

Parents' Perspectives: DMD and SLD

Parents' Perspectives on Coping with Duchenne Muscular Dystrophy and  
Concomitant Learning Disabilities

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## Abstract

This study addresses parental perspectives and coping strategies related to Duchenne muscular dystrophy and learning disabilities. Data was collected through individual semi-structured in-depth interviews with fifteen sets of parents. Participants were selected based on variables such as age of children, cultural background of parents, number of children with both conditions in the family, and geographical location. The sample represented families with sons aged 5-23 from twelve states. All the sons had varying rates of progression (age at which the boys no longer walked) from 7-14, and some form of learning disabilities. The interviews were taped, transcribed, and analyzed using grounded theory (Glaser & Strauss, 1967) and constant comparative analysis (Glaser, 1994).

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## Introduction

Worldwide, approximately 1 in 3500 males are born with Duchenne muscular dystrophy (DMD). Based on the 2000 United States Census (if this estimate of 1: 3500 remains constant), there are about 38,000 U. S. males with DMD. Using the accepted estimate that 30 percent of boys with DMD have some type of learning disability, there may be as many as 11,500 boys with DMD and concomitant learning disabilities (LD) in the United States.

DMD is a genetic disorder that affects the skeletal muscles and is caused by a lack of the protein dystrophin. An absence of dystrophin leads to damage and eventual death of muscle cells. Thus, DMD leads to progressive muscle wasting, which eventually results in severe debilitation and a shortened life span (Cwik & Brooke, 1996). There is no cure at this time, and death often occurs due to respiratory or cardiac failure in the late teen years (Brooke et al., 1989). However, proactive care and more aggressive treatments have indicated an increase in life expectancy since Brooke's report in 1989. Some adults with DMD are now living into their forties.

DMD is an X-linked genetic disorder passed through the X (female) chromosome. Because approximately 70 percent of instances of DMD are caused by genetic mutations in either a mother or a son, any male child may be born with DMD. Although DMD is present from conception, boys with this disorder appear normal at birth. It is when they begin to walk that discrepancies are often noted. In most cases, the child walks with a "waddling gait", tends to tiptoe, has overdeveloped calves, and uses Gowers' maneuver to rise from the floor. Named for English neurologist William Gowers, Gowers' maneuver is a method of getting to a standing

position by using the hands to “climb up the legs.” (Cwik & Brooke, 1996; Ivory, 1998; Porter, Hall, & Williams, 2001). Later, stair climbing becomes challenging (Cwik & Brooke, 1996).

#### Incidence of DMD and LD

LD are seen relatively more frequently in children with DMD (approximately 30 percent) (Culligan & Ohlendieck, 2002; Journey of Love: A Parents Guide to Duchenne Muscular Dystrophy, 2001; Muntoni, 2000) than in the general population (approximately 4.45 percent) (Turnbull, Turnbull, Shank, Smith, & Leal, 2001). Researchers believe this may be due to the effect dystrophin has on the brain.

#### *LD and the Brain*

Boyce, Beggs, Feener, and Kunkel (1990) reported that brain tissue is the only non-muscle tissue that expresses significant amounts of dystrophin. Their investigation led them to conclude that dystrophin in the brain is regulated by a promoter that works independently of the muscle dystrophin promoter. Therefore, it appears that only when both promoters are mutated do we see children with both DMD and LD. A lone mutation in the brain dystrophin promoter, however, does not produce the effects we see in DMD. This finding may help future investigators pinpoint the role of dystrophin in the human brain as it relates to LD.

In other studies, researchers examined human brain dystrophin. Uchino et al. (1996) studied the brains of three adults with DMD and cognitive disorders and five adult controls. They found dystrophin in neuronal cells and the vascular wall of the brains of the controls but not of those with DMD and concomitant cognitive issues. Moizard et al. (1998) concluded that cognitive impairment in some people with DMD may be related to mutations affecting dystrophin proteins Dp 71 found in the brain and Dp 140 found in the distal portion of the

dystrophin gene. Their conclusions were based on altered Dp 71 transcripts and two deleted Dp 140 DNA sequences found in four individuals with DMD and severe cerebral dysfunction.

Anderson, Head, Rae, and Morley (2002) examined the role of the absence or disruption of dystrophin on CNS function in boys with DMD and dystrophin-deficient mdx mice. The authors found that both the boys and mice had abnormalities and decreased neurons in areas of the brain associated with dystrophin expression. These various studies suggest that deficient dystrophin in the brain may cause cognitive impairment in boys with DMD.

