

Written Testimony for Kansas House Session Spring 2018 for HB 2602

By Melissa Webb

Lifelong Kansas resident, parent of two dyslexic children currently in Kansas schools

Our story starts with a bright, sweet, well behaved, goofy 5 year old girl, starting her first year of kindergarten at a Kansas elementary school. Within the first few weeks of school, she was DONE with school. She hated it. She was going to the nurse's office on a consistent basis complaining of stomachaches and headaches. She was getting punished by her teacher for not paying attention and this lack of attention they felt was causing her to have lower scores.

It took 2 years of struggling, to half way through second grade until her scores were low enough (below 15%) that she qualified for Title One support. They put her in an extra reading group. It didn't help, so they suggested getting her eyes checked and that 'maybe she has dyslexia, but they don't test for that until third grade', so check her eyes for now. She had never failed an eye exam, but we decided to take her to an eye doctor who specializes in pediatrics "just in case". We took her in for one appointment and they instantly decided she needed Vision Therapy. Vision Therapy is controversial in the medical community, so controversial that health insurance won't cover it, and the providers require cash payment from parents to the tune of thousands of dollars up front before they will start services as well as a contract saying they won't quit, and if they do quit, they don't get a refund on the prepayment. So we paid the \$5,000 out of pocket they wanted, pulled her from school early once a week and travelled to appointments 30 miles each way, and did tedious daily exercises at home after school. She was an amazing trooper through this...while she complained, she also tolerated a LOT. We did this all because we thought this would be the answer to her academic struggles. It became apparent after just a few weeks of this Vision Therapy that she didn't belong there. She could ace the 'exercises' the day the 'therapist' would introduce them yet she still had to go through the hoops. There was no noted improvement in school, she still struggled with reading, writing and math.

She started 3<sup>rd</sup> grade as far behind as ever, and in my initial meeting with the reading specialist, I told her how the vision therapy was a joke, and asked what the next plan was. She said 'Well she may have dyslexia, but we don't do anything different for that, so no reason to test for it.' The only thing I thought dyslexia was was when people flip their letters and read backwards. And my daughter didn't do that! Yet, I was a parent on a mission, and went home, straight to Google. That Google search opened an entire world of explanations on our daughter, and red flagged major problems with the Kansas educational system.

I quickly learned that the school district would not test for it, would not refer to anyone who does test for it, and didn't even think it was necessary because they would do nothing different. I found out just from reading basic information on Dyslexia that their stance was wrong.

I found out that when the reading specialist (who had 20+ years of experience) told me the prior spring 'they don't test for dyslexia until third grade' was wrong. Specifically picked screening and tests can pick up dyslexic kids at age 5 with 90+ percent accuracy, and the earlier it's identified and remedied the better the outcome for the child.

I found out that their stance of ‘we do nothing different’ was wrong. There are scientifically proven methods/curriculums, endorsed by the International Dyslexia Association, formerly known as Orton-Gillingham now called Structured Literacy that the dyslexic kids need, and Kansas districts didn’t use them.

I found out that if we just lived in Texas instead of Kansas, there are many, many more requirements of districts to properly address dyslexia. It would be hard to find a district in Texas that DIDN’T have a Dyslexia Handbook, detailing what they do to identify then work for a child who’s suspected of having it, all because of state mandates issued years ago. The Texas Scottish Rite Research Hospital in Dallas has its own unit that tests kids and educates teachers and parents on Dyslexia. We seriously considered moving down to Texas, in order to get proper education for our kids.

We didn’t want to leave the state or area we called home, so we tried very hard to get our school district to accept, accommodate, and provide the curriculum our now two dyslexic children needed. Two years’ worth of meetings, of increasing frequency and up the ranks of administration, we tried to find out what was standing in the way of this scientifically proven curriculum not being used for the 20 or so kids who could benefit from it. Hundreds, possibly thousands, of school districts in this country use the program successfully...and only two in Kansas. Excuses from our district abounded as to why they couldn’t. We offered to pay for a full ride scholarship to one of their teachers to get the training. We offered for me to go get the training, and I would come in for FREE and give the instruction to small groups, or hire as a para if legalities needed it. We were told they couldn’t ‘set a precedent’ by allowing this. We were told that it would be admitting they were failing to provide a FAPE if they allowed the curriculum in their doors. We were told that parents can’t dictate what a school does. The superintendent said I was welcome to remove my own child from the school and instruct her, but under no terms was I coming into their building to teach her, nor any of the dozens of other kids we knew could benefit from it. In the end, the administration shot down all our suggestions and supporting research presented to them. Their part time, on contract, Curriculum Director with no dyslexia training and legal counsel advised them that what they’d been doing all these years was ‘good enough’ by state standards. And if they didn’t want to change things, they didn’t have to. And they didn’t ‘want’, so they didn’t. Meanwhile, the 20 kids who could use it, continue to be taught there today using methodologies not meant for them.

Our kids are lucky. They have parents who are advocates, who do what it takes to lessen the burden of having this brain difference that makes them learn different and have the label of ‘Learning Disability’. Yet I don’t just fight for mine, I’m advocating for those whose parents and teachers are oblivious to what the child has, and for the child who is quietly suffering emotionally and academically, thinking themselves stupid and inferior to the majority of kids who are learning quickly. Those kids’ parents aren’t sending emails, or writing testimonies, and I hope my testimony and others’ testimonies here cannot just stand for the specific situations they talk about in detail, but are simple representations of what’s happening across our state.

The time to act is now. The can has been kicked in Kansas for years, with multiple house and senate Dyslexia bills introduced that fail in committee. In 2018 it needs to stop, and action needs to start. It will not be a quick, instant fix. Even after the bill is passed from the hard work of all involved, there’s going to be more work to be done in districts and schools. Yet, the

benefit 5-10 years down the road will be that state test scores will improve, the emotional damage to these dyslexic kids will lessen by early identification and intervention. Yes, dyslexic kids will still have to work twice as hard in many areas of their education, but maybe reading instruction won't have to be one of them. And my ultimate dream is soon there won't be any little 7 year old girls in ANY district in this entire state begging not to have to go to school because she has stomach aches from the stress of being an unidentified and improperly instructed dyslexic child.