

October 20, 2017

Chairwoman Sen. Chang-Diaz  
Chairwoman Rep. Peisch  
24 Beacon Street  
Room 111  
Boston, MA 01233

I couldn't attend this hearing  
due to a sick kid - I hope  
that this legislation passes  
soon - so many kids like  
mine need it...

TESTIMONY IN SUPPORT OF DYSLEXIA LEGISLATION:  
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BILL NUMBERS: H.330, H.2872, S.313, and S.294

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To: Chairwoman, Senator Sonia Chang-Diaz, Chairwoman, Representative Alice Hanlon Peisch  
and the Members of the Joint Committee on Education

Dear Joint Committee on Education:

Please consider my testimony in support of acceptance of the scientific definition of dyslexia in line with the neuroscience and research in all Massachusetts schools, and the critical early screening for all students at age 5 based on the key indicators that are shown by NIH research to identify students at risk for dyslexia. The current "wait to fail" approach has failed our students, our teachers, and our economy. Please act now a definition should go into effect immediately to inform teachers, parents, and districts. Screening could start as soon as the 2017 – 2018 school year if the Legislature takes action. According to Dr. Nadine Gaab, one of the cheapest and easiest screenings is to ask parents if it's in the family – there is a 50 percent chance that if a parent has it, a child will be born with dyslexia. There are many simple tests that can be conducted in a minutes that would identify a child that will have trouble reading. If we don't act now, more children will fail and feel like failures.

My family's story begins with my son Owen (age 12) in the first grade in 2012. He enjoyed pre-school and kindergarten, but he began to hate school in the first grade. His teacher would frequently complain that he would fidget too often and couldn't sit still. His teacher was new to teaching and we had never been worried about him not being able to focus and sit still. He did have difficulty with homework and many tears were shed when I would help him with it at night. Halfway through the school year, we received a letter requesting we meet with his teach and the principle. During the meeting we were told that he was behind in reading and was receiving help with reading in a small group. The principle asked what topics Owen was interested in and suggested that if "we find the right book, it will just click". He said that with some kids it just took a bit longer and an interesting book would help get him reading. It was during this meeting that

my husband brought up the fact that he was dyslexic. We asked if that could be the problem. This was dismissed and we were told to “wait and see”. Less than a month later, we received a letter from the principal stating that Owen would be held back due to poor academics. And so our journey began...

Owen was seen by his pediatrician, who recommended he be seen by a neuropsychologist. The neuropsychologist that he recommended didn't have any openings until 9 months out. I found a neuropsychologist in Andover, who had an opening in March. It cost us \$800 out of pocket because insurance does not cover the Educational Evaluation portion of the bill. Furthermore, we began having him tutored at the Commonwealth Learning Center in a specialized reading program called Orton Gillingham, which costs us \$70/hour (2 times/week). After he was tested, it took 8 weeks to get the evaluation report, which concluded he had dyslexia and anxiety due to his reading disability (which is expressed by fidgeting). Even with this diagnosis, the school was still adamant that he would stay back, even though studies show this is inappropriate and potentially harmful to the child. Furthermore, the school system doesn't provide any information on how to get help for your child – there was no guidance on what our options were. We didn't even know what an IEP was or that we could have requested the school test him.

At the end of the school year, my son felt like a failure. He felt different and stupid. He was anxious and couldn't read the simplest books. I chaperoned a field trip with his class to the zoo shortly before school was out. All the kids would proudly read the signs out loud to me, except my Owen, who would lower his head and look at the ground (this still gets me weepy). Owen's self confidence was so low and his anxieties with reading so high that we had him see a therapist for about nine months (co-payment \$35/session).

The school system we were in was not very forthcoming with information. Furthermore, anytime we said the word dyslexia in a Team meeting, our Team leader would jump on it – stating that we could not say that word. No matter how many times I pointed out that I paid quite a bit of money to say it, she would point out that because the school can't diagnose dyslexia, we can't say the word. At meetings, it always felt like we had to fight to get even the littlest amount of help for Owen. Over the years, we continued to have him privately tutored because I was concerned that he wasn't getting enough support. The school did not offer any 1:1 support, which I felt he needed. They also didn't offer Orton Gillingham, which he seemed to do better with than the Wilson program, which was offered at school.

Owen has just completed the 6<sup>th</sup> grade, which was a significant struggle for him. Unfortunately, even with the diagnosis of dyslexia, he never received enough support in school and is still considerably behind in reading. I don't understand why there isn't proper definitions for Dyslexia in the Department of Education either – how could you properly treat something that isn't defined? This year I hired an advocate, which I should have done in the very beginning. Our school system never conducted the proper testing to determine if the intervention he was receiving worked! So now we wait for more testing to be done and results discussed sometime in the coming fall. I am so frustrated and sad – and just want my son to get the support he needs. Had he received the proper support when he was first diagnosed, he

wouldn't need as much support as he does now. Early intervention, when done properly, is proven to help children with dyslexia. MRI's of a dyslexic child's brain before reading intervention and proper reading support show a marked difference in where they light up. Brains can be rewired and reading can become easier. There is no cure for dyslexia, but proper intervention can work wonders. Of course this not only benefits the child immensely, but also benefits a schools budget. If a school uses more resources properly in the early years, when a child is learning to read, less will need to be spent throughout the child's later school years.

