

Testimony to Senate Education Committee on Task Force for Dyslexia

I strongly support the establishment of a task force on dyslexia. It is far overdue in Kansas for us to look at this issue, as many states have already mandated testing in early primary school to effect early diagnosis of this condition. Dyslexia can be diagnosed as early as 5.5 years of age with 92% accuracy.¹

Reading is the most fundamental skill needed to engage in society today. Without it, jobs are limited, civic engagement is strained, and the ability to provide for one's self and one's family is severely tested. Dyslexia is the most common learning disability, affecting approximately 15% of the population, with the estimated range being from 5-20%, depending on who you ask.² It represents 80-90% of all learning disabilities.³ It is estimated that 80+% of children in special education have a form of dyslexia, even though it might not be formally diagnosed.⁴ It has also been proven that the incidence of a learning disability such as dyslexia is significantly higher among the incarcerated, meaning our prisons are full of people who were unable to reach their full potential.⁵ The stakes for these children, as well as for society, are high. Only 4.5% of children in public schools in the US are diagnosed with a 'specific learning disability', a category that includes dyslexia, among other things – the gap between the number of children *with* dyslexia and the children who are *diagnosed* with dyslexia is huge.⁶ Why is that important? You can't fix something if you don't actually know what the problem is, especially since dyslexia requires specific remediation.

Dyslexia is a neurologically-based language disability – it is not the mere reversal of certain letters as is commonly thought. A diagnosis of dyslexia is not the end of the world by any means – with appropriate instruction most people with dyslexia can learn to read fluently, and many go on to do impressive things. The operative phrase here is “appropriate instruction”. Regular reading instruction methods do not work, and special education classes that use regular reading instructional

¹ <http://www.decodingdyslexiaon.org/dyslexia-facts/>

² For example: <http://dyslexia.yale.edu/advocacy/ycdc-initiatives/multicultural-outreach/>

³ <http://dyslexia.yale.edu/category/dyslexia-in-the-news/>

⁴ <http://www.dyslexia-reading-well.com/dyslexia-statistics.html>

⁵ [http://journals.sagepub.com/doi/abs/10.1177/1044207315616809;](http://journals.sagepub.com/doi/abs/10.1177/1044207315616809)
<https://www.ncbi.nlm.nih.gov/pubmed/10876375>

⁶ [https://nces.ed.gov/fastfacts/display.asp?id=64;](https://nces.ed.gov/fastfacts/display.asp?id=64)
<https://www.apmreports.org/story/2017/09/11/hard-to-read>

methods do not help as much as they should. The good news is that we already know what appropriate reading instruction for these kids looks like. The gold standard method for remediation is the Orton-Gillingham method, and it has been around since the 1930's.

If a child with dyslexia starts appropriate reading intervention before the end of third grade, he or she has a 92% chance of learning to read fluently. If not, then there is a 76% chance that he or she will never be a fluent reader. The statistics are sobering. Dyslexic children also suffer much higher rates of anxiety and depression, linked to the numerous educational failures they often endure.⁷ The biggest barriers to appropriate remediation are a) timely identification that dyslexia is present, and b) appropriate instruction.

How do I know all of this? Aside from the fact that as a professor, pedagogy – the theory and practice of teaching – is my thing, I also have a son who has dyslexia. He is 7 years old, and quietly brilliant, with the most amazing imagination, and I can give you first hand testimony about how incredibly broken the Kansas education system is for a dyslexic child. In fact, it is so broken that I started a nonprofit to try and fill in for gaps in the education system, called **Ad Astra Learning Guild, Inc.** We tutor and provide IEP support, and we are setting up summer school classes for kids with dyslexia or suspected dyslexia using Orton-Gillingham methodology because the summer slide – where students regress in their learning over the summer break – is far more catastrophic for these kids than other children. We are at the fundraising stage right now.

My son struggled with reading in Kindergarten, but it was no big deal because different kids learn at different speeds. In first grade, it was a bit worrying because the other kids in his class were learning their sight words, and my son wasn't. Some days he would seem to have a handle on a few, and then the next day he didn't. I finally stopped my denial – “there's nothing wrong with him, he's just learning at his own pace” – when I sat down with him to concentrate on his sight words. We spent 20 minutes on “the”, breaking it down, sounding it out, finding it in sentences, and everything I could think of to do with it. He had it cold. We moved on to the next word – “is”, and he got it right away. We returned to “the”, and it was like he had never seen it before in his life, even though we spent 20 minutes on it, ending less than 30 seconds before. I knew then that was more than just “learning at his own pace”. That is when I got serious about advocating for him in the Kansas educational system.

