

Manheim Township School District

1/25/07

Lancaster, PA 17601

Re: Joshua Koch

To Whom It May Concern:

Pursuant to the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, this is a request for a special education due process hearing in order to secure my son, Joshua Koch with an Individual Education Plan under IDEA or a 504 Service Plan under section 504 of the rehabilitation act.

To better understand the history leading to this request, please allow me to describe my son's past school experience and present school situation.

Josh has a wonderful smile and an easy-going attitude. As a little boy Josh was so eager to please, he always seemed to be way beyond his years in maturity. We used to call him our little old man because he was always so sensible.

I knew Josh had Tourette Syndrome by the time he was 4, I kept hoping I was wrong since my older brother has TS and I saw the struggles he had at school and continues to have in his life. My mother didn't know what was wrong with her child when he was in school. Teachers and administrators told her to accept the fact that Lowell was slow, had emotional and psychological problems, and would probably never be college material. My mother was the administrative director of a 120 bed mental health center at a hospital near my home in NY. I remember years of battles with teachers, principals, and the school district. Lowell is now an accomplished photographer and filmmaker. He made a documentary on TS that has aired on PBS and was nominated for an Emmy Award. He has written a book and is currently working on his second. Lowell holds a master's degree and teaches photography at a college in NY. I never thought I would be faced with the same challenges my mother faced over thirty years later.

"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.” **Tourette Syndrome Association**

We enrolled Josh in the Spanish Immersion program at the Manheim Township School District. The Immersion Program is a program in which one class of twenty-five students spends the day learning their curriculum in Spanish. It was only the second year of the program’s existence but we felt it was an opportunity too good to pass by and we were thrilled to have him speak a second language at such a young age. Josh did well in the program although there were a few bumps along the way. Josh had some trouble learning to read in English, but we weren’t too concerned since he was learning all of his subjects in Spanish. Josh successfully learned to read in English by the time he was in third grade.

Schoolwork has always taken Josh longer than his peers, it took me a while to realize this since he is my first child and I had nothing to compare to. It became clear quickly that Josh’s mind works differently. Some teachers along the way have noticed this, some may chalk it up to a lack of organization and they’d be right, except that Josh’s disorganization is in his brain. Josh doesn’t process information like other kids. This processing is what makes things take longer for Josh.

In third grade, Josh’s handwriting problems were becoming clear. At the time, I didn’t know what dysgraphia was, but I have since learned that dysgraphia is a learning disability that affects writing abilities. It can manifest itself as difficulties with spelling, poor handwriting and trouble putting thoughts on paper. Mr. Rosario worked with Josh to try and improve his writing, but was unsuccessful.

It was about this time that Josh told me he had been having disturbing thoughts, thoughts that he couldn’t keep out of his head. Recurring thoughts that were interrupting his schoolwork and his playtime. I took Josh to a psychologist who ran a battery of tests on him and then sat me down and told me that she felt Josh was psychotic. Of course you can imagine the panic that I felt at that meeting! The psychologist referred me to a child psychiatrist who she felt was more able to make a final diagnosis. That was when I took Josh to see Dr. Mary Davis. Dr. Davis assured me

that Josh was not at all psychotic, just a child with Obsessive Compulsive Disorder. It was now third grade and Josh began meds for his OCD.

*“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.” **Tourette Syndrome Association***

In fourth grade when Josh was diagnosed with TS, I chose not to tell his teachers and the school district. I didn't want Josh to be labeled. I didn't want Josh to feel labeled and I didn't want Josh to grow up viewing himself as disabled. Josh knew he had to work harder than the other kids to get the same grades, he always has. Now Josh feels he is being punished for having that attitude.

Josh completed the Spanish Immersion program in fifth grade and went on to the Neff 6th grade building where life became more of a challenge. Changing classes, lockers, binders, all of this was new to Josh and a bit overwhelming. Josh spent hours each night on homework, his binder looked like a war zone, and his locker looked like something had exploded inside of it. Josh was having a hard time keeping up with his assignments and projects, but we as parents didn't realize what was happening with Josh. We just thought he was a disorganized pre-teen. On parents night I remember a conversation with Josh's science teacher, Mr. Rohrback. He told me what a pleasure Josh was to have in class (as all of his teachers did) but then he said:

“You know, Josh is an interesting character. When I'm telling the kids how to get from point A to point B; instead of going there in a straight line, Josh takes the scenic route. He gets there, eventually, but it takes him much longer than the other kids.”

