

504, IDEA & IEPs: I know what my child needs to be successful in school, but what are these numbers and letters all about?

by

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In my administrative role in the Jackson Township schools, I was responsible for everything in the school district concerning students and then some. I was in charge of special education, student attendance, guidance, and health services among other areas. I had a unique view of the overall functioning of both regular education, and special education, as well as the various points at which they met. Little did I know when I first came to Jackson Township that it was the tick capitol of New Jersey. We literally had hundreds of students with various stages of Lyme Disease on any given day. I knew this because I was the one person responsible, who had access to the medical, guidance, and special education records and reports. Because of this high incidence, the board of education had approved a clinical study by a major research institution that took place during the 1990s in Jackson Township. Most of these students were being treated by their family doctor and responded well to conventional antibiotic therapy. This group did not require any additional educational supports or services to make up for lost time in school as they suffered none of the major Lyme Disease symptoms for more than a week or so. My own son fell into this group just a few years ago. He always had sensitive skin from birth on and had a bout of psoriasis when he was 12 years old. When my son at age 18 was infected at a back yard barbeque, he became covered head to toe with hundreds of classic bull's-eye rashes. The rashes ranged in size from a silver dollar to a football. He was actually very lucky. We knew immediately that his cold symptoms and body aches were due to Lyme Disease. He was promptly treated with oral antibiotics and responded well to the treatment. 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 school physicians can be among those who do not recognize the term "chronic" when dealing with students who have Lyme Disease. This article will deal with those students who do not respond well to conventional treatment for Lyme Disease and require educational accommodations and or some level of special education while they are fighting their disease.

Children with Chronic Lyme Disease can have a multitude of symptoms. We all know about the common musculoskeletal symptoms, rashes, and the like. This article will deal with the neurological and neuropsychiatric symptoms as they can wreck havoc in the child and their school environment. These symptoms and the severity of the symptoms can change week-to-week, day-to-day, and sometimes hour-to-hour. Since every child is different, school

pupil committees (child study teams, etc.) need to listen carefully to the students, parents, and the family physician that is treating the student for the disease.

Many neurological and neuropsychiatric symptoms can occur in isolation or in various combinations. I will attempt to provide examples of the most common that affect students in school. The most common Symptoms of "Neurologic" Lyme Disease are short attention span, memory (especially word retrieval), headaches, facial palsy, seizures, muscle weakness & pain, sound and light sensitivity, thinking (slow processing), expressing thoughts, reading, writing, and other eye problems. The most common Symptoms of "Neuropsychiatric" Lyme Disease include but are not limited to, mood swings, irritability, increased separation anxiety, phobias, disordered thinking, disordered behavior (uncharacteristic outbursts), fatigue, disordered sleep, general anxiety (attacks), motor or vocal tics, obsessive compulsive disorder, autistic behaviors (regression), depression, lowered self esteem, decreased stamina, cannot sustain attention, confusion, feeling overwhelmed, eating disturbances, feeling isolated, personality changes, and panic disorders.

Some children have their REM sleep interrupted by the disease and would have significantly more functional learning disabilities in the morning and have a very difficult time getting out of bed. I have found that allowing these students 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 session. This may continue for a few weeks, many months or even years depending on the success of the medical treatment and the course of the disease. 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 or other stimulant medication. 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 do not 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 neurologic and psychiatric implications of Lyme Disease and they need to understand that these children would much rather be well and attend school full time just like everyone else, than to be sick. Whenever you deal with a person with any 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.

As you can see, children with chronic Lyme Disease require many educational accommodations. Your assignment as a parent is to navigate all the letters and numbers listed above in order to provide the specific educational accommodations appropriate for your child's condition. 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 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 reasonably assumed for a given student. For example, if a child only needs some classroom accommodations and some homework 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 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.

The second 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. Some states may 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".

A third option, which is available in most states, is what we once called in New Jersey, a Pupil Assistance Committee or PAC. Schools in New Jersey are required to have a local school based problem solving committee to help students with minor learning and behavior issues. In New Jersey, this committee is made up of teachers, nurses, guidance counselors

