

Due Process Hearing

Opening Statement

by

Josh Koch

Disability, its not an easy thing. If any of the parents in the room have children with a disability, they can see the pain and anguish their children must go through everyday. No child should have to live through that.

Over one-hundred years ago three famous doctors emerged: Charcot, Freud and Tourette (who was a student of Charcot's). Charcot worked with people who had movement disorders. Tourette was interested in a particular group of these people who were different from the others. But when Charcot and Tourette couldn't figure out how to treat these people, they directed them to Freud (who had been having success with these weird types of disorders). Freud diagnosed TS to be a psychological disorder. Thus, for over half a century Tourette Syndrome was *misclassified* as a psychological disorder. In 1975 congress passed the Education for All Handicapped Children Act. For the next 30 years Tourette Syndrome was again *misclassified* and misunderstood by schools and congress alike. As a result these students did not receive the services they needed and were misunderstood. On August 3, 2006 Secretary Spellings recognized the need to list Tourette Syndrome under OHI because students were not getting the services they were entitled to. *How much longer are we going to misclassify students with Tourette Syndrome?*

The text book definition of Tourette Syndrome is a neurological disorder characterized by tics.

Tourette Syndrome (TS) is a neurological disorder characterized by tics; involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The term, "involuntary," used to describe TS tics is sometimes confusing since it is known that most people with TS do have some control over their symptoms. What is not recognized is that the control, which can be exercised anywhere from seconds to hours at a time, may merely postpone more severe outbursts of symptoms. Tics are experienced as irresistible and (as with the urge to sneeze) eventually must be expressed. People with TS often seek a secluded spot to release their symptoms after delaying them in school or at work. Typically, tics increase as a result of tension or stress, and decrease with relaxation or when focusing on an absorbing task.

But as we know now TS *isn't just* the tics. TS is often accompanied by many co-morbid disorders (especially OCD & ADHD) and students tend to have visual-motor integration problems, dysgraphia, non-verbal learning disabilities, as well as a tendency to process things at a slower level.

Some people with TS also have obsessive-compulsive behaviors where they have an uncontrollable urge to complete certain rituals. They may feel compelled

to redo their work many times because of tiny, barely perceptible imperfections. Some children may perform rituals such as 'evening up,' i.e., tapping one arm the same number of times as the other, or performing some kind of touching or hopping ritual before entering a room. As they grow older, some may begin to believe that something bad will happen to them or others if this ritual is not performed. Because the child is "driven" to perform these behaviors, he may become quite upset when school routines interfere. Another manifestation of this condition is having repetitive thoughts. At times, these thoughts may be very upsetting. No matter what the content, the obsessions can and do "take over." In the classroom setting, obsessive-compulsive symptoms make it quite difficult to complete work in an efficient way

"A significant percentage of children with TS also have visual-motor integration problems; therefore tasks that require these students to see material, process it and then write it down are very difficult and time consuming. This problem also affects copying from the board or out of a book, completing long written assignments, neatness of written work and prescribed times for completion of written work. Even very bright children with TS who have no trouble grasping concepts, may be unable to finish written work because of visual-motor impairments. Sometimes it may appear as though the student is lazy or avoiding work, but in reality the effort to get the work down on paper is overwhelming to these students.

Yet students with Tourette Syndrome generally have average or above average IQ's. This is the real problem with TS... its not the tics or ocd, it's that schools view students with TS as smart, which they are, and dismiss the fact of all the other problems that students struggle with academically. I will not argue today that I am not smart or that have a low IQ, because that is not true. But I will argue that like all the other kids with tourette syndrome, I *learn* differently, I *test* differently, I *work* differently. These are the things that are impacting my education. These things are not so evident in test scores and grades but the evidence will show that when we break down the grades and the test scores the problems are apparent.

Everyday I wake up, its a challenge. Everything I try to do, is a challenge. When it comes to school, *its still a challenge*. It is hard living your life every day at a place where its all about "being normal." And in addition to that, *dealing* with the actual schoolwork. I am compulsive in nature about my schoolwork, so I will do whatever it takes and whatever the cost to try to do well. But because of my slow processing speed, because of the non-verbal learning disabilities, because of the visual-motor integration, because of the impact TS and OCD, it makes things so much more difficult. I have taken lower classes before, and these problems don't go away. They are there in no matter what classes I take because I *still* process things slower and take longer. And I have accommodated by myself up until this point, I have sacrificed things that I enjoy to make

these accommodations. This isn't the students responsibility, now its time for the *district* to accommodate and take on *their* responsibility.