#### *Types of LD Seen in DMD Population*

Several studies measuring the cognitive functioning of boys with DMD have found the mean score on such measures as the Wechsler Intelligence Scale for Children (WISC) (Wechsler, 1949), Wechsler Pre-school and Primary Scale of Intelligence (WPPSI) (Wechsler, 1967), Goodenough-Harris Drawing Test (Harris, 1963), and the Bender Gestalt Test (Bender, 1938) to be about one standard deviation, or 15 points, below the standardized mean of 100 (Leibowitz & Dubowitz, 1981).

Contemporary studies have been undertaken to ascertain what types of learning problems affect this population. Hinton, DeVivo, Nereo, Goldstein, and Stern (2000) concluded that boys with DMD, of high or low intellectual function, did most poorly on tests of digit span, story recall, and comprehension. The overall conclusions indicated that specific areas of disability included verbal skills, math computation and concepts, written skills, memory deficits, and attention problems. Emotional and behavioral skills may also be affected, leading to social problems such as making and keeping friends. Cotton, Crowe, and Voudouris (1998) conducted neuropsychological tests that would not be affected by impaired motor skills on a group of children with DMD matched for age, verbal intelligence and depression with a group of control

subjects without DMD. Those with DMD did less well on tests of complex attention, verbal fluency and nonverbal memory functions, suggesting that the cognitive deficits associated with DMD are specific rather than global.

Because 30 percent of boys with DMD also have LD, this study was undertaken to address a lack of information regarding parental perspectives and coping strategies in relation to this dual disability. Specifically, the author wanted to find answers to the following questions:

1. How do parents cope when their children are diagnosed with the dual disabilities of DMD and specific learning disabilities?
2. What are the strategies parents use to improve their child's quality of life, academic performance, and social functioning?

Whelan (1987) found that test scores, which measured immediate verbal and nonverbal memory and verbal fluency, were lower than other tests of cognitive ability. His study suggests that there may be distinct neuropsychological subtypes of children with DMD.

Karagan and Zellweger (1978) tested a group of 53 boys under age 10 with DMD who were still able to walk, using the Wechsler Intelligence Scale for Children (WISC). Mean Verbal, Performance, and Full-scale IQ's were all significantly lower than the standardization sample. In the sample with DMD, the mean Verbal IQ (VIQ) was 80.66, mean Performance IQ (PIQ) was 88.06, and the mean Full Scale IQ was 82.58 (as compared to VIQ 101.2, PIQ 100.3, and FSIQ 100.8 in the standardization sample). Despite little or no physical involvement, these children had significant verbal deficits.

Karagan, Richman, and Sorensen (1980) used the Hiskey-Nebraska Test of Learning Aptitude (HNTLA) (Hiskey, 1966) to assess a group of seven boys with DMD. The HNTLA consists of 12 individual subtests, which measure verbal mediation and visual-spatial ability.

Instead of mental age and IQ scores, the HNTLA uses a composite learning age and deviation quotient, DQ. The mean DQ was matched to previous scores on the verbal and performance portions of the WISC. The mean HNTLA DQ of 103.43 was significantly higher than the mean VIQ of 86.71. However, the mean PIQ of 104.14 was not significantly different than the HNTLA DQ, which suggests that the abstract reasoning and categorization skills of males with DMD are relatively good but memory function is impaired.

### Parent Perspectives Regarding Children with Disabilities

Studies based on parent perspectives regarding their child with a disability, although scant, add valuable information to the research literature. Beresford (1994) reported that there is a dearth of research about coping strategies parents use in raising a child with disabilities. She suggested that coping skills studies have greater implications for understanding and improving ways to help. Beresford concluded that a consistent finding in both qualitative and quantitative studies is the usefulness of active coping strategies such as planning, direct problem solving, and information seeking.

From the time of the diagnosis of a genetic disorder in a child, parents are faced with challenges. Because parents may view the birth of a child as an extension of themselves, they are apt to feel that such a diagnosis reflects upon them. Mothers, in particular, have the added burden of knowing that they are most likely the unwitting carriers of the gene responsible for the disorder. As the disease progresses, mothers may develop an attitude of self-blame (Rubin, 1987). Both parents react with feelings of disbelief, denial, anger, anguish, anxiety, guilt (Buchanan, LaBarbera, Roelofs, & Olson, 1979; DMD Forum Guides for Parents-Parenting, 2001; Rubin, 1987) fear, confusion, powerlessness, rejection (DMD Forum Guides for Parents-Parenting, 2001), and parent-related and child-related stress (Beresford, 1994; Krauss, 1993).

