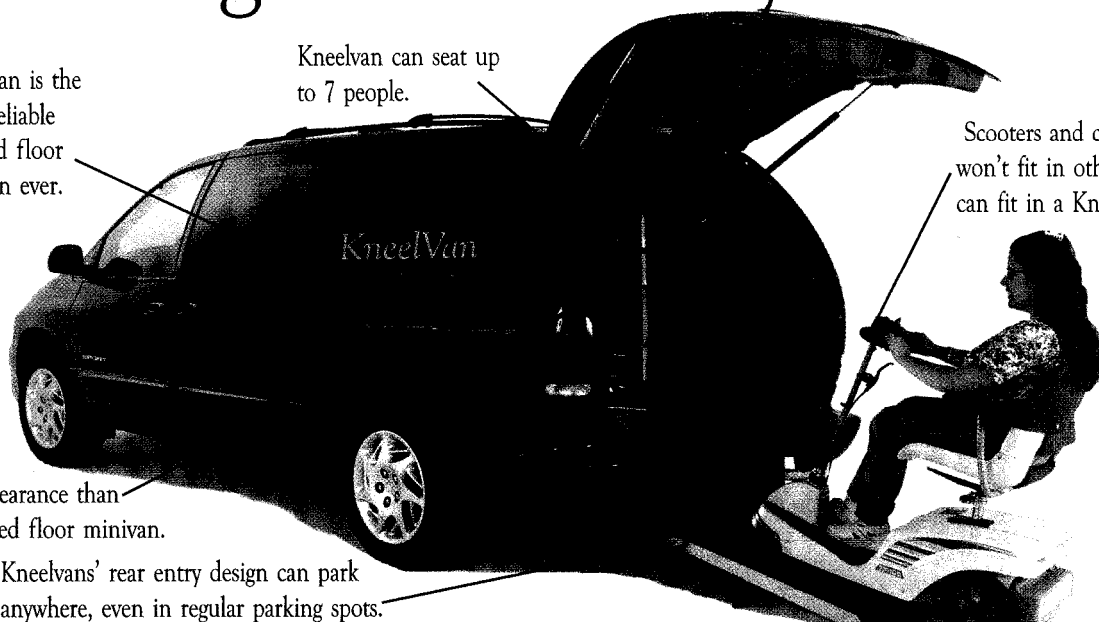
Kneelvan is the most reliable lowered floor minivan ever.

Kneelvan can seat up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

More ground clearance than any other lowered floor minivan.

Kneelvans' rear entry design can park anywhere, even in regular parking spots.