I knew Josh's mind worked differently so that didn't surprise me. I shared with Mr. Rohrback that Josh had TS and OCD and that this would contribute to that “roundabout” sort of thinking.

At this point I still didn't realize just how much extra time Josh was spending on schoolwork as compared to his peers. I thought the curriculum was just getting tougher now that he was in middle school and that all kids were putting in this kind of time. Sixth grade was the first time Josh received a C on his report card. He was very upset and vowed to work harder for the As and Bs he knew he could achieve.

Seventh grade was a wonderful year for Josh. We enrolled Josh in the Landis Valley Project. LVP was a non-traditional year offered by the MTSD to have the students learn the same curriculum as other 7th graders, but it was taught (approximately 50% of the time) at the Landis Valley Museum campus. When traditional 7th graders were learning about flax and how it was used throughout Europe, Josh and the other LVP kids were out in the field *harvesting* flax. It was very hands on. Most of the learning was done on an auditory basis, it makes perfect sense now to look back and see why Josh thrived this year; there weren't many written assignments and there wasn't a lot of reading to do. Josh received straight As on his report card for the first and only time in his educational career. He was in his glory.

Having found such success in LVP, we enrolled Josh in the EEP program for 8th grade. EEP was the Environmental Ecology Project. It had the same curriculum as regular eighth grade, just with an emphasis on ecology and the environment. There was not nearly the amount of time spent out of the classroom as there was in LVP and there was a demanding reading program of 25 books to be read during the school year. Josh fell behind on his reading, and for the first time I was called into school by his teachers. They assured me that he'd be fine, but there was a red flag here and they wanted me to know about it. Josh's teachers said that Josh was simply unprepared, and disorganized. I shared with them the facts of Josh's TS and OCD, they were surprised to learn this about Josh. This was the only time that Josh received a D on his report card.

In high school, Josh began 9th grade with enthusiasm and a love of learning. His grades were somewhat erratic. Homework and class work grades were good and then there was a drop when it came to tests and quizzes. A dramatic drop. Josh seemed to understand the material as reflected by his grades on homework, but when it came to tests and quizzes, the grades did not reflect this at all. Josh was spending more and more time doing homework and studying and less and less time with friends and family.

By the middle of tenth grade, Josh was seriously struggling. His grades were now Bs and Cs and Josh was getting more and more discouraged. Josh had been receiving an excessive number of Fs on reading checks in Mrs. Peffley's English class. These were comprehension issues, but Mrs. Peffley stated that she believed Josh to be "ill prepared for class." In Mr. Shelley's Geometry class, Josh rarely finished his tests.

I was getting concerned for Josh's well being. Looking ahead to his junior year of high school and knowing that Josh was having trouble with testing, we were worried how Josh would perform on his SATs. At the end of tenth grade, I e-mailed Joyce Shopp, director of Pupil Services and asked her how to go about getting Josh extended time on his SATs. Ms. Shopp advised me to speak with Mr. Linden Bates, a guidance counselor at the high school. I informed Mr. Bates that Josh had TS and OCD, his advice was to seek a 504 service plan for Josh and he seemed confident that we could get him one. I didn't know what a 504 service plan was. I didn't know what an IEP was. I don't recall ever receiving any information from the district describing such programs.

I asked the district to consider Josh for a 504 service plan. At that point the only accommodations we were asking for were extended time on tests and quizzes and a quiet place to take tests where Josh would not have to be embarrassed by his tics or vocalizations (which are usually more pronounced during stressful situations such as this). I assumed that since the district was now aware of Josh's TS and OCD, there would be some sort of evaluation to see if there were any other co-morbid disabilities and other learning disabilities as often appear in children with TS.

On June 8, 2006 Josh and I attended a meeting with the 504 team. I thought that this meeting would be to discuss such testing for Josh. I was wrong. I presented the team with a letter from Dr. Steven Gottlieb, Josh's neurologist, stating Josh's need for extended time on tests and telling how the OCD and TS had negatively impacted Josh's schoolwork and life. We also gave the district a letter from the Tourette Syndrome Association stating that students with TS require testing accommodations in order to demonstrate their appropriate abilities. Without such accommodations, students are not able to read at a speed that is necessary to complete their tests in the time allowed. The copy of this letter in Josh's school file has a note on it saying: "This letter is not about Josh, it is about a "student with Tourette Syndrome." " The note is signed by Ms. Shopp.