According to Mearig (1992) and Strong & Sandoval (1999), the additional diagnosis of LD brings added stress. Parents are sensitive to their child's varying ability levels. Mothers are apt to find this more stressful than fathers. Middle and upper class mothers are especially prone to stress produced by societal reactions to children who may appear to be undisciplined or poorly brought up, who are impulsive, and who exhibit auditory processing problems. Fathers, on the other hand, are reported to interact minimally with their sons, deny the LD, or minimize the effects of the LD (Mearig, 1992). It is important that families and schools provide realistic expectations, modeling, informal teaching, structure, support, and reinforcement to children with DMD and learning disabilities. Schools must work with parents to ensure that these children have successful academic and social experiences in the school setting.

Based on the previous findings, the present qualitative study was designed to examine the coping mechanisms and strategies parents use when they and their child are faced with the combined disabilities of DMD and LD. When parents are able to share a common lived experience with other parents, coping is easier. Therefore, this study was designed for and around parents, and the research questions were developed with that design in mind.

## Methodology

### *Participant Recruitment*

The sample consisted of volunteer participants. Volunteers were recruited by posting a request on two Internet sites for parents of children with DMD, DMD Forum and Parent Project Muscular Dystrophy (PPMD). At the 2001 PPMD conference, the author discussed the future study and formally requested volunteer participants. Such methods allowed for networking with parents to find additional participants. The sample, though small, represented a broad base of participants. The final 15 families were selected from 31 volunteers based on the age of the boys

in the study, family demographics such as number of sons with DMD, racial diversity, and geographic locations. The final group represented 12 states throughout the eastern, mid-western and southwestern United States. The sons who ranged in age from 5-23 had varying rates of progression (age at which the boys could no longer walk) from ages 7-14, and some form of LD. Two of the families had two sons with DMD and some associated learning disabilities. In one case, two sisters who each have a son with DMD and LD were interviewed together. Boys in this study all had the Duchenne form of muscular dystrophy.

*Table 1 Study Participants*

Name and Chronological Number	Number of Sons	Age	Family Dynamics	State
Sam—01	1	13	European American; mother, father, 1 son, 1 daughter	CT
Rav—02	1	5	European American; mother, father, 3 sons	NY
Nick—03	1	6	European American; mother, father, 1 son, 1 daughter	NY
Ben—04	1	6	European American; Jewish; mother, father, 2 sons	NJ
Robert—05	1	12	European American; mother, father, 2 sons	VA

Rod—06	1	13	European American; mother, father, 2 sons, 1 daughter	VA
Jared—07	1	17	Armenian Jewish; mother, 2 sons	MD
John—8A	1	11	European American; mother, father, 1 son, 2 daughters	PA
Jerry—8B	1	11	European American; mother, stepfather, 3 sons, 1 stepson	PA
Jeff, Gary—09	2	14 7	European American; mother, father, 2 sons	PA
George—10	1	14	European American; mother, 1 son, 2 daughters	OH
Tony—11	1	12	European American; mother, father, 2 sons, 1 daughter	MN
Jake, Joel—12	2	24 18	European American; mother, father, 2 sons	WI
Stefan—13	1	10	European American; mother, father, 2 sons, 1 daughter	OK
Reed—14	1	7	African American; mother, father, 2 sons, 1 daughter	KS
Alan--15	1	6	European American;	NE

mother, father, 2 sons

### *Data Collection*

The individual semi-structured in-depth interviews were conducted with 16 families (one father, seven mothers [two who were sisters], and seven sets of parents) to gather the data. Each taped interview lasted from one to two hours although the interviewer took time before taping to establish rapport with the respondents through casual conversation. As a means of checking for understanding, accuracy, and verification throughout the taping, the interviewer frequently rephrased questions, asked the respondents to elaborate, made comprehensive notes as soon as possible after the interview, and provided respondents access to the interview tapes, transcriptions, and final write-up. [Insert sample post-interview notes]

### Post-Interview Notes

Family 03 “Rav”, age 5 October 13, 2001 NY

Mother is nurse. Professional vs. mother role

Diagnosis at age 1. Near drowning. Rav had heart arrest. CPK elevated. Remained elevated. Dr. called parents on cell phone on way to funeral. Mother insisted on hearing diagnosis.

No family history. Rav one of 3 boys. Brothers no DMD.

Mother tried to be clinical about diagnosis. Father opposed to clinical attitude.

Some speech delays.

Still rides bike w/TW  
Climbs stairs

Knows he has MD.

Family very involved in fund raising. Older brother and Rav go house to house for hop-a-thon donations. Dad slow to become involved with MDA. Helped wire for telethon production in NY.

