



New Jersey Chronic Fatigue Syndrome Association, Inc.

Presentation to the Chronic Fatigue Syndrome Advisory Committee

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By:

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I have been invited by this Distinguished Committee to address issues pertaining to the ability of adolescents to cope with Chronic Fatigue Syndrome, specifically in the school setting; with additional discussion of models of best practices that could help adolescents with CFS manage their illness and schoolwork. In inviting me, the Committee noted that it recognized that school age children with CFS encounter many issues in the education system including:

1. Inability to complete school credits and keep up academically as a result of variations in school resources and the difficulty in obtaining school credit other than in person attendance. It was further noted that many students simply give up on the school system and take the high school equivalency exam after their peers graduate.
2. Hesitancy on the part of school officials to allow part time schedules with additional supplemental education at home as a result of an “all or nothing” attitude which is essentially inadequate, unstructured and unmonitored.
3. Separation from peers due to school absence and a “strange” invisible illness. Social isolation and rejection by peers which becomes a significant issue, as well as the embarrassment and difficulty with re-entry due to feeling “different.”
4. Adolescent (age appropriate) attitudes and maturity make it difficult for patients to use assistive devices including wheelchairs, motorized wheelchairs and resting rooms, etc. And negotiating a large, often older school building, with long distances between classrooms, etc., may be difficult to tolerate physically.
5. Adolescents with CFS, due to their age and level of maturity are often less able to deal emotionally with the personal loss of CFS and thus suffer secondary mood symptoms with low insight and lack of support systems. These symptoms, and avoidance of school/peers due to isolation become difficult to distinguish from primary CFS symptoms and these patients who often have less ability to tolerate medication, and have more

difficulties as a result of being suspicious of medication are more likely to be non compliant with treatment.

As a preliminary matter, I should note that I suffered from chronic fatigue syndrome in the late 1980s when little was known about the illness. I was fortunate to have a Primary Care Physician who was familiar with the 1988 CDC Case Definition of CFS and diagnosed me based on that criteria, and treated my symptoms with a variety of medications. Ultimately because I had a very understanding law partner, I was able to gradually return full time to the practice of law. I did so with a profound determination to educate my colleagues, the insurance industry and the government about the devastating effects of this illness.

Several years later, my daughter, then an adolescent, began to demonstrate moderate to severe CFS symptoms. I was quite fortunate to have her treated by a number of noted CFS specialists with whom I have had the privilege of working on several Committees and Boards. Despite my knowledge of the illness, and those of her physicians, we encountered all the obstacles that families of children with CFS do in an academic setting. My daughter's neurocognitive test results documented her severe cognitive deficiencies in a number of areas including memory and concentration, directional and spatial problems, inability to remain on task, speed of processing, among other things. In addition, her fluctuating bouts of fatigue and recurrent flu like symptoms (headaches, sore throats, abdominal complaints, muscle and joint pain and weakness) impeded her ability to predictably report to school. Her life was a series of "good days" and "bad days." Typically she would overdo on her good days which would then cause severe post-exertional malaise afterwards which often translated into a series of bad days. Her emotional response was the only thing predictable about her condition: Why me?

Unfortunately, this good day/bad day phenomena was misunderstood by school officials and many of her friends to be "proof" that she was actually healthy and was merely choosing to take days off when she felt like it. When teachers, administrators and peers were told that she suffered from chronic fatigue syndrome, the response was typically, "Well, I'm tired too." Needless to say, the school environment became a source of frustration and upset for her and my family. I was ultimately forced to incur the expense of a private school where her academic needs were honored and her CFS was fully accommodated.

As a college student, her studies have extended beyond a traditional four year program but I am happy to report that she has consistently been on the Dean's List and will graduate at the end of the Fall 2008 semester. And while it has taken her five and a half years to reach this academic milestone, her health has remained status quo, and she has emotionally adjusted to the reality of her "good day" "bad day" existence, and the social, educational, and medical differences between her and her peers. All in all, our outcome was positive. But we are quite fortunate. There are many parents of children afflicted with CFS who do not have our financial resources, fund of knowledge, contacts in the medical community or other special circumstances.