Josh was flatly denied a 504 plan. No testing was done. We were told that Josh's grades were too good. Since the district said he was succeeding in school, his TS and OCD must not be having a significant impact on his learning. When told how Josh stays up past midnight each and every night to finish homework and study, the committee sited Josh's schedule as being very demanding and would be taxing on any student. They also shared that any student would benefit from extra time.

Not only did the district fail to provide an appropriate evaluation to assess the need of a 504 plan when they were informed of his diagnosed disabilities, they took no action to further investigate the possibility of co-morbid conditions. This was a clear violation on the districts part to find and assess Josh in all areas related to his disability in accordance with IDEA.

The district says they believe Josh is succeeding. What they don't see is what's left of him when he gets home. That's what I see. They don't see the pain and anguish, frustration and exhaustion, that's what I see. I shudder to think where we might be today if Josh were not such an outstanding young man. Would Josh have found unacceptable ways to escape his pain? If Josh had been receiving an appropriate education he would not be feeling as depressed as he is today. The district continues to overlook Josh's functional and developmental well being as stated in the new regulations of IDEA; not only neglecting to provide an appropriate education but damaging Josh's physical and emotional health as well.

I then wrote to Ms. Shopp and asked if there was any way to resolve this situation without going to a lengthy appeals process. She responded that she agreed with the team, Josh was not entitled to a 504 service plan because his disabilities of TS and OCD do not substantially limit his learning.

At this point I requested that Josh have a psychoeducational evaluation by the school psychologist. I specifically asked for Josh to be observed and tested for fine motor impairment, auditory processing problems and a lengthy handwriting test.

In a letter dated June 20, 2006 from Ms. Shopp said, "I am somewhat confused as to how such tests relate to Josh's possible classification under OHI or other IDEA-defined areas of disability. You can help us a great deal by reviewing the enclosed section of IDEA regulations and marking with a highlighter, area(s) of disability that you suspect that Josh "has." This will help us plan and

propose an evaluation.” I was under the impression that it was the school’s responsibility to determine which tests are appropriate for a child’s given disabilities. I guess that was too much to assume. All of the tests I had asked for directly relate to TS and OCD under OHI.

I went to Ms. Shopp to meet one-on-one and further explain the difficulties that Josh was having and how his TS and OCD impact his learning. She reassured me that both she and her staff were well trained in the areas of TS and OCD and their impacts on students. She told me that her hands were tied, and she simply could not provide him with accommodations under a section 504 since he did not qualify. She also said that we all would like to have straight A students, but that sometimes that just wasn’t going to be. My goal is not to have a straight A student. My goal here is to have my son get the services to which he is entitled under section 504 and IDEA.

On July 26, 2006, I received a letter From Ms. Shopp saying that she inferred from our discussion that we were no longer desirous of an evaluation to determine if Josh is a child with a disability as defined by the IDEA and if she was incorrect and we were still requesting such an evaluation, she was again asking me to indicate which area of the IDEA defined areas of disability I suspected in regard to Josh. She went on to say if she did not hear from me, she would conclude that I was no longer requesting the evaluation. I never said, nor signed off that I did not want Josh evaluated, but I never responded to that letter. I have exhaustively researched IDEA and see no provision whereby the school district can give an ultimatum to re-request an evaluation once it has already been requested. At this point I was fed up with the “experts” asking for my help to identify my son with a disability under IDEA, wasn’t that their job? Aren’t they the ones trained in this field?

On August 22, 2006, Josh filed a complaint with the Pennsylvania Department of Education (PDE). In our conversations over the phone with PDE they were outraged and said that the district couldn’t deny Josh a 504 based on his grades. On PDE’s report submitted September 28, 2006 by Dr. Malcolm Conner, it was concluded that no corrective action was required. Dr. Connor also notes: This Advisor lacks jurisdiction to determine the appropriateness of the student’s educational program and the appropriateness of the 504 evaluation.

We decided to have Josh evaluated by Dr. Margaret Kay, a nationally certified neuropsychologist at the recommendation of the Tourette Syndrome Association. Dr. Kay’s Independent Education Evaluation took place in October of 2006 and concluded that Josh displayed learning disabilities in both written expression and reading fluency. Now events from elementary school on made

sense. The handwriting issues in third grade, the ease of seventh grade, the frustrations of failed timed tests and poor grades on writing assignments.