Interesting comment. Mother's mother was watching telethon before Rav's diagnosis. Commented on putting "deformed children" on TV. Who cares about DMD? Mother now very involved. Attended PPMD this year with Rav's mother.

Twelve of the individual family interviews were conducted in the parents' homes. The other three interviews were conducted in an office, a restaurant, and a meeting room in a public library. A tape recorder was used to record interviews for later transcription and analysis. The interviews were based on the following sample questions developed by the researcher: [Insert sample questions here]

1. First of all, I'd like to know more about your son.
2. Could you describe the early symptoms that made you wonder, "Is my child different physically, behaviorally, or in the way he learns?"
3. Describe your experiences before and after both diagnoses.
4. What were your reactions to each diagnosis? Mom? Dad? Siblings? Your son's? Describe what that time was like for your family.
5. Describe the strategies you use to help (name of child):
  - With schoolwork.
  - Accept his disabilities.
  - Overcome his disabilities.
6. What advice would you offer to parents in the same situation?

As the interviews progressed, other questions that arose based on the statements and responses made by the families were included. This allowed the researcher to gather additional data to support and corroborate the emerging theory.

A professional transcriber transferred the taped information to written transcripts for data analysis. Each transcription included a heading with the identification number of the person

being interviewed, the time, date, site of the interview, and reminders of the content. Each page of the transcript had a wide left margin for coding and comments. New speakers were identified as “M-15” (for Alan’s mother), “F-11” (for Tony’s father), or “I” for interviewer. Completed transcriptions were filed in chronological order pending analysis.

### *Data Analysis*

Before starting the data analysis, an extra working copy of each transcript was made. Data analysis began with coding to find patterns, relationships and themes (key concepts) (Bogdan & Biklen, 1998). This process, originated by Glaser & Strauss (1967), is known as grounded theory. Constant-comparative analysis (Glaser, 1994) was used to arrive at this grounded theory, which included coding, memoing and analyzing five transcriptions at a time. According to Bogdan and Biklen (1998), Punch (1998), and Strauss (1987), there are three types of coding used. They are:

1. Open coding, which is the initial coding. Its purpose is to produce concepts that fit the data thereby “opening up” the inquiry.
2. Axial coding. In axial coding, the researcher codes around single interconnected categories.
3. Selective coding. At this stage of coding, the final categories are selected.

The author began by open coding the interviews in three sets of five. In the first interview, the author looked for codes, words or phrases based on units of data, within the text of the transcription. Each code was written in the left hand margin next to the appropriate units of data. In the example below, each open code is underlined. [Insert sample here]

### Sample Interview

I: How did you discover that Jake had learning disabilities?

M-12: The public school had observed him and decided that he had emotional disturbance so they labeled him ED and sent him off to the ED classroom. By then I was suspecting that he had some kind of learning disability. He couldn't read the text books in third grade, but if I read the material to him, he understood it perfectly well. He just couldn't read it all himself. About that time, my younger son Joel kept having ear problems. We went to the audiologist who also asked about Jake. When Jake was tested by the audiologist, he was found to have auditory processing problems. Later, we realized that he also had visual perception problems. When he drew pictures, he would draw curved instead of straight lines. His drawings looked like pictures taken with a wide angle lens close up.

I: My son also has auditory processing difficulties. You cannot tell him five different things to do at once because he will not remember more than one or two.

M-12: Oh yes, that is true. If we give Jake several instructions, he asks us to write them down.

Joel is the same way.

The open coding list at this stage looked like this:

- Emotional problems
- Reading difficulties
- Ear problems
- Auditory processing
- Visual perception
- Visual distortions
- Poor short term memory

After all of the interviews in this set were open coded, the list had expanded to look like

this:

Social dog	Fundraising
Descriptive traits	Self-esteem
Eye problems	Home activities
Age at diagnosis	Process of acceptance
Reaction to diagnosis	Accommodations/Modifications

Parent responsibility	Normal life
MDA/PPMD	Fix problems
Special education	Improvement
School cooperation	Cognitive delays
Treatment options	Testing
Changes lives	Phone diagnosis
Sensory issues	Educational needs
Progression	Good from DMD
Life quality	Interests
OCD (obsessive-compulsive disorder)	Wheelchairs
Puberty	Family history
Medical personnel	Heart problems
Depression	DNA
ADHD-type behaviors	Self-control
Autistic issues	Mobility
Relates to others	Humor
PT/OT	Pregnancy options
Accessibility	Frustration
Accepts limitations	Motor delays
Husband's role	Communication issues
Marriage problems	Ear infections
Muscle biopsy	Teaching strategies
Children of parents with DMD	Support from others
Behavior modification	Early symptoms
Transitions	CPK
Aides	EMG
Siblings	Mother/sibling diagnosis

