

Testimony for Senate Bill 44

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“Cannot write the letter, but he can write the letter if sound is given. Cannot identify the name of the letter. Cannot identify the sound if the chosen sound is in the middle of the word. Connects the pictures/sounds to the letter rather than learning the sounds that go to the identified letter. Difficulty keeping up with work. Low self-esteem. Letter recognition is lower than peers. Has learned some things and attempting to close the gap. Phonemic awareness is low.”

The above passage is from my son’s first Student Improvement Action Plan in November of his first year of school 2005.

Paul was high energy most of the time but he often would sit and play for a couple hours, by himself, while I made dinner, cleaned, or did other chores around the house. My grandmother would always say how lucky I was that Paul could entertain himself. I remember many times driving while Paul in the back seat playing away. He could play with anything; his figures, cars, the window scraper, and even a foam cup holder. He was imaginative and energetic often singing, play fighting with his toys, and giving these objects voices.

Paul’s energy level was not appreciated in school and the questions began during that first meeting. “Is he on medication?” According to his teacher Paul was disruptive, unfocused, and needed constant reminding to stay on task. I asked about dyslexia and noted how he wrote, turned letters and the number 3 and was told a lot of kids do this at first.

First grade came and Paul’s Student Improvement Action Plan stated, “Continues to be below level in Reading and Spelling” as a concern and under Changes to Intervention Plan; “Consider physician appointment”. Here, clearly, were issues with reading and spelling early on and the educational team’s answer was to see a doctor. I again asked about dyslexia and the likelihood this was the issue with no direct response. That spring the school gave Paul the DSM-IV Diagnostic Criteria for AD/HD, the Conner’s Rating Scales, and the Wechsler Intelligence Scale for Children.

I spoke with Paul’s pediatrician and she said there was no way he had AD/HD and suggested I have his eyes checked. We did the April of 2007. The optometrist, who specialized in vision related learning issues, found that Paul did have some tracking issues at age 7. That summer Paul attended eye therapy (\$1200). I drove Paul 20 miles three times a week to therapy and we worked nightly with colored lenses or covering one eye then the other. Paul ended up wearing glasses for about a year whenever he read at home or in school.

In second grade Paul’s teacher reported no problems what-so-ever with Paul in her class. I found this odd that his first two teachers had such concerns with his behavior and now she had no issues. I asked, about this difference and suggested again that maybe there was a learning disability. But the focus on ADD and how medication has helped other students was the response.

I went ahead and had Paul tested for ADD (\$800) even though his pediatrician felt strongly that he was not. The therapist felt Paul did have hyperactive tendencies. Much like the difference in teachers I felt the same about his "diagnosis". His 1st grade teacher "couldn't handle him" but his 2nd grade teacher, "had no issues with him and found him to be a pleasure to have in class". I took this label with a grain of salt, however his school embraced the label telling me about how other students call their (ADD) pills their "magic pill" or their "happy pill". It was then that I started to wonder, was I doing my son a disservice by not putting him on medication for ADHD? I was torn. Was this the answer? I wanted my son enjoy school and schoolwork before he began to hate it.

I really began to notice Paul's reading and writing issues in 3rd grade. He was behind the other kids. His handwriting was terrible and he spelled phonetically. So I purchased a reading program to work on at home (\$30) as well as handwriting guides he could wear to help the position of the pencil in his grip.

In the middle of 3rd grade we moved to a nearby town and a new school. This was a larger school. His IEP followed and I hoped that at a larger school with more resources, tutors, etc. I would find the help and advice needed to give Paul the training he needed. Unfortunately that was not the case. Just like the smaller school/town while I was asking, "Could he be dyslexic?" They refused to even speak the word instead focusing on his inability to focus and stay on task. Of course this was better or worse depending on the person.

This went on through 4th grade. I was working with him at home with handwriting, spelling, and reading books. His reading was slow and frustrated but we kept it up nightly. Paul would spend the week studying and memorizing spelling words to get him through each spelling test. At first he was doing well with short lists. As these lists grew he would miss more and more. Paul would bring his spelling tests home and I would try not to show my disappointment. He worked so hard all week often spelling the words out loud perfectly but when it came test time he would miss them. His anxiety was growing; he was getting headaches and often acted ill so he didn't have to go to school on test day.