The district will argue today that my grades are good and I am in very demanding classes and therefore am not in need of specially designed instruction or accommodations. On the whole my grades are good and are *appropriate*. What is **not appropriate** is the time and cost that I must put forth in order to achieve these grades, this has been damaging to my health and emotional well-being. Disability should not restrict children to what courses they take and should not force them to dumb-down their education. Disability is not something which should slow students from achieving what is appropriate for their level of intellect and should not prevent them from preparing for their future.

Who you see here standing up today is a smart kid with Tourette Syndrome. You see everything that is happening verbally. What you won't see, is it what happens the moment my pencil hits that paper and switches to things happening non-verbally. This is where the main problems occur.

I'm defending myself today because *this is wrong*. And I want to show you that kids with disabilities can be just as intelligent as any other person, but can still need help. I need you to understand that. I need you to understand that teachers and school personnel alike look at the verbally smart aspect and associate all of the non-verbal problems to procrastination and not trying hard enough. I'm asking you to see what they *can't*.

This is not a typical case, I understand that. There are students who are so much worse than I am and they need those services beyond any doubt. But we can't be discriminatory and comply with the common misconception that students who are achieving do not need any assistance. Grades are only part of a picture. In some cases with children with autism and mental retardation, that picture might suffice. But for kids with TS and disabilities like it, we need to be looking at more of the picture. The problems don't come up clearly in the grades. We need to consider what makes up the grades, the effort put forth to obtain them and the cost and sacrifices students like me are making. I need you to step out of the mindset of the cases you've done in the past and look at this case individually, and hopefully come to a conclusion that kids with disabilities can be smart, but can still need help.

I ask you to please pay attention the new regulations of IDEA. I like to think laws change for a reason and hopefully that reason is to help people for the better. Secretary Spellings incorporated Tourette Syndrome under IDEA for a *reason*. The new regulations that specifically talk about the functional and developmental well being of the student were incorporated for a *reason*. The new IDEA regulations also clarify that students who are not failing and passing from grade to grade should not be excluded from eligibility. This clarification happened for a *reason*. Students like myself, who are intelligent, but were being impacted by their disability were not getting the support they needed because of this intelligence. That is discrimination. This is what Section 504 and IDEA are all about preventing. These laws are meant to help students who's disabilities are impacting their education, not push them away. We shouldn't be punishing students who need help for doing well. We shouldn't be waiting until the students get to a point where they are fail-

ing and suffering, until we give them help. These laws are to help the students get through their education and help to identify them *before* they get to that point. We can stop that misconception today, because its not true. I *need* help from the district and I need help from *you*.

I am asking is to be protected as student with disability under IDEA or Section 504, so that I will be protected under the law and so that can help prepare for further education and independent living. The school recently offered some of the accommodations, I understand that. But these accommodations without the protections from the law are neither required by this district nor will colleges be required to accommodate me in the future.

I am asking for reimbursement of out of pocket expenses.

- Independent Evaluations and Consultations with Dr. Kay
- Costs for outside council
- Costs for other outside evaluations
- Costs for material(s) provided to the district and for hearing.

I am asking for a 504 Plan or IEP that have the following provisions:

- An assistive technology evaluation to find computer based programs that could improve my fluency and accuracy in completing written work an cut down the time I spend on homework
- Reduced assignments when possible since I have difficulty completing expected work for classes within a reasonable timeframe
- extended time on tests and quizzes along with a quiet distraction-free testing area
- extended time on big projects or longer assignments
- avoidance of the use of op-scan or scantron answer sheets, allow me to take tests on a computer or mark my answers directly on the test booklet
- provide teacher prep notes and study guides prior to class lectures

All of these accommodations are appropriate for the given disability.

I recognize that this case goes into a very gray area. I recognize that this decision will not be an easy one. The terms, *in need of specially designed instruction* and *adversely impacting educational performance* are very vague and are all subjective. But when these areas are unclear I ask you to please think about what congress and the writers of this law intended it for. Ask yourself why these laws were written and what is the *purpose* of the law.

To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

This is what I need you to think about when you are making your decision. Thank you.