The open codes were then narrowed down to the following axial codes:

- Treatment
- Descriptive traits
- Physical challenges
- Diagnosis
- Mental challenges
- Coping
- Support
- Education
- Quality of life
- Sensory issues
- Mental challenges
- Socialization
- Modifications
- Behavior

Siblings  
Strengths  
Parent Involvement

The researcher began coding and memoing simultaneously. While coding, many ideas are apt to occur to the researcher. These ideas are recorded as memos. In data analysis, memoing links coding with proposition development. Coding as the systematic and disciplined part of analysis is balanced with memoing, the creative part of analysis (Punch, 1998). During this process, each open code, axial code and memo was entered into a loose-leaf Concept Notebook (Mostyn, 1985) for ease in compiling memos for each concept and organizing the data. [Insert sample Concept Notebook page]

#### Sample Concept Notebook Page

##### “Educational Needs”

Nick’s mother: Nick started early intervention services at age two for autistic-like symptoms: speech regression, lack of socialization, inability to relate to anyone but mother. He transitioned to kindergarten with appropriate speech therapy, physical therapy, occupational therapy, and special education services under IDEA.

My reaction: My son began early intervention for speech and language delays, lack of socialization, and behavior difficulties in public school after he was expelled from nursery school at age four. I believe strongly in the power of early intervention for students with disabilities.

Jerry’s mother: Jerry also has autism. He has attended a support class for children with autism since he was four. His principal allows him to go to the office whenever he is having a moment and hang out in the big futon chair. He is now partially included in a general education classroom. His school also instituted a program whereby the students in general education classes visit the support class to encourage normalization.

Jared's mother: Jared's learning disabilities were not being addressed. Instead of modifying his English class to meet Jared's specific needs, the school transferred him to a class with lower expectations.

My reaction: We moved when our son was nine. He had been reading at fourth grade level in a self-contained class for children with learning disabilities. When the new school tested his reading, they placed him on a first grade level. As a teacher, I had access to the same reading series. I tested him at home. Although he read the material orally rather than silently, he scored at a sixth grade level. The school had to adjust their expectations. But his needs would not have been met if I hadn't been knowledgeable. Knowledge really is power.

Alan's mother: It's finding ways to help your educators teach your children. We want to get the most out of education as possible.

My reaction: For children with progressive muscular dystrophy, it is imperative to take advantage of every opportunity to enable them to achieve quality of life in spite of physical disabilities. We have to strongly encourage schools to set high academic expectations and help students meet them.

For the selective stage of coding, each concept in the each of the lists of axial codes was analyzed to combine or eliminate those that were redundant. From that final coding, the following core categories that pertain to this article emerged: coping with DMD and coping with LD.

A modified version of the cut-up-and-put-in-folders method (Bogdan & Biklen, 1998) was selected to complete the analysis. The modified cut-and-file method consisted of 1) underlining the material in the transcripts that answered each of the original research questions, 2) making a separate file folder for each question, 3) cutting the sections of the manuscripts that

answered each question into strips, 4) preparing a topic outline based on the answers, 5) sorting the strips by topic, 6) placing the strips into plastic zip-lock bags labeled by topic, and 7) storing the zip-lock bags in the appropriate folders pending analysis. As the synthesized report of the data was written, the author referred to and documented the results based on the material in each folder. [Insert Example Summaries of Results here]

Table 2 Example Summary of Results—Theme 1 Coping with DMD

Main Topic	Subtopic	Examples
Diagnosis	Early Symptoms	<ul style="list-style-type: none"> <li>• I've got kids half his age that can run and jump. Jared can't run and jump.</li> <li>• Alan was toe walking, and he was falling a lot.</li> <li>• Robert never crawled properly; he crawled using only his arms.</li> </ul>
Diagnosis	Reactions to Diagnosis	<ul style="list-style-type: none"> <li>• You just want to scream 'no' from the bottom of your soul.</li> <li>• I felt as if somebody had punched me in the stomach as hard as they could.</li> <li>• Our whole world stopped.</li> </ul>

Table 3 Example Summary of Results—Theme 2 “Coping with LD”