By fifth grade Paul was being pulled from class four times a week for additional reading and spelling remediation. He was reevaluated for eligibility and moved from Special Education to Specific Learning Disability but no one could tell me what that learning disability was. Homework would involve making him read his homework, ever so slow and choppy, and then write, equally slow and messy, the answers. Often I would become frustrated thinking he wasn't trying or doing his best, and he would end up crying. I would also cry after he was in bed. I would lie in bed and think "What can I do to help my son?" His IEP did not change in the least. It was just more reading classes, smaller groups, fewer test questions and repetition, repetition, repetition.

School was not fun anymore for Paul. He hated it. Nightly homework was a struggle. We often spent two hours a night with Paul ending up in tears before it was completed. His anxiety about school, disappointing me, and his feeling that he was stupid was increasing. Homework just was about trying to keep his grades up, he was not learning anything.

I began thinking about medication again and decided to take Paul to a therapist to talk about school and his frustrations as well as the option of medication (\$125). The therapist had had experience with dyslexic

students and advised me to pursue a special learning difference program before we tried medication. I began looking into these programs.

Though this search I found Dr. Barbara Berg in Topeka. I decided to have Paul tested, yet again, in February of 2010 to establish what learning difference he had, be it dyslexia or something else. This was the spring of 5th grade. Thankfully I had kept all copies of Paul's prior testing and Dr. Berg felt that she could review this and not have to retest most tests thus saving me a great expense. This appointment only ran me an additional \$400.

Dr. Berg met with Paul and diagnosed him dyslexic.

Paul and I left Dr. Berg's office with an answer, validation, a direction. I cried when I spoke the words to my mother who had come with us, "I was right, I knew there was something more." Paul also had an answer, he wasn't stupid, he had a neurological disorder that caused his brain to process and interpret information differently. As he learned more about it he had an answer to his peers when they ask him why he couldn't read well.

After I received Dr. Berg's official report I went back to the school and called another IEP meeting with a doctor's diagnosis that Paul had a learning difference and it indeed had a name. I was eager to find out how his school experience would change and improve. To my disappointment I was presented with the same remediation that he had been receiving prior. Nothing would change. It was more repetition, repetition, repetition, and nothing specifically focusing on how Paul learns differently. No one was skilled in the remediation Paul required. On the up side they stopped talking about ADHD and medications. Also Dyslexia was mentioned on Paul's IEP review;

"If KAMM or Alternative is selected, explain why the general assessment is not appropriate: Paul has been diagnosed with dyslexia and he needs a longer processing time than other students."

They still didn't get it and had no advice when I asked about tutors that could work with Paul after school. I decided to find a tutor skilled in working with reading disabilities. None were to be found in my area trained in any of the recommended programs. I knew that if Paul was to be successful I would have to try and tutor him myself.

I found a class in Wichita at Fundamental Learning Center that instructs teachers and parents in a multi-sensory reading and spelling program. I took a weeks' vacation and spent the week driving back and forth to Wichita for this class at my own expense. (\$700+90 miles each way) This was in July of 2011. I started tutoring Paul the beginning of September after school started. At my request I scheduled an IEP meeting at the beginning of 6th grade instead of the end. I asked, again, if any teachers – anyone – was trained in a specialized program for dyslexia and was told no. Paul would have no para, no proper remediation, just the modified and extended reading and math classes.

In these modified classes Paul found out that it was difficult to get additional help in this class as there were quite a few behavioral issues with other students. Often the teacher was busy dealing with a behavior problem or Paul was seated next to a disruptive student and he couldn't get his work done.

First semester was a struggle to inform his teachers that he was dyslexic. I had to contact them individually because his IEP was not sent out until the end of September, almost a full 6 weeks after school started. The reaction I got from his teachers was, "I knew there was something. Thank you for letting me know." Paul has had to become his own advocate. He found that often substitutes did not know about his learning difference and would count off for spelling and handwriting.

