

Members of the House Education Committee,

Thank you for the wonderful and informative discussion yesterday regarding the HB2602 Dyslexia bill. We were in attendance with our daughter, Jillian and felt that it was very important, as well as educational, for her to witness government in action. We have always taught her that she needs to be her own advocate, and yesterday was a great experience for her.

We are proponents of this bill. Our daughter, Jillian is dyslexic. Here is a bit about our struggle.

Since Jillian was born, we read to her every chance we got. We made a nightly ritual of reading to her, just like we did with our oldest daughter. When she became a toddler, we began identifying sight words within the stories (like we did with our oldest) and realized something wasn't right. Initially, we brushed it off as she was just not interested. We even had her screened at the Early Childhood Screening offered by the state, with no issues raised.

Once Jillian began school, however, our concerns grew. She struggled with phonetics, letters, and sight words. A sight word introduced in one sentence was completely unrecognizable in the following sentence. She had a huge disconnect in reading and despite our hard work outside of school, she was still struggling. In first grade, she qualified for Title 1 reading, but still improvement was slow to lacking. To her teachers, she appeared to be bright, but disinterested. Jillian could focus on other activities for hours at a time, it was just with reading. They were not hesitant to mention attention disorders, but wouldn't breathe the word dyslexia. We visited with our pediatrician, about her learning concerns, and his solution was to try ADD/ADHD medicines on her. He said we need to become more flexible where medication was concerned. We knew better and he was fired.

The worst day, however, was during the last week of school in first grade. Myself and several parents volunteered all year to work individually with students on sight words using flash cards. When Jillian came in to work with me, she began to cry. One of the other students, whose parent also helped in class, told Jillian she was a "delayed reader" and she stunk at spelling. We were devastated, as was the teacher. In that moment, every bit of hard work Jillian had done, went straight out the window. It affected her for many years to come.

When Jillian was in 2nd grade, we discovered vision therapy and paid thousands out of our own pocket to get her the help we thought she needed. The school was great, accommodating us to take her out for individual vision therapy sessions. While our efforts helped with her vision, it didn't help her reading, even though she was still working with additional reading groups at school. She was now going into 3rd grade and falling further behind.

In third grade, we had an evaluation with the school and they brought in an outside expert to evaluate Jillian. Everything this expert mentioned, directly coincided with dyslexia, however they wouldn't say it. They said it was a learning disability in phonetics and reading. (Why couldn't we call it what it truly was.) When we told Jillian the results, we saw that same deflated look until we explained what dyslexia was. She realized it wasn't because she wasn't smart enough, but rather her brain simply learns differently. The word dyslexia may not have mattered to the school, but it mattered greatly to Jillian.

It was during this time, that we actually had to seek a licensed psychologist to work with Jillian. She had increased anxiety and being teased and struggling at school took a toll on her. This therapist, also diagnoses learning disorders and while she hasn't performed an official testing on her, she agrees Jillian is dyslexic by observing her during therapy. As a parent, it is extremely frustrating to not be able to use the term, dyslexia, at school. It is also stressful not having an exact diagnosis. (If we want a diagnosis, we have to PAY a psychologist or licensed professional to evaluate her.) We have held off on the official diagnosis, because we want to make sure we don't pay for testing that won't be recognized by the state or the district.

Since the end of 3rd grade, Jillian has had an IEP and accommodations have been put in place. Now in 6th grade, she is finally excelling. She had all A's last nine weeks and was on the honor roll for the first time. She is excited about school and loves to learn. She has lots of aspirations for her future. The only reason this happened is because we didn't give up and kept fighting. However, we are constantly in fear that she will lose her IEP and accommodations because she does not have the official diagnosis and because she may be excelling too much. Our fears continue for her future. We worry about if she will have accommodations while taking the ACT/SAT and about what kind of help she will get once she gets to college.

I have researched for any and all information on dyslexia I could find and was excited when I learned of the proposed bill. Meeting fellow families with dyslexics was full of mixed emotions. I was happy to hear that I was not alone but extremely saddened by how hard we have had to fight for our children's rights.

I didn't have time to prepare my story for the hearing, but would like to address some of the issues the opponents brought up during the discussion.

“Screenings are already in place through statutes and regulations that provide appropriate identification and evaluation of students with all disabilities equally, not just learning disabilities.”

Heath Peiene, USD 353

Yes, there are screening in place. My daughter was screened. But, as Rep. Aurand's so perfectly mentioned that it was like "Groundhog Day" as this issue keeps coming up during his 25 years. I say the reason it keeps coming up should indicate that what we have isn't working for dyslexic children. Of all children with learning disorders, 80% are dyslexic. That is a huge number. Proper DYSLEXIC screening at a very early age could identify and begin strategies that work earlier. This would eliminate the "kicking the can" approach that is currently being used and may even improve the dismal fourth grade reading scores for our state. I was an involved parent with knowledge of my parental rights and my school followed all the standards. We still didn't get the IEP until the end of 3rd and beginning of 4th grade. The sooner dyslexia is identified, the better.

“Identifying a child as dyslexic, learning disabled, emotionally disturbed etc. etc., is not of paramount importance.” *Bert Moore, Superintendent/Director of Special Education*

I disagree. It helps the child and parent better understand what they are dealing with. It should also be important to educators and administrators to identify if they are seeing increases in specific disabilities. Not only could it help them define what strategies are working, it could help them determine if it would be more cost effective to utilize a specific reading program choice for all their students. (Orton Gillingham, for example, works well with both dyslexics and non-dyslexics.) If dyslexia is recognized under IDEA, then why don't we start saying what it is? Remember that while some learning disabilities can be cured, dyslexia can not. Not identifying it may make it harder to explain and to receive accommodations when you get into higher education and in the workforce.

“A school psychologist or speech pathologist who is employed by a schools district is going to use many of the same diagnostic tools as a professional outside of school, but at no cost to the student or family.”

G.A. Buie, Executive Director, United School Administrators of Kansas;

Amy Haussler, Director of Special Education, Holton Special Education Coop

If this is the case, then why can't the school psychologist or speech pathologist be certified to diagnose and save the state and parents money? Seems like a win/win.

Due process protections for teachers was also mentioned.

I agree completely. Most teachers I have encountered are extremely caring and passionate about what they do. They are also our first line of defense in identifying learning disabilities. They should be able to identify students for further help or screening without fear of losing their job.

In conclusion, we believe HB2602 is a great beginning. It provides protection for students who are struggling with dyslexia; appropriate screening; and most importantly, education for our current teachers on identifying and understanding dyslexia. I agree that all learning disabilities are important, but I also feel that one that is so prevalent and unique, should be better screened, treated and understood, especially if we want to improve our state's education scores and reputation.

Sincerely,

Arlena, Michael & Jillian McLaren

Baldwin City, Kansas