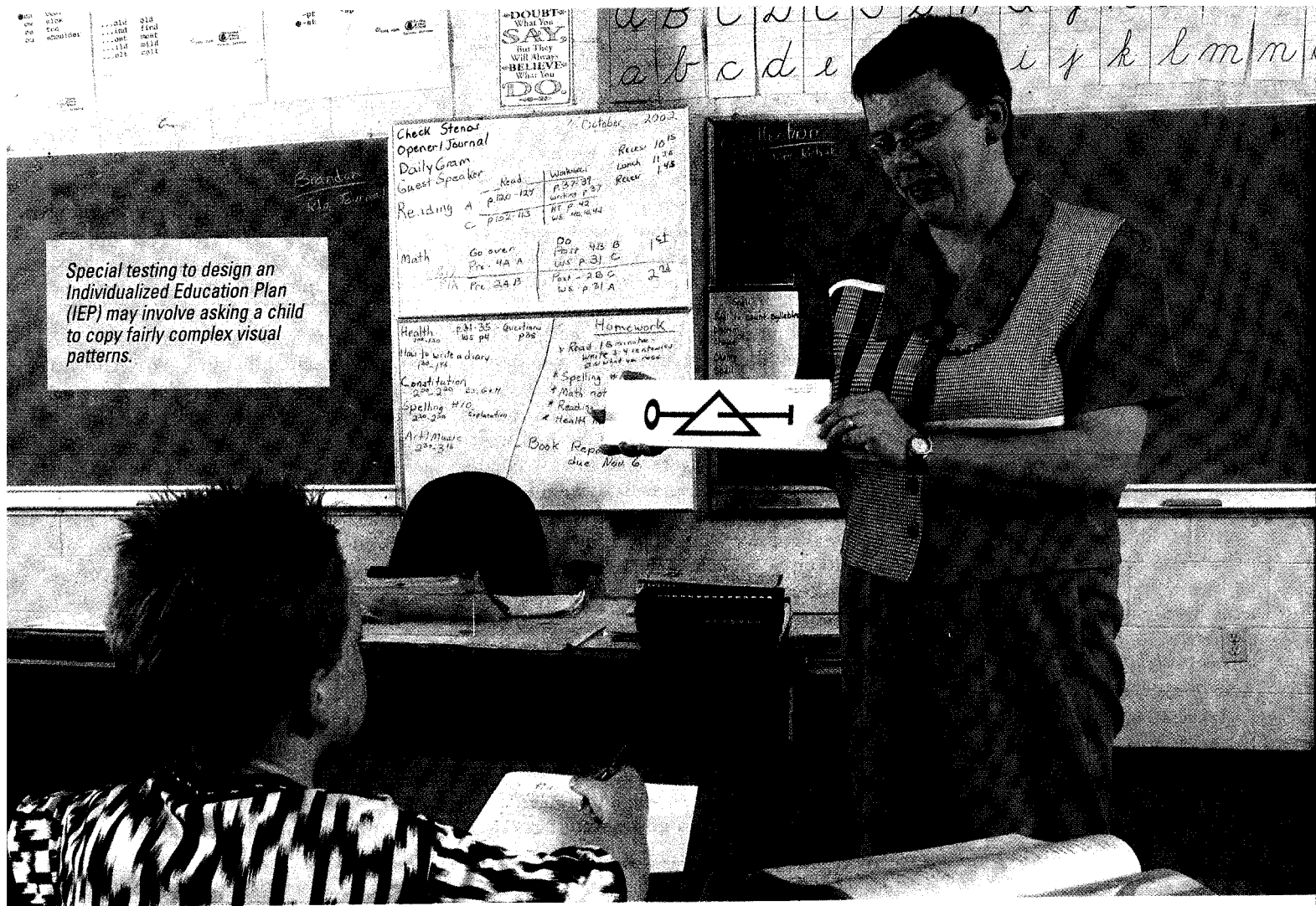


Designed with you in mind, the Kneelvan is simply the easiest way to travel. Unlike side-entry conversions, we designed the rear entry KneelVan so you can never get blocked by someone parking beside you. Kneelvan is the original rear-entry minivan, don't accept imitations.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our new free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."



law and represents children with disabilities nationwide.

The problems and obstacles are the same, whether your child has a specific learning disability, or has both physical and cognitive disabilities, said Pete Wright, co-author of *From Emotions to Advocacy: The Special Education Survival Guide*.

"I don't see a greater frequency in one area or from one disability to another disability. The problems are fairly pervasive and across the board regardless of the nature of the disability or the severity of the disability," said Wright of Deltaville, Va.

Wright and his wife, Pam, a psychotherapist, have written several books on the topic, give seminars about special education law and advocacy, and operate the Web site www.wrightslaw.com.

Wright said problems in special education generally stem from larger issues that aren't easily remedied: lack of resources and lack of properly trained staff.

The level of training in teachers can differ not only from state to state, but within cities, Wright said. One school

district might have staff trained in the latest, most successful methods for teaching kids with cognitive disabilities, while a nearby district may have had no new training in the last 10 years, Wright said.

Parents Can Learn

To help you succeed in getting your child the education to which he's entitled, many resources are available.

The Wrights advise that you keep meticulous written records of all contacts with the school, including phone calls, messages, conversations and correspondence.

"Because documents are often the keys to success, advocates keep written records. They know that if a statement is not written down, it was not said. They make requests in writing, and write polite follow-up letters to document events, discussions and meetings," they write.

See the books listed in "Resources" for examples of letters, logs and tips for organization of your documents.

The Wrights say that detailed record

keeping is part of an overall mindset that parents should adopt: The best way to avoid litigation is to prepare for it. In other words, assume that you'll have to seek due process to have an IEP dispute or other problem settled, and the records you keep will help you build a solid case, Wright said.

"At the same time, though, you are on a mission of salesmanship. You want to 'sell a product' to these people so that when you are through, they will want to buy it from you. That is very, very hard," he said.

The Wrights advise their clients to learn and live by the most important section of the Individuals with Disabilities Education Act (IDEA): section 1400(d), which outlines the federal law's purposes: "...to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living."