Dr. Kay's report also notes that "Josh needs to concentrate so hard when he is writing and taking notes, that he has problems listening to what is being said. Josh has difficulties breaking down the ultimate goal into its sectional objectives. At times he is unable to separate the outcome of a project into its pieces in order to arrive at a finished product. He struggles to coordinate the segments that he has completed to put it all together at the end." These things are evident in Josh's written work.

"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." **Tourette Syndrome Association**

"In the area of reading, Josh is effectively caught in a double bind in timed conditions requiring comprehension. When he speeds up, his reading comprehension declines; but when he takes his time to insure comprehension he is unable to complete the work within a reasonable timeframe. Josh does not have difficulty with the phonetic decoding of words or with word recognition. His reading fluency difficulties are the result of slow processing speed and obsessive-compulsive tendencies which are part of the Tourette, therefore, he requires extended time to read and reread information in order to grasp important content, make predictions and inferences and comprehend concepts." *Dr. Margaret Kay*

Dr. Kay's report was sent to the MTSD for review along with her recommendations for an IEP and an assistive technology evaluation. The district responded to me by saying that they would now like to evaluate Josh (of course I had already requested testing of Josh by the district month's before). I again gave my written permission for the district to test Josh and he was evaluated by Ms. Ravert, the district's school psychologist. Josh was never, however, given an assistive technology evaluation.

On November 25, 2006 I requested (for the second time) that the district conduct a lengthy handwriting assessment on Josh by an Occupational Therapist to determine the extent to which his dysgraphia is impacting Josh's educational performance and what adaptations needed to be implemented in the classroom setting to assist Josh with this handicap. I was told that the district did not believe that such an evaluation was necessary to conduct an appropriate evaluation for Josh. I asked how the district was planning to assess Josh's dysgraphia issues without such an evaluation? Ms. Ravert's response was that dysgraphia is not among the areas of disability that IDEA recognizes.

I then sent Ms. Ravert a long, detailed e-mail containing information about dysgraphia from the National Center for Learning Disabilities and the National Institute of Neurological Disorders and I again requested the evaluation. I received no response.

At the Multi-Disciplinary Team meeting on December 21, 2006 we had Gretchen Torres, a representative from the Tourette Syndrome Association and Mary Donecker, Josh's AP Psychology teacher, present as advocates for Josh. Ms. Torres noted that the accommodations which we were requesting were common among students with TS since they have processing problems and often need more time on tests, quizzes, and assignments. She suggested that perhaps Josh could have a reduction in homework in some classes. A reduction in homework would allow Josh to learn the concepts being taught in class and relieve some of his exhaustive studying. Ms. Shopp and Ms. Ravert responded that when assignments are reduced and extended time is given, students can fall behind and actually be harmed by such a practice. Ms. Torres disagreed.

Ms. Donecker read a statement before the group stating "Each day I see Josh I can see the toll this year is taking on him. Numerous times I have commented to Josh about how tired he seems. How long can a young person such as Josh continue to push himself through a system that will not give him a safety net?"

The district kept reiterating that Josh is taking very demanding classes and is succeeding. So even though they realize that Josh has to work this hard and that his TS and OCD do make the tasks of homework and studies more of a challenge for Josh, he is still doing better than average. I specifically asked about his math scores, since he tests so much lower on them than he does on

his homework and class work. Ms. Shopp told us that then Josh is like 90% of all the other high school students and assured us that his grades are fine. In his Trigonometry class Josh has scored either a D or an F on 7 out of 15 quizzes and tests. In my view, grades of D and F on half the year's tests and quizzes is anything but "fine." Most of these tests are timed, some are one-six minute quizzes. The reason Josh's overall grade is at a C or B level is because he excels in the homework and class work as he does in most of his other classes.

When the final evaluation Report came in the mail on January 7, 2007 we received the district's conclusion. It had been 84 school days since we initially requested that the district test Josh, 24 days past the deadline for such testing to occur. By exceeding the mandatory timeline for an initial evaluation the school district failed once again to provide Josh with an appropriate education. Their report found no learning disabilities and they do not find Josh to be a child with a disability under OHI.

The district did however consent that they recognize Josh's diagnosis of TS and OCD and said that if Josh were required to take high-stakes tests of 2 hours or more in duration, that the effects of Josh's TS and OCD would interfere with his ability to demonstrate his skill level. With this said, I immediately contacted Ms. Shopp to make arrangements for Josh to have extended time on his midterms later that week. Josh informed me that it was the first time he has ever completed a math midterm or final. He scored an 83%, six points higher than the class average.