Main Topic	Subtopic	Examples
Types of Learning Disabilities	Education Issues	<ul style="list-style-type: none"> <li>• Alan fits Dr. Hinton’s profile. He has trouble communicating and interacting socially with others. He processes information slowly.</li> <li>• Robert has trouble with phonemic awareness. He still cannot read using phonics. He is a complete and total sight reader.</li> <li>• It’s hard for Rod to remember sequences of oral instructions.</li> </ul>
Types of LD	Teaching Strategies	<ul style="list-style-type: none"> <li>• The preschool worked very hard with Nick. You know, establishing routines, doing a lot of repetitive teaching initially, drawing Nick out, and giving directions that took into account his muscle disability.</li> <li>• With Stefan’s math, we used touch math and visual cues to help him feel successful.</li> </ul>

		<ul style="list-style-type: none"> <li>• It would take Jake two or three times longer than anybody else to learn spelling words and math facts. I would drill him and drill him. He learned his math facts using a computer program.</li> </ul>
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Results

The first issue that parents face when their son has DMD is the diagnosis. Boys with DMD usually manifest symptoms after they begin to walk. Families in this study noticed some atypical physical signs and behaviors before the diagnosis. Others discussed the frustration they felt by an initial inability to convince the doctors there was a problem.

[M-9] When my oldest son was about a year old, we noticed he was tip-toeing and falling a lot so I took him to my basic physician. The doctor told me I was just an overprotective mother.

[F-6] His muscles were pronounced like a little wrestler. I remember he had trouble going up stairs. One of the doctors we saw said he was fine and would outgrow it.

Though these parents found the symptoms frustrating and perplexing, they were in no way prepared for the actual diagnosis of DMD. The respondents in this study indicated that the diagnosis was a low point--the defining point of no return.

[M-3] Any way you get the diagnosis, it is bad.  
But some ways are worse than others.

[M-7] Jared's CPK test came back at 17,000. They took blood samples from Jared, my older son, and me. Because of our insurance, we couldn't get the payments straightened out so the blood sat for a while. Then, they misplaced the blood samples. When the test result finally came back, it was inconclusive. We had to opt for the muscle biopsy. All in all, it took us a year to get Jared diagnosed.

[M-2] When Rav was about a year old, he had a near drowning incident and a heart attack. He was in the hospital where they were following his CPK levels, which are always elevated after heart attacks. However, Rav's CPK levels never came down. The doctors followed up and discovered that Rav had DMD.

Once the DMD diagnosis is made, the earliest and most common reactions include various stages of the grief process. In all but one of the interviews, the sixteen families described their immediate reaction in one word, "devastation."

[M-15] We were overcome with grief. For a week straight, I was sick to my stomach. Neither of us could really eat, and we just really were tender and gentle with one another.

[M-8B] When Jerry was born, they did a supplemental newborn screening, in which there were 12 to 14 supplemental tests done on newborns. I got a call saying that his CPK levels had been elevated and that they needed to retest him. So I took him to have the CPK redone. On July Fourth while I was hosting a family party at my house, the pediatrician called to tell me my son had Duchenne's dystrophy. I couldn't believe that someone would call on a holiday to tell me such awful news.

Once the initial shock wears off, parents react by developing the coping skills they will use to deal with DMD.

[M-1] Then one day, I realized, ‘What does Sam think of his life if it makes his mother so profoundly sad? The only way I can get through this or keep my sanity is just to do it one day at a time.’ I wanted to do everything I could to be sure that his life was fulfilling and happy as it could be.

[M-15] We try to live day to day, and we don’t think about the long term.

After the diagnostic process, parents begin a new life with a son who has DMD.

### *Living with DMD*

Although there is no treatment to halt the progression or cure DMD, willing and enlightened parents have several treatment options available. Some doctors advise parents to rely on normal activities such as swimming, horseback riding, and modified sports and games as long as possible. Daily stretching of the joints is a must to prevent contractures, which hinder movement.

[M-1] When Sam was in first grade, he called muscular dystrophy ‘stretching disease’ because we instituted a stretching program at school. Every morning, everybody in his class stretched along with Sam.

[M-6] The physical therapist helped Rod to isolate his muscles that are still in good shape, like his abdominals, and taught him how to use them when he’s sitting.

Doctors have begun to prescribe steroids to slow progression and keep boys walking longer. This treatment, although proven to increase muscle mass, strength, and pulmonary strength (Cwik & Brooke, 1996; Porter, Hall, & Williams, 2001), is controversial among parents. Steroids may produce side effects such as weight gain, fluid retention, eye cataracts, diabetes, osteoporosis, and severe psychological conditions (Porter, Hall, & Williams, 2001).

[M-1] We never put Sam on steroids. We didn't like the possible side effects, and were more concerned about Sam's quality of life.