I asked for testing the first week school was back in his first grade year – in August – because his speech therapist had floated that I should do so the previous spring. I

⁷ <http://www.decodingdyslexiaon.org/dyslexia-facts/>;
<https://www.ldatschool.ca/learning-disabilities-and-mental-health/>

kept getting put off by the school with platitudes like “in another week or two, we’re just a little busy”. I even asked if I should get a private assessment, to speed things along, and I was told to not bother because they wouldn’t accept the results of a private assessment anyway. So I waited. My son was finally assessed the final weeks of November, and the beginning of December, and the results were “we know there is something wrong, but we don’t know what – does not qualify for services because he has no cognitive deficit.” His first grade teacher was livid – he was clearly struggling, was falling farther and farther behind with every day, and we had just been told he wasn’t about to get help – in retrospect this was primarily because Kansas does not test for dyslexia. There is also a terrible lack of information out there about dyslexia, even among special education teachers with actual Masters degrees in special education – dyslexia is found in people who do not typically have cognitive deficits, and that is the grounds on which he was initially denied services! He is, on many indicia, textbook dyslexic, and the system failed him.

Within days, I had secured an appointment with an specialist educational psychologist in Kansas City, and after the initial assessment, where orthographic problems were identified, we returned for a full day of assessments. We found out in short order that he had a form of moderate dyslexia, and was “unlikely to read without intervention”. The regular school psychologist who tested him was actually qualified to make this diagnosis, but because it was outside of the parameters set by the state of Kansas, did not do so. All told, it cost me almost \$2,000 to get a formal diagnosis of dyslexia, that I then used to get him intensive reading intervention – how many families of moderate means can afford this?? This is why so few children in the lower grades have formal diagnosis, because it is prohibitively expensive to obtain. Also, how many people would back off when the professionals told them that their child doesn’t qualify for services, and play the recommended waiting game to see how the kid did next year (after possibly being held back, or simply experiencing a year of frustration and failure)? I know some who did just that, and in doing so cost their child a year’s progress. Thankfully, I am not someone who takes “no” for an answer when it comes to my children.

All told, in order to get services for my child, I had to be the most obnoxious, abrasive version of myself that I could stand. I had to be argumentative, and not ‘trust’ the professionals who said there was nothing they could do. As a law professor, a lawyer, and a generally aggressive person, I was able to do this. Many people do not have my stomach for conflict. This shouldn’t have to be the case.

When we finally secured reading intervention for my son, we found out that not one of the teachers on the special education staff at the school where he takes his services had experience, education, or training whatsoever in remediating dyslexia. In fact, the head of special education services for the entire school district we live in called me right after he started his services to let me know that if she had been part of his IEP team, he wouldn’t have received one minute of reading intervention whatsoever, because “mark my words, he’ll grow out of this” because he hadn’t lost all his baby teeth. (She didn’t give me the empirical basis for this statement when I

asked, but she assured me it exists). This is the level of ignorance we have to deal with, the misinformation, and prejudice. This all made me wonder if I had secured a pyrrhic victory, securing services after months of fighting but having those services be useless. However, thankfully, the teacher assigned to be his reading specialist was willing to learn, and she did some research and made some phone calls at my urging, to use a program that utilizes Orton-Gillingham methodology.

I was still worried about how this was going to shake out, and since dyslexia does not go away, I then did something most people would be unable to do – I signed up to be trained as an Orton-Gillingham educator. I spent a great deal of time and money taking coursework from a Fellow of the Academy of Orton-Gillingham Practitioners and Educators. I have now completed my Foundation level and Associate level coursework, and am in a practicum so I can continue to advance my knowledge on my way to becoming a Fellow of the Academy who can do the training of other educators myself. I have multiple university degrees, including multiple law degrees, and am one of the few federal and state income tax law experts in the state of Kansas, and I can honestly say that that was the hardest coursework I have ever taken. It also had the highest stakes.

In addition to the special education services my son gets from the school district, I tutor him an additional 3+ hours a week, tailored to the coursework his general education teacher is doing each week. I also provide resources to his general education teacher, who as a stroke of luck is a former special education teacher. Most areas of the state do not have a qualified Orton-Gillingham tutor available to privately help these students, let alone the fact that these tutors do this for a living and in doing so have to charge around \$100 an hour (there is approximately 1-2 hours of lesson planning, note-taking, and preparation for each hour of tutoring). Best practices dictate 3 hours of remediation at minimum each week – the price tag of \$300 a week (nondeductible) is more than most people can afford. Going for private remediation is not an option for many normal Kansans.

And here is the good news part of my testimony – my son, “unlikely to learn how to read without intervention”, started his reading intervention services almost exactly 1 year ago, on March 1st, 2017. He was reading at a Fountas and Pinnell level B at that time (mid-Kindergarten), and could recognize 8/52 primary-level (ie. Kindergarten level) sight words. He was reassessed two weeks ago, at a banded level K-L, mid-way through second grade, which is the grade he is in, and he has all but 2 of his 3rd grade sight words mastered!!!! His fluency still needs work, and he has to work really hard for his gains, but this shows it can be done. This year he has scored 100% on his report card for spelling at his school for each of the first two quarters in his very academically-focused and challenging private school, and is on track to do the same for this quarter. These children do not need to be left behind. And the first step to making sure this happens is getting the appropriate assessment to unlock access to the appropriate services they need.

Children should not need an overly-educated, financially well-off, aggressive and argumentative parent to ensure they get the assessment they need to access these services. My son is getting what he needs – I'm making sure of it - but now it's time to make sure all Kansan kids get what they need, and this task force will be the first step in doing this. Kansas families deserve this.