and other school professionals and headed by the building principal. This committee, because of the principal's authority, has a great deal of discretion in making student accommodations without going through a formal 504 or IDEA referral. A few years ago, I was assisting a family as an educational advocate in New Jersey and the family called me in a panic. They said that the school was refusing to let their child be referred to the IDEA and/or 504 team. The parents were afraid that their school was about to deny their child with Lyme Disease the educational accommodations that their child needed. We came in ready to do battle with the school and to our pleasant surprise the principal and his "problem solving committee" offered all the necessary accommodations without all of the delay and extensive testing that usually accompanies a formal IDEA or 504 referral. This child's needs could be met with accommodations that did not cost the school any additional financial resources. Briefly, students under IDEA go through very formal proceedings and sometimes extensive testing. They have a great deal of rights and protections under the law. Students under 504 go through a less formal process, usually less testing as they often rely on previous existing records. 504 students still get all the rights and protections under the law. Students who receive accommodations from their local school committee/principal do not at this point have any rights or protections but can obtain those rights and protections simply by the parents requesting a 504 or IDEA referral. The less formal the proceeding, the faster accommodations can be delivered to your child. Schools and school districts would prefer a child to be handled under IDEA if their program/accommodations are somewhat costly. Children under IDEA receive both additional state and federal funding. Children under 504 or a local school committee do not receive an additional state or federal school funding.

In order to decide which program is right for your child and exactly what accommodations your child requires you must complete the following steps regardless of which path you choose. First and foremost, you must make sure that a clear and comprehensive "Present Levels of Educational Performance" (PLEP) be written into the plan. This was formerly known as "current educational status". Regardless of what you call it you should have a clear "snap shot" of your child's educational abilities and disabilities. While I am using IDEA terms these concepts apply to the 504 and local school committee proceedings as well. The next phase is to make sure that clear and measurable educational goals and objectives are formulated. Once we have these items in place we can then come to unanimous and meaningful accommodations and program determinations. A comprehensive picture of the child's abilities and disabilities drives the goals and objectives and the goals and objectives drive the accommodations and program. Throughout any of these procedures, remember you have a right to have copies of any and all reports that are written about your child and you have the right to have these records corrected if they contain false information. You also have the right to walk away from the meetings without agreeing to anything if you want more time to think over what is proposed. It is also good practice to ask for all reports that are going to be used at your child's meeting at least one week before the meeting date so that you can digest the information and be prepared to be an active participant in your child's education plan.

The following is a list by category of some of the more common educational accommodations that may be appropriate for a student with Lyme Disease. By no means is this a complete list for any individual child. I would challenge my child study teams in Jackson Township to think "outside of the box" so as to make meaningful and appropriate

accommodations for our students. These accommodations only level the playing field they do not give unfair advantage to children with disabilities. Being "fair" does not mean everyone is treated the same or held to the exact same standards all the time.

Curricular Goals and Objectives

Modify material for essential content
Modify the pace of content delivery
Focus on the array of skills with appropriate materials

Instructional Groupings & Scheduling

One to one teaching
Home instruction
Alternative school starting and ending hours
Selective scheduling (part-time home instruction with part-time school attendance)
Teacher directed small group
Cooperative learning groups
Peer partners/peer tutoring
Instructional aide
On line approved high school & college courses
In-class support
Remedial assistance
Resource center

Instructional Materials

Alternative strategies to retain concepts
Alternate curricular materials that transition into regular curriculum materials
Study guides
Materials for the Blind (books on tape)
Multi-sensory materials
Manipulatives
Computer programs
Tape recorder
Auditory trainer

Performance Assessment Content

Alternative strategies to assess completion of course objectives
Demonstrations
Work portfolios
Projects
Extended time
Extended school year to either start early or complete course work
Alternate testing format and/or content
Individual or small group testing

Personal Assistance

Assistive technology
Note taker
Reinforcing
Redirecting
Prompting
Highlighting
Gesturing
Cueing
Clarifying
Modeling

Environmental Conditions

Reduced auditory and visual stimulation
Physical arrangement of the room
Accessibility of materials and workspace
Special lighting

School-Classroom Practices

Modified classroom rules
Individual student management
Modified classroom management
Behavior modification
Behavioral contracts

Learning Activities

Learning stations
Audio-visual presentations
Computer assisted instruction
Demonstration and projects

Your child has the right to any and/or all of these accommodations based on the particular areas affected that interferes with their educational functioning. Keep in mind that they are entitled to a "free and appropriate public education" (FAPE). Students also have these same rights if their private or religious school accepts any federal or state monies. You might be surprised how much public monies flow into private and religious schools under a number of state and federal programs.

For information that is, more detailed please check out these Internet sites with extensive information. [<https://sites.ed.gov/idea/>] contains a link to the text of the Individuals with Disabilities Education Act. The web page [<https://www.hhs.gov/civil-rights/for-individuals/disability/index.html>] contains many examples of Section 504. The Special Education Advocacy website home page [<https://www.disabilityrightsca.org/publications/17-special-education-advocacy-tips>] and law page [<https://www.doe.mass.edu/sped/links/Advocacy.html>] has a great deal of useful information. The data contained in these sites will make you an informed participant when making educational decisions for your child regardless of which law best fits you child's needs.