[F-6] Rod is on the steroid deflazacort and doing well with it. He can still stand at age 13.

The most invasive treatment is surgery. In younger boys, this includes ankle, knee, or hip tendon release. The tendons are surgically cut to prevent disabling contractures. In older boys who use a wheelchair for mobility, spinal fusion is done to prevent scoliosis (curvature of the spine).

In addition to specific treatment options, parents and their sons rely on special equipment to prolong mobility. The first pieces of equipment a boy with DMD is likely to use are ankle-foot orthotics (AFO's) and night splints, which are plastic braces used to prevent contractures of the ankles and feet.

[M-3] AFO's make it easier for the child to do things, and also prevent contractures. Nick has daytime AFO's that allow some bending. He wears them at school for four hours every day.

As boys with DMD get weaker, they use equipment to keep them mobile. The parents of newly diagnosed boys think of a wheelchair as the "beginning of the end."

[M-1] You never imagine that a wheelchair is something to look forward to. But, by the time Sam needed to use one, it was a relief.

[M-12] I look at a wheelchair as a tool that helps Stefan maintain his independence.

#### *LD Component*

Soon after the diagnosis of DMD, parents or teachers may notice other symptoms such as lack of phonemic awareness, difficulty with abstract reasoning, poor organization skills, and language difficulties. Veronica Hinton's study indicated that boys with DMD often have

communication and auditory processing difficulties (Hinton et al., 2000). In the present study, at least five of the boys had speech and language delays.

[M-4; M-15] Two things worked well with our boys when they were younger. We used sign language and pictures as visual clues to help them understand what we wanted them to do.

Eleven boys also had diagnosed processing difficulties.

[M-12; M-6] Our sons have auditory processing disorders. They have difficulty remembering a series of instructions and carrying them out.

[M-4; F-15] If you ask them a question, you may have to repeat or rephrase it because they don't respond right away. Sometimes, they'll be searching for a word and all of a sudden it just comes out in a sentence.

Although short-term memory is also a weakness, visual memory and long-term memory are often very strong for boys with DMD.

[M-1] When Sam was a young child, he had a great memory for maps and directions.

[M-14; M-15] Our boys remember a lot of facts, particularly about subjects that interest them.

### *School Issues*

Interestingly, the diagnosis of specific learning disabilities is usually made about the time when boys begin to feel the physical effects of DMD. Therefore, education becomes a very important issue to parents. In this study, fourteen families are active participants in their children's education. The parents of the younger boys believe in early intervention for speech and language delays, occupational therapy, physical therapy, counseling, and socialization. Parents of the older boys are more concerned with developing appropriate Individual Education Programs (IEPs) to meet their sons' learning needs. All of the families highlighted the importance of home-school cooperation in dealing with this dual disability. They believe they

have the primary responsibility in ensuring that their sons receive an appropriate education, and achieve this by being proactive, knowledgeable, and assertive.

[M-6] Home schooling has physically benefited Rod by enabling him to spend more time standing and to have access to the necessary accommodations. Academically, he has benefited from one-on-one instruction, strategies tailored to meet his particular needs, and the opportunity to learn based on his interests. You are your son's primary educator. Don't shrink back and let other people take over in the area of education.

[M-15] We can't expect an educator to be well versed in all these different disabilities. You have to educate them, and the more you do that, the more willing they are to work with the children.

The most important part of the education process for boys with DMD and LD is probably the IEP. However, an IEP itself does not guarantee that students will receive appropriate services. As members of the IEP team, parents have the right to insist on those services.

[M-7] I had to get a pro-bono lawyer to help me get Jared's IEP written to take into consideration his learning disabilities, which were not being addressed by his teachers.

The parents had definite ideas about what was needed to improve their children's education.

[M-10] George's needs are better met in a small school because he needs assistance. He needs to be more than just a face in the crowd.

[M-8A] When John went into first grade, we realized that something was wrong. John didn't want to learn. He wanted to play, mostly. At end of first grade, his school put him in the specialized classes instead of holding him back. His grades are passing or failing, instead of the

number since he is in the learning disabilities class. He does less writing and more experiments and hands-on stuff.

[M-13] Stefan has benefited from being held back a year and regularly getting help from a tutor.

[M-14] Reed has a full-time aide to keep him on task and help him do everything the rest of his classmates do.

### *Teaching Strategies*

Twelve families discussed the advantage of one-on-one instruction.

[M-10] With individual help, George actually started succeeding with schoolwork.

Another strategy that works is repetition.

[M-3] Nick's preschool helped a lot by establishing routines and practicing repetitive teaching.