Sixth grade work came with additional challenges. The work was different, Paul had multiple teachers now so I was constantly emailing them and checking on work. Reminding them what works and doesn't work. I filled out many a word search on vocabulary with Paul and would tell the teachers repeatedly that searching for words upside-down and backwards does not help Paul learn new vocabulary. Oh yes, they would say he doesn't have to do that then. Then we would get another one. Paul then looked to his classmates to help him find the words.

Paul has had various reactions from teachers. He could tell by the way they addressed him during conferences or during class that either they understood his needs or they didn't. Most did not know how to teach him and still suggested that he be timed on his multiplication facts or meet the timed expectations for cold reading of passages. He often worked with a peer on these skills rather than a teacher.

As 6th grade continued I found it harder and harder to tutor Paul an hour each night when he also had over an hour of homework. While Paul was great about working with me on the program we often butted heads during homework due to his frustrations. I still expected him to read and write all of his answers with spelling help. It wasn't until I saw a Susan Barton video explaining tips on getting through the homework. Her suggestion: Read the questions to your child and scribe his answers. After I started using this suggestion the homework dread was lifted. Now I tell all his teachers that they will see my handwriting on his homework as I act as his scribe.

Paul's 6th grade spring IEP included accommodations such as the Write Outloud computer program. Then it turned into Co-Writer. Neither of these programs worked as described. After waiting months to get the program loaded onto a computer Paul could use he and I came in after school to learn the program. It was not the appropriate program for his needs. I suggested other programs and they never were downloaded for use.

I started learning more about technology aids for dyslexics and registered Paul with Learning Ally (formally Recordings for the Blind and Dyslexic) for downloading books, including textbooks. This is an annually fee of \$99. Paul uses this on his Ipad in class for reading class. We also have downloaded the textbooks available. I purchased an Ipad (\$550) for the assistive apps such as Dragon Naturally Speaking for dictation. I shared this program with the school and was assured it would be downloaded for use. They did, however, as of this date (February 1, 2013) Paul has not been shown this program at school. We have used it at home but he has not been shown how to utilize this in class.

The following is from my son's 7th grade Individualized Education Plan, September of 2012. On the 2nd to last page under;

"If KAMM or Alternate is selected, explain why the general assessment is not appropriate: Paul has been diagnosed with dyslexia and he requires more time to read and process information.

Reading

The team has determined that there are no concerns at this time.

Assistive Technology

The team has determined that there are no concerns at this time.

Written Language

Paul does not necessarily like to write because of the difficulty with organizing his thoughts and being unsure of how to spell commonly used words. He uses correct capital letters and end punctuation most of the time and can generally pick out words that should be capitalized. Spelling is difficult for Paul and sometimes gets in the way of what he wants to say. He often leaves out words which make his writing hard to understand."

Though it all, my son, Paul has remained a sensitive, imaginative, happy, and polite young man. He owns his dyslexia now and speaks openly about it with classmates and teachers. Just the last week in January he had to educate two of his adult classroom assistants who were not aware he was dyslexic. He has included it in an art project using colorful words to describe him. I credit some of this to the movie "The Big Picture: Rethinking Dyslexia" which has recently been released. He has shown this movie to friends and family opening the dialog about why he has trouble reading and spelling.

I recently began tutoring Paul again at home attempting to finish what we started in 6th grade. His modified math class and regular reading class is not developing the skills he will need in his future education. While he uses an expanding his vocabulary when I scribe for him he still dumbs down his answers when he has to write.

I like you to consider if those who needed glasses to read were not given any during school. They were not allowed to sit at the front of the class nor given a larger font to read. They couldn't see the lines on the paper when writing their answers making their handwriting difficult to read. Yet they were expected to keep up just by verbal information. They had to remind their teachers and helpers that they couldn't see well and often were counted off for their poor penmanship. Would this be addressed? Much like glasses Paul is in need of the tools to read and express him. He needs to be taught how to break the reading code. He just needs the educational system to give him an equal playing field to learn.

I urge you to recognize the need for children to be screened for dyslexia early. I urge you to require that our educational system train their teachers in the appropriate educational methods to teach dyslexics how to read. I urge you to pass Senate Bill 44.

Thank you,

Brenda and Paul Gunder