I agreed to accept the invitation of this Committee to honor those CFS families who are not as fortunate. My presentation is intended to explore the myriad dimensions of the problem in an effort to develop practical suggestions to ensure that all CFS families realize the benefit of a "free **appropriate** public education" for their children. The federal government has existing

resources and guidelines in place at this time to provide assistance to these families to ensure that their children's right to a free appropriate public education is protected and that their dealings with educators, school administrators, physicians and other health providers is productive and positive.

I thank the Committee for this opportunity.

I) IDEA: The Individuals with Disabilities Act (2004) and the Federal Rehabilitation Act of 1973 (commonly referred to as Section 504)

There are two Federal Statutes which will be discussed here. The first is the IDEA which is a federal funding statute whose purpose is to provide financial aid to states in efforts to ensure adequate and appropriate services for disabled children. The second is Section 504 of the Federal Rehabilitation Act of 1973. It is a broad civil rights law which protects the rights of individuals with handicaps in programs and activities that receive financial assistance from the US Department of Education. Both of these laws require a free public education to eligible students covered under them including individually designed instruction.

Section 504 identifies all school age children as handicapped who meet the definition of a qualified handicapped person: 1) has or 2) has had a physical or mental impairment which substantially limits a major life activity, or 3) is regarded as handicapped by others. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself and performing manual tasks. The handicapping condition need only substantially limit one major life activity for a student to be eligible for 504 protection. As will be discussed below, the IDEA requires a written Individual Education Plan (IEP) for the child with specific content and a required number of multi disciplinary team members. Section 504 requires a Plan but not a written IEP document. Under 504, a Free Appropriate Public Education (FAPE) defines "appropriate" to mean that a child is entitled to an education comparable to education provided to non handicapped students requiring reasonable accommodations be made. Related services, independent of any special education services defined under the IDEA may be a reasonable accommodation.

Section 504 does not require that the handicap adversely affect educational performance (as the IDEA does) or that the student need special education to be protected. Unfortunately Section 504 does not provide additional funds, and worse, IDEA funds may not be used to serve children found eligible only under Section 504.

Section 504 has regulations concerning building and program accessibility which requires reasonable accommodations be made. And while IDEA provides for independent educational evaluation at the school district's expense if a parent disagrees with an evaluation obtained by the school and the hearing officer concurs, 504 does not provide for independent evaluations at the district expense.

Both the IDEA and Section 504 implement placement procedures which require interpretation of evaluation data and making placement decisions and require school districts to: Draw upon information from a variety of sources (medical, family, guidance counselors, etc); assure that all information is documented and considered; ensure that the eligibility decision is made by a group of persons knowledgeable about the child, the meaning of the evaluation data and placement options; and ensure that the impaired child is educated with non-handicapped peers to the maximum extent appropriate in the least restrictive academic environment.

While the IDEA requires an IEP review meeting prior to a change in placement, Section 504 does not require such a meeting. Section 504 requires districts with more than (15) employees to designate an employee to be responsible for assuring district compliance with its provisions and requires the existence of a grievance procedure for parents, students and employees. The IDEA does not require a grievance procedure or the existence of a compliance officer.

However, both statutes require school districts to provide impartial hearings for parents who disagree with the identification, evaluation or placement of a student. Section 504 requires that parents have an opportunity to participate and be represented by counsel with other aspects of the hearing to be determined at the discretion of the local school district. Notice of procedure and policies must clarify the details of the hearings.

IDEA requires a free and appropriate public education for all children with disabilities. An adolescent with a sufficiently severe form of Chronic Fatigue Syndrome is generally construed as falling under the IDEA disability classification of “other health impaired” which is defined as demonstrating “limited strength, vitality or alertness, including a heightened alertness to environmental stimuli that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as a heart condition, TB, rheumatic fever, arthritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, ADD, ADHD and diabetes and adversely affects a child’s education performance...” The definition also includes “Other Health Impairment Criteria” where a student’s disability affects her/his performance in the following areas: written work, math skills, listening comprehension, oral expressive skills, gross and/or fine motor skills, reading skills, concentration for an extended time, organizational skills, emotional and/or behavioral issues.”