The teaching strategies that parents use are practical and employ common sense. Together, parents and teachers have developed effective strategies for specific subjects. In the present study, twelve of the eighteen boys had disabilities related to language.

[M-5] Robert does not have phonemic awareness. He is a sight reader who does not understand phonics. I used a video based phonics program that incorporated hearing, listening, and writing that worked for him.

[F-11] My wife cut Tony's spelling words out of sand paper. Tony picked up the sand paper word, rubbing it and looking at it at the same time. Tony needed to touch and see to make the connection.

[M-1] To help Sam improve his creative writing, his teacher told him that every sentence he wrote had to contain as many words as his age.

For eleven of the boys in this study, math is difficult.

[M-14] Math seems to be a little too abstract for him. It's fine if he can use an abacus, counters, or a number line.

[F-13] We use touch math and visual cues to help him succeed.

Parents have positive, but realistic, goals for their sons. They want the same types of things for their sons with DMD and LD that most parents want for any of their children. Their goals can be summarized in the words of Stefan's father, "My wish for Stefan would be that he can reach his objectives, that he will find his life worthwhile, and that he will contribute to society."

## Discussion

### *Coping with DMD*

Parents in this study recognized the need to adjust their attitudes to improve the quality of life for their sons with DMD and everyone else in the family. This is in contrast to parents' reactions noted in the literature, such as Buchanan, La Barbera, Roelofs, & Olson (1979) who found parents used the coping mechanisms of magical thinking (expecting a magic cure to occur), overprotection, and lack of child discipline. Holroyd and Guthrie (1986) found that parents of children with neuromuscular disease were pessimistic about outcomes relating to the disease and had negative feelings toward the children, most of the parents in this study coped positively. They recognized the need to adjust their attitudes to Firth, Gardner-Medwin, Hosking, and Wilkinson (1983) reported that parents experienced a large variety of problems in dealing with sons who had DMD. These researchers also found communication within families to be a major concern. However, the families in the present study appear not to have a problem communicating. Perhaps, in light of the changes in DMD treatment and awareness, parents have

become more proactive over time, are able to adjust, and cope more realistically as the disease progresses.

As Beresford (1994) suggested, research studies involving families of children with disabilities should focus on how these families cope with caring for their children. Coping skills studies have greater implications for understanding and improving ways to help. The findings here suggest that parents of children with disabilities adapt quickly to their situation and begin to make changes in their lives. Most of them operate on the theory “knowledge is power.” Like parents of children with all exceptionalities, parents of children with DMD and concomitant LD seek information by contacting support groups, examining the literature, consulting with medical professionals, and using the Internet. In a very short time, they become knowledgeable experts on both of the disorders and their ramifications. They also establish a sense of community and sharing of information to empower others like themselves.

#### *Coping with LD*

One of the earliest teams of researchers to suggest a relationship between DMD and LD was Karagan, Richman, and Sorenson (1980). Their findings indicated that abstract reasoning and categorization skills of boys with DMD are relatively good but memory function is impaired. Whelan (1987) found boys with DMD scored lower on tests that measured verbal and nonverbal memory and verbal fluency than on other tests of cognitive ability. The research of Hinton, DeVivo, Nereo, Goldstein, and Stern (2000), in which several of the families from the current study participated, corroborates those findings.

This study testifies to the value of relying on parents as sources of expert and practical advice. It helps to establish a possible link between DMD and LD, particularly in some boys, to increase our understanding of both disorders. It occurs at a time when DMD awareness is

increasing due to the MD Care Act, passed by Congress in 2001, the establishment of DMD Awareness Day on September 17 of the same year, and the hope4md website, created in 2002, which promotes awareness and fundraising for research.

Tony's father summarized the implications of the study beautifully with these words:

I believe that every life is valuable or meaningful in some way. Life with DMD and concomitant specific learning disabilities is not in vain. This research study, the work my wife and I are doing at the sensory integration clinic we founded, or other parents' daily battling in the trenches proves that these lives have had an impact for the better. Somewhere out of tragedy has to come something good.

#### *Recommendations for Future Research*

Throughout the study, several questions were implied that warrant future investigation.

The author suggests future research to seek answers to the following questions:

1. Why do one-third of boys with DMD appear to be susceptible to specific learning disabilities?
2. How does dystrophin affect the central nervous system, particularly the brain?
3. What are the effects of various learning strategies on boys with DMD and specific learning disabilities?
4. As medical science develops treatments to prolong the lives of people with DMD with and without specific learning disabilities, how will adults with the disorder cope with additional issues such as higher education, employment, health care insurance, sexual relationships, marriage and parenting?

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