The latter part of the statute can be used to guide your advocacy, Wright says. For example, at an IEP meeting,

when someone proposes a class or activity that doesn't sound appropriate for your child, you can ask, "How is this designed to meet this youngster's needs? How is it designed to prepare them for independent living?"

The statute applies no matter what the realistic goals for your child are.

"That goes into basic functional life skills. Being prepared for independent living may mean the acquisition of toileting skills," Wright said.

Part of "selling" the school system on your child's educational needs is designing your communications to make a good impression. Letters, especially, should try to tell a story and present why your situation is unique. You must remain dignified and not express anger and blame, no matter how frustrated you are, Wright said.

Losing control of your emotions and creating a negative situation between you and the school won't get the results your child needs, he said.

Ditto that for dealing with "gatekeepers," people whose job it is to limit the number of children who have access to special education services and limit

the services children can receive.

"Your job is to change the gatekeeper's mind," Wright said. The outcome of a due process hearing or other decision will likely be more favorable for parents who adopt an almost "Miss Manners" approach.

A Web of Support

Networking with other parents can be a source of inspiration and fresh ideas for advocating for your child. Parents of kids with special needs can connect through support groups, Internet chat rooms and message boards, and advocacy organizations.

In many places, parents form Parent Advisory Councils (see "Resources") to act as watchdogs over the special education process and to help advocate for each other. Check with the special education coordinator at your child's school or your state's Department of Education to see if such a council already exists.

Brodsky said she's received valuable support from a case coordinator who first became involved with her family

when her boys were preschoolers. The case coordinator sometimes attends IEP meetings with her, and has introduced her to several valuable state programs, such as one that made accessibility improvements to her home.

"I'm the advocate for my boys, but she is an advocate for me and the boys," Brodsky said.

Brodsky also facilitates an MDChat group, a twice-weekly online discussion for parents of children with DMD. During the chat, parents share experiences, tips and friendly conversation.

"You always learn from other parents' experiences," Brodsky said.

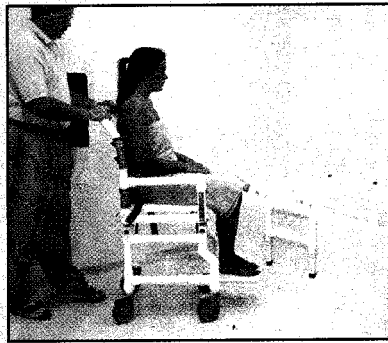
Wright agrees, and advises parents not to limit their networking to families of children affected by the same disabilities that your child has.

By getting to know parents of children with a variety of disabilities, who are advocating for their kids' education, you can see that "the issues are the same, they are just played out slightly different," Wright said. "One will come in and shed some light on a different way that they got around the same kind of problem." □

Accessibility without renovation! Eliminate bathroom transfers!



Go from commode to tub and never transfer again!



Roll patient into position next to the tub and inter-lock to tub frame.



Entire seat slides over the tub.



Care giver removes the rolling chassis for easy access. Enjoy your shower!

Shocked at the HIGH cost of 'roll-in' shower renovations...you need the "SLIDER"!

The SLIDER, bathing system eliminates costly 'roll-in' shower renovations, bathroom transfers and other family members don't lose access to a bathtub. The SLIDER works with any standard built-in tub and rolls directly over any commode. Easy access pull out foot rest, adjustable tension back support, push handle, seat belt and open front, padded commode seat for easy access to the perineal area are standard. The SLIDER utilizes 5" total lock casters and has two swing-away arm rests for lateral transfers. Sliding seat functions in either direction. Tilt-In-Space, Pediatric, Narrow and Extra-Wide models available. The SLIDER bathing system... a **cost effective** alternative to bathroom renovation. SLIDER dimensions: Between arms - 17", Overall width - 21", Seat depth - 18", Seat height - 24", Weight capacity: 250 lbs, Ships: UPS.