According to the The National Dissemination Center for Children with Disabilities (hereinafter NICHCY), the Individual with Disabilities Act was previously called the Education of the Handicapped Act, and the Education for All Handicapped Children Act, and even earlier the Elementary and Secondary Education Act. The name change to IDEA was done to “reflect a movement toward people first language.”

Those of us who inhabit the CFS world understand full well that name designations can either help or hinder a cause. So the “people first” policy implications underlying the name change to IDEA must be emphasized in any course of action in implementing change in favor of CFS adolescents in the school setting.

The NICHCY reports that the “IDEA authorizes special education and related services to the United States. More than 6.8 million children with disabilities are served under its provisions.”

As Dr. Jason's "Community Based Study of Chronic Fatigue Syndrome" confirmed, the number of CFS sufferers is underreported, and even more so in the urban minority communities. (see- Leonard A. Jason, PhD; Judith A. Richman, PhD; Alfred W. Rademaker, PhD; Karen M. Jordan, PhD; Audrius V. Plioplys, MD; Renee R. Taylor, PhD; William McCready, PhD; Cheng-Fang Huang, MS; Sigita Plioplys, MD *Arch Intern Med.* 1999;159:2129-2137)

Almost certainly, therefore, the number of children with CFS, particularly in minority communities are underreported as well, and not receiving the benefit of IDEA related services. Therefore "the wide range of supports to improve the results and outcomes that children with disabilities achieve in our schools and communities..." which "includes fiscal programmatic support for research, technical assistance, dissemination of the field's knowledge base" is being denied many adolescents suffering from CFS.

IDEA defines a "free appropriate public education" (FAPE) to mean "special education and related services which are provided at public expense, under public supervision and direction and without charge." (Section 300.17) The FAPE must be provided in accordance with an individualized education program (IEP) that meets other IDEA requirements.

In the context of a CFS adolescent, like those of other disabled adolescents, the written IEP must be the result of collaboration between the participants of a multi-disciplinary IEP team. As Dr. James Oleske, M.D, Jonathan Sterling, MA (Former Chairman of the Board of the CFIDS Association of America, former President of the NJCFSA, and former Principal in New York City), Donna Palumbo, LCSW and Terri Lynn Evans, noted in the Chapter on "CFS in Children and Adolescents" in "A Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome" (2002):

"Superintendents, principals, supervisors of special education, guidance counselors, school social workers, and psychologists are very much involved in IDEA eligibility evaluations; yet often the role of school nurse as a bridge between the medical and school communities has been overlooked. Both in the eligibility evaluations and in the IEP meetings, the school nurse's medical knowledge could be invaluable in successfully planning a program that would meet the education needs of children with CFS...It is important that a multidisciplinary approach addresses the needs of student and families and ensures that the student's teacher(s) participate. The process should also allow for parent/student involvement. Consultations with the student's physician(s) should be periodic; in light of the relapsing/remitting nature of the syndrome. As many as 40% of students with CFS are too ill to attend school full time and home tutorial services should be provided. Where students can attend school for all or part of the day multiple accommodations have proved successful in helping schools provide appropriate educational settings for students with CFS."

Among the recommendations made by the Chapter authors were the following:

- Less rigid attendance and tardiness policies
- Extra Time for tests and assignments
- Classroom committees and copies of lecture notes
- Make-up work

- Flexibility in scheduling with classes and assignment deadlines
- Provision of syllabus or schedule of upcoming assignments so the student can keep up with the class when unable to attend school
- Access to the school elevator
- Tutor(s) for class work assistance and/or Home Instructors for classes taken at home
- Extra sets of textbooks to and from school for home and school
- Transportation to and from school
- Flexibility with course requirements, e.g.-omitting physical education
- Permission to graduate from high school in more than four years and/or decreasing the required number of credits to graduate

Additional accommodations and services were suggested for adolescents suffering from CFS by Shannon McQuown, a Special Education Coach and author of *“Harnessing the Wind: Chronic Fatigue Syndrome and My Son”*:

- Scheduled rest breaks
- Part time school based education
- Making medications available in the nurse’s office
- Allow student to adjust positions as needed
- Provide access to a keyboarding device (an “alpha smart” and a computer)
- Observation by an occupational therapist who can advise how to make a child’s environment more productive
- Provide voice recognition visual technology
- Provide large diameter pencils, pens and art instruments
- Shortened assignments to address cognitive deficiencies
- Provide verbal responses rather than written if child has dysgraphia
- Provide demonstrations of mastery in a variety of modalities (video, posters, timelines)
- Audio recorded lessons (provide a voice activated recorder in the classroom)
- Repetition of instructions
- Provide calculators, math charts, tables and formulas to save energy and time
- Provide a spell checker to conserve energy and stress
- Test by sections rather than chapters (to get information while it is fresh)
- Provide word banks (e.g-5 words to choose from)
- Multiple choice questions
- Reduce number of concepts or problems per page
- Provide graph paper for math problems (to keep child organized)
- Allow for delay in processing time
- Provide pre-printed materials
- Provide study guides
- Books on tape
- Enlarged print
- Large screen calculators
- Screen magnifiers
- Color coding
- Iconic directions (pictures rather than words)
- Frequent immediate feedback to reinforce information

- Reduction of distracting stimuli
- Headphones or earplugs to filter out noise
- Breaks as needed for digestive issues such as crackers or ginger ale to settle stomach or laminated restroom pass to use the bathroom without asking
- Where light, auditory, smell or other sensitivities are a complaint: to provide small group settings
- Mask for science class
- Use of sunglasses
- Permission to dress in layers
- Early dismissal from class
- Exemption from loud group activities such as pep rallies
- Where immune dysfunction is pronounced: advanced notification of widespread viral illness in the school, have a plan in place for extended absences, medication available for use in nurse's office

Ms. McQuown emphasized that because most children with CFS fall under the general "Other Health Impairments" category of the IDEA, and to secure cooperation from the school to deal with the needs of the CFS child, an appropriate physician letter is critical. She recommends the physician letter include specific details of the child's CFS symptoms, things the child cannot do, and specific directives on addressing those complaints and limitations in a school setting. Ms. McQuown notes the importance of including the doctor's credentials, and toward that end she developed a model letter:

Dear Special Education Administrator:

My patient, John Doe, has been diagnosed with CFIDS. He experiences the following: (fill in the blank). (In the sample letter she developed, she used the following symptoms: extreme fatigue, joint and muscle pain, some visual disturbances, sensitivities to light, noise, too much movement. John has difficulty concentrating and processing complex concepts. He also experiences some delayed auditory processing. John has difficulty following multi-step directions. There is difficulty with reading comprehension. John also has sensitivity to temperature. I therefore ask the school system to conduct a full evaluation to determine if John is eligible to receive special education services under the IDEA. A list of my recommendations for accommodations and modifications is attached. Please do not hesitate to contact me if I can be of any further assistance.

Sincerely,

Dr. Smith"

Therefore, a missive from a CFS specialist is crucial in establishing parameters for the recommendations for accommodations, modifications and special education services of the CFS afflicted student. However, some students do not have the benefit of treatment by a CFS specialist, so educating other physicians about CFS is imperative to establish a gateway to special education services for this population of students.

II) Additional Federal Efforts To Legitimize the CFS Diagnosis Must Occur to make any real inroads in Addressing the Special Education Needs for Students with CFS

For implementation of any of the above IDEA and Section 504 services to benefit Adolescents with CFS, medical support and treatment of the child by a physician with sufficient knowledge of the Pediatric Diagnostic Criteria for Diagnosing CFS in Children is a necessity. Toward that end, the New Pediatric Case Definition for Chronic Fatigue Syndrome developed by an international working group of the International Association for Chronic Fatigue Syndrome (IACFS/ME) which appears in print in the Journal of Chronic Fatigue Syndrome (Jason et. al, 2006) and which is available on the IACFS/ME website (www.iacfs.net) should be part of the U.S. Department of Education literature on special education services provided to all school districts throughout the nation. This effort could be done jointly by the Department of Health and Human Services and the US Department of Education.

