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What Every Parent Needs to Know About Educating Their Child With Chronic Lyme Disease

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More often than not children who contract Lyme Disease are treated with antibiotics for a few months and do not require any additional educational supports or services to make up for lost time in school. This is the rule for the majority of children who contract Lyme Disease, *however* there are many children who have a difficult time responding to standard treatments, for any number of reasons, and other children who become re-infected one or more times. These children are considered to have "Chronic Lyme Disease". They have a multitude of symptoms and problems that make it impossible to keep up with their schoolwork without special accommodations and services from their teachers and school. It is important to note that some physicians in the medical establishment do not recognize the term "Chronic" Lyme Disease. Some school physicians are among those who do not recognize the term "chronic" when dealing with students who have Lyme Disease. If your child suffers from Lyme Disease and needs special education services or accommodations you may get a hard time from your school district if your local director of special education either had the disease or knows someone close to them who had the disease and was cured with a couple of months of antibiotics. These people are among the lucky majority that never become re-infected and respond positively to standard antibiotic therapy. This article however, will deal with those students who do not respond well to standard treatment and have a variety of needs for special education services and or accommodations in the classroom.

While all states have their own special education laws there are two federal laws that protect students with Lyme Disease and supercede state code and regulations. The first law that parents need to become familiar with is the Individuals with Disabilities Education Act or IDEA. This law deals with all students who have some form of disability. Students with Chronic Lyme Disease may fit several different categories depending on how severe the Lyme Disease has impacted on the child's ability to profit from regular education. Some classifications or categories could be "chronically ill"; "other health impaired" or "learning disabled". You will need to obtain a copy of your state's special education code and read it carefully in order to become an active participant in the decision making process for your child. Many states have slightly different categories and definitions than those given in IDEA. Remember that, *the IDEA law supercedes all state special education laws except when the state law is more protective of your child's rights or offers more services.* It is also possible to have your child qualify under other more intense terms such as "multiple disabilities" or other categories depending on how the disease manifests itself at a particular time during the course of the disease. There can be, in extreme cases, both neurological and psychiatric problems that may require additional medical and educational treatment. A "*red flag*" for parents when dealing with their school or school district, would be a suggestion to classify a child with Chronic Lyme Disease as "orthopedically disabled". This would show some archaic thinking on the school's part if they believed that Lyme Disease was like arthritis. The most significant educational impact of Lyme Disease lies with lack of vitality to produce schoolwork, the ability to focus and sustain attention, memory and the overall ability to process and synthesize what is being taught. If a child with Lyme Disease had some severe orthopedic symptoms they would most likely also have some of the learning problems as well and this would qualify under the term "multiple disabilities".

Children with Chronic Lyme Disease can have a multitude of symptoms. These symptoms can change week to week, day to day and sometimes hour to hour. Every child is different, so parents and school special education committees (child study teams, etc.) need to listen carefully to both the students and the family physician that is treating the student for the disease. Some children have their REM sleep interrupted by the disease and would have significantly more functional learning disabilities in the morning. I have found that allowing them to stay home in the morning and bringing them in at lunchtime provides them with a greater vitality needed for learning. I would then provide home instruction between 4 and 7 PM for the subjects that were missed in the morning. This may continue for a few weeks or many months depending on the success of the medical treatment. A very common problem for these students is the

inability to focus and attend. In fact some children with Lyme Disease have been misdiagnosed with ADD or ADHD and have been treated with Ritalin. It is important to remember that Lyme Disease is diagnosed by excluding other diseases and disorders since there is still no 100% accurate test for Lyme Disease. Another very common problem is memory loss and the ability to organize one's schoolwork. Any insult to the central nervous system can cause memory problems and once again the student's abilities can change day to day or hour to hour. Motivation is also a key factor to learning. When children don't feel well they will have a tendency to become depressed and develop feelings of hopelessness. This will have a negative impact on their ability to perform academically. Children with Lyme Disease have been accused of "faking it", trying to get out of homework and generally trying to beat the educational system. Educators need to fully understand *all* of the neurological and psychiatric implications of Lyme Disease and they need to understand that the children would much rather be well than to be sick. Whenever you deal with a person with a disability you should provide them with an educational program that not only meets their needs but also provides them all the experiences and opportunities that a child without disabilities would encounter. Children with Lyme Disease should lead as full and as normal life as they are capable given their individual symptoms and the severity of those symptoms at any given time.

The second federal law that is applicable to students with Lyme Disease is Section 504 of the 1973 Rehabilitation Act. This is not educational law. It is primarily civil rights legislation that prevents students from discrimination, if they have some type of disability that substantially limits the child's ability to learn. School districts and parents together can decide which of these codes and format could best serve the child. While there are whole day workshops on the differences and similarities between Section 504 and IDEA I will attempt to highlight some issues to keep in mind. As a former public school special education administrator I based the decision of whether to provide service to a student under Section 504 or IDEA on the projected outcome and level of service that could be reasonable assumed for a given student. For example if a child only need some classroom accommodations and some home work modifications that could be performed by the regular classroom teacher I would prefer to see that child served under Section 504. While Section 504 requires a written plan signed by the parent, as does IDEA, there are far less procedural issues and students can be served faster than through IDEA in general. The written 504 plan itself is less complicated, faster and easier to write than an IDEA plan. Parents need to remember that *all IDEA students are 504 students but not all 504 students are qualified under IDEA*. There can be some cases that that 504 students would not qualify under IDEA but these cases are rare. However, students with Lyme Disease *often* fit into these rare situations, primarily due to their ever-shifting medical and educational condition.

In general any service or program that can be delivered through IDEA and also be delivered through Section 504. In most cases districts would prefer using IDEA rather than Section 504 since there is no state or federal financial aid available to school districts through Section 504. As I mentioned above, as a special education administrator, I would prefer that a child who would need special transportation, tutoring or other services that would increase their cost of education, be handled through IDEA. If a student's needs can be met with accommodations and modifications that do not involve extra expenses to the school district, I have always felt that Section 504 was a quicker way to go without compromising the quality of service provided or the student's/parent's due process rights.

Parents basically have the same "Due Process Rights" if they become in conflict with their school district with IDEA and Section 504. Most state departments of education use the same conflict resolution procedures for both IDEA and Section 504. You need to check these state procedures with your state department of education. Ultimately the United States Department of Education, Office of Civil Rights will hear both IDEA and Section 504 complaints against school districts. You can call your state department of education to get the address and phone number of your nearest U.S. Department of Education, Office of Civil Rights. If you are reading this and saying to yourself " This seems fine if my child is in public education but my child attends a private or religious school". You are correct in thinking that all of this is may not apply. Times are changing. Since the "1990 Americans with Disability Act" the rights of all students, public, private, religious and even *home schooled children* have been expanded through various court cases. I recently read a federal court decision in which the judge reinstated a preschool child with disabilities back into a *private preschool program* that had recently dismissed the child. Most states have child advocacy organizations that can provide some guidance in conflict resolution or direct you to where you can obtain legal advice. I have found two Internet sites that can be very helpful. One is [<http://www.ideapractices.org/>]. This site contains the entire 1997 edition of the Individuals with Disabilities Education Act and Regulations, which can be downloaded and printed. The second site is [<http://www.504idea.org/>]. This site contains the entire text of Section 504 of the 1973 Rehabilitation Act (which again, can be downloaded and printed) and gives a detailed comparison between IDEA and Section 504. This data will make you an *informed* participant when making educational decisions for your child.