Our story has two more parts to it, which I could write about for another 3 to 4 pages. I have a daughter, Tess (age 10, going into 5<sup>th</sup> grade) and Nathan (age 9, going into 4<sup>th</sup> grade). Apparently I hit the lottery with dyslexia, as my daughter may have it and my son does have it. Nathan's neuropsychological evaluation cost us over \$1800 out of pocket. I hired an advocate because of my daughter. When my other two children were in kindergarten, I requested the school test them because of Owen's diagnosis and because of family history of dyslexia (I wish I knew how important family history was earlier). Both Tess and Nate were placed on IEP's due to "developmental delays" in areas of reading and decoding. This past fall, the school system re-tested Tess and found her to be ineligible for an IEP due to the fact that she had never been diagnosed with a specific learning disability and is reading better. I was beside myself and disagreed with the Team which concluded that her support should be discontinued. I rejected their results and arranged to have her tested by an outside neuropsychologist (which would have cost \$2025). I ended up hiring an advocate instead. Our advocate pointed out that the testing the school conducted on Tess was not comprehensive enough and had me formally request some specific tests that should show what areas of weakness she has in reading, thus showing she has a specific learning disability. Tess is a very bright girl, but she struggled with the MCAS reading homework throughout the year. When a child can't remember what she read to answer the multiple choice questions, there's a problem. Also, homework should not be filled with tears and self doubt.

Regarding Nathan, I had him tested outside because I worried the school wasn't doing enough for him. He was on an IEP and was receiving support but, I worried that he needed more support and wasn't sure how to ask or show that he needed it. Nathan's test results showed him to be a double deficit dyslexic, with ADHD and an additional learning disability involving speech and language. It was recommended that he be placed in a Language Based Classroom, with children that have similar needs. Nathan is smart, funny, and athletic. Nathan reads at a first grade level, but is in the 3<sup>rd</sup> grade. Had I not been able to afford the testing, we would not know how much more significant his learning disabilities are, as school testing was not comprehensive enough.

I could go on and more in depth with our family's experience with this school system and dyslexia, but I don't want to lose sight of the main points. I believe had there been even the simplest testing in place at kindergarten, my children would not be as far behind and harmed by a school that failed them. I think that by having this testing, schools will also bear more responsibility to their students. In forcing our schools to recognize Dyslexia, they will act more to provide the support that students need. According to the International Dyslexia Association, perhaps as many as 15–20% of the population as a whole—have some of the symptoms of

dyslexia, including slow or inaccurate reading, poor spelling, poor writing, or mixing up similar words. I'm surprised at how many people, including teachers, do not know what dyslexia is, when it is so prevalent in our population! How is it that in the state of Massachusetts does not even recognize Dyslexia? We are so proud of how great our education system yet, we allow so many of our students to fail. Many states surrounding MA have already passed bills like these including; CT, NH, ME, NY.

We should not leave so many students behind. It causes so much harm to these children, which reach beyond the classroom. It affects self-image and many students with dyslexia don't finish school. Just imagine how many people could be helped by a simple test in kindergarten, followed by early intervention. Also, think how much money could be saved when the appropriate support is offered in a student's early years. My oldest son will hopefully be receiving a more intensive reading program this fall – it cost money for the school to purchase the program and pay a properly certified instructor (he's been receiving support since 2<sup>nd</sup> grade – but not the appropriate help). The point here is that had he gotten what he needed, the school wouldn't have to fork over more dough to fix a problem they neglected. It's very frustrating as a parent to see your child struggle and not know how to help them. Another point is that I have some money to spend on testing and tutoring, but it has hurt us financially. We are lucky we could afford some of this, but there are so many kids that are just being held back and not getting the support they need.

On a positive note here – dyslexia might stink for a child right now in school, but many dyslexics eventually see their disability as a gift. Albert Einstein, Thomas Edison, Richard Branson, and Henry Winkler were all considered stupid and lazy while in school. However, they went on to do many great things because of their dyslexia. A dyslexic's brain is wired differently, which allows them to think in more creative ways. Dyslexia is one of the most studied learning disabilities, perhaps because it is so fascinating. The International Dyslexia Association has a wonderful website that provides loads of information and even a simple test to take to see if you are dyslexic!

Dyslexia shouldn't be a dirty word that we are not allowed to say in school. Please help us say dyslexia, define dyslexia, and test for it in kindergarten.

Respectfully,



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