Moreover, the continued skepticism about the validity of CFS as a medical diagnosis persists. The Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome which was published jointly by the Academy of Medicine of New Jersey, The University of Medicine and Dentistry of New Jersey and the New Jersey Department of Health and Senior Services remains the only monograph of its kind in the country. It was published in 2002 and Dr. James Oleske, M.D, MPH, the Chair of the present CFSAC Committee served as the Associate Editor, and Chapter Author, along with Dr. Joseph John, M.D who served as Editor and Chapter Author, and the lead Chapter on “Pathophysiology in CFS” was authored by another former member of this Committee, Dr. Kenneth Friedman, PhD.

The time has come for the federal government to add gravitas to this effort to legitimize this diagnosis by putting its imprimatur on the existence of CFS by funding a National Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome. It must include a section on Pediatric CFS, and of course, it should include the diagnostic criteria cited above, and a comprehensive approach to CFS Primary Care and Case Management.

Such an effort would add the weight of the federal government to fight against the persistent lack of understanding of this syndrome. Again, a National Consensus Manual for the Primary Care and Management of CFS could be distributed jointly by the Department of Health and Human Services and the U.S. Department of Education not merely to Primary Care Physicians around the country, but also to school nurses who play a vital role as part of the multi-disciplinary team addressing issues of CFS students with special education needs, particularly in the context of an IEP.

All of the above issues and recommendations are of little meaning if school officials do not believe in the validity of the CFS diagnosis. It seems to me a logical extension of the ex-officio representation to this committee to have a special education program level official from the US Department of Education regularly attend these meetings. I am sure that person could, with the help of this Committee, provide valuable insight into how the Department could begin to help educate school officials to achieve the objectives set forth above.

Recently, a mother of a 16 year old girl with CFS shared a story with me about her daughter's experiences with her high school. While the IEP was implemented, the teachers announced the special accommodations which were being made for her to the entire class. Specifically, the IEP required the teachers to provide that tests be administered verbally to the young woman to accommodate her cognitive deficits. The teachers were uniformly scornful and announced to all the students in her classes that they would all have the "benefit" of verbal testing so that she did not gain "unfair advantage." Clearly the young woman was mortified and was made to feel she was seeking an "unfair advantage" which was not actually required as a result of her medical condition. The young woman was also so physically weakened from CFS muscle complaints that she was recently required to use a motorized wheelchair to get to her classes. Unfortunately, the school building was old, and she had classes on different floors. There were no elevators in the building. She was told by a teacher that she should get out of her wheelchair and descend and ascend the stairs by using her buttocks. It is impossible to imagine a child disabled with MS or debilitating cancer symptoms being told to do that. And yet, that is how children afflicted with CFS are routinely treated: with scorn and derision. Such attitudes change with information. And a federal publication authored by noted medical and other experts in CFS can well serve as a catalyst to that sort of change in attitude.

In closing, I will share a recent New Jersey court case on this topic. It dealt with a female high school student who was disabled from severe CFS. Despite profoundly debilitating CFS symptoms, she managed to graduate as valedictorian of her school as a result of an effective IEP. However, the school determined that fairness dictated that other students with lower GPAs than hers also be designated as co-valedictorians because the IEP provided her with an "unfair academic advantage." Fortunately a federal court in New Jersey disagreed and ordered that she be designated as sole valedictorian because any other result would punish her for achieving such an honor in spite of her profound disabilities. It is doubtful that the school district would have insisted on such a course of action in a case that did not involve CFS. The Federal Court had the benefit of the medical literature and a wide breadth of CFS related cases before it.

Attitudes change with education. There is a desperate need to educate school officials, physicians and school nurses on these issues. Frankly, the need extends to our nation. Dr. Oleske and Jon Sterling have conducted CFS educational presentations for the New Jersey Education Association and other groups. But more comprehensive federal action is necessary. The information exists, the experts are available all that remains missing is federal action.

I would like to extend special thanks to both Jon Sterling and Betty McConnell who is Vice President of the New Jersey Chronic Fatigue Syndrome Association for the valuable advice and efforts they provided.