I can't help wondering, if the district is willing to grant Josh these accommodations on some tests, why not others? And why not with the protection of a 504 or an IEP?

Josh is wonderfully good-natured. He is cooperative and willing to help out whenever asked. Josh rarely has a bad day and when he does, it's usually out of frustration from something that has happened at school like not being able to complete or go over a test the way he would like to. He finds it incredibly frustrating to have the school district tell him he's doing "well enough." Josh only wants what he feels is his right to have. Josh is extremely committed to his studies. He is willing to work far beyond what his peers have to do in order to finish his assigned work. Josh has been doing this for years and without a complaint. This is the first time he has asked for help. The stress of trying to keep up is taking its toll on Josh. Josh has gone from being happy-go-lucky to being sullen. He has no social life. He comes home from school, delivers newspapers (a job he's had since he was twelve) and goes directly to his desk.

His dedication, hard work and commitment to his schoolwork the district calls “commendable.” Josh’s work is beyond commendable; his attitude is nothing short of amazing. I don’t think I could do what he does day after day. When the rest of the family has come home from school, finished homework and had dinner, we relax together; reading, playing board games, watching TV. All without Josh. Josh is not absent sometimes, Josh is *never* there. Josh is in his room, at his desk. Always. Josh does homework or studies until past my going to bed, every night. Josh rarely goes out with his friends. Josh has no life other than school and studies.

I have seen Josh go from a happy teenager to being a depressed boy reaching out for help. Josh is succeeding in his classes due to his dedication and drive. Late nights of studies are taking their toll, Josh is exhausted. He fights falling asleep during his classes.

Josh has made several trips to the nurse’s office this year to have a “safe” place to release his tics when they are especially bad. He naturally finds it embarrassing to be ticking during class. I should also mention that Josh has not missed a single day of school in his high school career. Josh will not let me take him out of school early for a doctor appointment since that would endanger his perfect attendance. Josh goes to school when he’s frustrated, exhausted and feels lousy. Very commendable.

Had Josh’s commitment and drive not been so intense, he’d most likely have gotten accommodations long ago. If Josh was to spend the amount of time that the “average” student his age spends on schoolwork, his grades would plummet and maybe then he’d be viewed as someone with a disability who was in need of special services.

On January 19, 2007, Josh’s seventeenth birthday, we received a letter in the mail from College Boards granting Josh 50% extended time on all College Boards exams. SATs, PSATs, AP exams, and even the subject tests which are only one hour in duration. If the professionals at College Boards can see Josh’s need for these accommodations, why can’t the Manheim Township School District?

In January of 2007, we took Josh to see Dr. Michael Labellarte, a psychiatrist who specializes in the areas of TS and OCD. Dr. Labellarte diagnosed Josh with major depression and anxiety as well as compulsive behaviors. Dr. Labellarte goes on to say: “TS and OCD commonly co-exist,

and persons with TS and OCD are vulnerable to depression related to demoralization and overwhelmed coping strategies. Josh has been demoralized and more emotional over the past 8 months, including symptoms of physiological anxiety, e.g. tearfulness, irritability, shallow breathing, sweatiness and stomach upset. He is often ambivalent has increased sleep, low mood, decreased enjoyment capacity, decreased motivation, and decreased concentration.”

We submitted Dr. Labellarte’s statement to Ms. Shopp at our resolution meeting and asked for Josh to be considered once again for a 504 based on this new information. Within a week we received a letter from the 504 team (which consisted of Ms. Ravert and Ms. Shopp) stating that they do not believe Josh is entitled to a 504 service plan.

We propose the following resolution:

- Josh be considered for either a 504 Service Plan or an IEP
- An assistive technology evaluation to find computer based programs that could improve his fluency and accuracy in completing written work and cut down on the time he spends on homework.
- Reduced assignments when possible since Josh has difficulty completing expected work for college prep. classes within a reasonable timeframe.
- Extended time on tests and quizzes
- Extended time on big projects or larger assignments
- Avoid the use of op-scan or scantron answer sheets and allow Josh to either take tests on a computer or mark his answers directly into testing booklets.
- Provide teacher prep notes and study guides prior to class lectures
- Reimbursement of out-of-pocket expenses including independent evaluations, consultations and attorney fees.

We believe that the Manheim Township School District has violated Josh’s civil rights, failed to provide him with a free and appropriate public education, and are out of compliance with section 504 and IDEA. This is why we are filing a due process complaint.

Respectfully submitted,

Lillian H. Koch