Assistive Technology Inc. 530 S Whittaker St, #240 New Buffalo, MI 49117

PHONE: 800 478-2363, 219 522-7201 FAX: 219 293-0202

E-MAIL: info@pvcdme.com

WEB SITE: www.pvcdme.com

RESOURCES

QUEST ARTICLES

- "The ABCs of an IEP," 1996, no. 3.
- "The Brain in Duchenne Dystrophy," 1997, no. 1.
- "Congenital MD: When Muscular Dystrophy Starts Early," 1999, no. 3.
- "Keeping Your Focus: Eye Care in Neuromuscular Disorders," December 2000.
- "Mitochondrial Disease in Perspective: Symptoms, Diagnosis and Hope for the Future," 1999, no. 5.
- "Mitochondrial Myopathy: An Energy Crisis in the Cells," 1999, no. 4.
- "Parent Advisory Councils: Parents Helping Parents Help Kids," February 2001.
- "Sorting Out Speech Services," February 2001.

OTHER MDA RESOURCES

- "Facts About Duchenne and Becker Muscular Dystrophies"
- "Facts About Mitochondrial Myopathies"
- "Facts About Myotonic Muscular Dystrophy"
- "Facts About Rare Muscular Dystrophies" (includes the congenital MDs)
- "Journey of Love: A Parent's Guide to Duchenne MD"
- "A Teacher's Guide to Duchenne Muscular Dystrophy"
- MDAchat, www.mdausa.org/chat/calendar.html

PUBLICATIONS

- The Complete IEP Guide: How to Advocate for Your Special Ed Child (2nd ed.)*, by Lawrence M. Siegel, 2000, Nolo Press, www.nolo.com.
- From Emotions to Advocacy: The Special Education Survival Guide*, by Pam Wright and Pete Wright, 2002, Harbor House Law Press, www.harborhouselaw.com.
- A Guide to the Individualized Education Program*, by the Office of Special Education and Rehabilitative Services, U.S. Department of Education, 2000, free, (877) 4-ED-PUBS or www.ed.gov/offices/OSERS.

Myotonic Dystrophy: The Facts, by Peter Harper, Oxford University Press, 2002.

Wrightslaw: Special Education Law, by Pete Wright and Pam Wright, 2002, Harbor House Law Press, www.harborhouselaw.com.

SPECIAL EDUCATION ADVOCACY RESOURCES

- www.ed.gov/offices/OSERS/OSEP/ — Office of Special Education Programs, part of the U.S. Department of Education.
- www.fcsn.org — Federation for Children with Special Needs.
- www.ideainfo.org — IDEA Partnerships, federally funded projects to study the 1997 landmark reauthorization of the Individuals with Disabilities Education Act (IDEA). National summit in Arlington, Va., June 2003.
- www.pacer.org — Minnesota-based parents' organization to enhance quality of life of children and young adults with disabilities and their families.
- Parent Training Information Centers (PTIs) — Funded by the U.S. Department of Education's Office of Special Education Programs and the FCSN. www.fcsn.org/ptis/ptilist.htm.
- www.wrightslaw.com — Extensive collection of resources about special education law, advocacy and related topics.

TESTING AND RESEARCH

- American Academy of Clinical Neuropsychology Offers a list of neuropsychologists who perform testing www.theaacn.org (734) 936-8269
- Veronica Hinton is recruiting boys with DMD and BMD up to age 16 for her ongoing studies of cognitive functioning in these disorders. She would prefer families in which an unaffected sibling or cousin is also available for testing. Parents will be given a detailed report of their child's test results. Contact: Robert Fee
Columbia University
(212) 305-2394
feerobe@sergievsky.cpmc.columbia.edu

ful. Then they couldn't get enough. They wanted to know everything."

Stigma, Denial and Discipline

Dealing with a cognitive disorder can be frustrating, time-consuming and costly. But ignoring it could be even worse.

"There are still a lot of kids that get labeled as 'troubled kids,'" Mehler reports. "Often their parents send them to special schools or put them under strict supervision — things that are not necessarily the way to go."

Mehler notes that other kids can make life especially difficult for a child who's trying to deal with a cognitive disorder. "The traumas inflicted by their peers could well create behavioral problems."

Stigma can also extend toward the parents, as well-meaning friends, family and teachers offer advice on how to deal with cognitive symptoms, particularly the behavioral ones.

Mehler especially takes issue with those who advocate a "tough love" approach.

"That's what we call 'abuse,'" Mehler says flatly. "I think the problem is that our society still has a taboo about things that are behavioral."

John abandoned the "tough love" approach for a simpler reason: It didn't work.

"When they were younger I used to get after them, spank them and such," he recalls. "Now I think back on it and I realize that they just didn't know any better. They couldn't understand what I was doing. They didn't have the ability to understand."