

Dyslexia: The Parents Who Got Away

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Do you want to know what keeps me up at night? No? Well, I am going to tell you anyway. It's not my bills, my aches and pains, a good guest host on Saturday Night Live or even the excitement of an upcoming vacation. What keeps me up at night are the parents that come to my office, who tell me their story, trying their best to hold back tears, and who leave my office with the reality of their situation laid out before them *and never come back*. They tell me about their frustrations with the school, the lack of a diagnosis, the burgeoning emotional distress of their struggling child, and then I hear the words that foreshadow their fate: "Ok. I am going to take this information to our next meeting with the school. Thank you so much for your help." I'm often left wondering what happened at that school meeting and which 'untruths' they were told, which myths were perpetuated and how many people from the school were sitting on the other side of the table. I imagine that the school talked them out of everything I had spent quite a bit of time educating them about. Then I think, how sad for their child.

Do you what is even sadder? I have to caution parents that one of the most detrimental things they can do is listen to the school when it comes to a child with dyslexia. Below is the most common 'advice' parents are given by well-meaning school personnel and what they reveal about what the schools know about dyslexia and dyslexia and the law.

"Your child is receiving intervention via RTI (Respond to Intervention) so we won't test him until third grade anyway."

Well you know what I would say, right? But we'll save the curse words for another time. The problem here is threefold.

First, early detection is the key. From now on, when you hear this from anyone connected with the school, I want you to ask them the following questions: What exactly are we waiting for? How is waiting going to be helpful if RTI does not work?

Secondly, this response reveals that the school personnel does not understand or know the education code. Your response should be: Can you please show me the written school policy and the IDEA law that supports your decision to wait until third grade? Are you aware that IDEA does not support your decision to deny testing because you want to try RTI?

Third, we know that children with dyslexia need a program that is explicit, structured, sequential and multisensory intervention. So, you need to ask: Can you please describe the RTI intervention you are using and describe to me the teacher's training in that intervention? Can you please show the research the supports the use of the particular program with a student with dyslexia?

Remember: question, question, question. Question everything and question it often, but question it in writing and request it in writing. This is the classic wait to fail model, and I have seen many parents 'fall' for it simply because they desperately want to trust the school.

Is this what they hear and why they don't come back?

'Well, we really don't work with dyslexia, so testing won't help anyway.'

I am quite sure that I will spontaneously combust if I hear one more time that "my state/district/school does not acknowledge dyslexia." If you live in the United States on the planet Earth, your state/district/school does work with kids with dyslexia, and they do acknowledge dyslexia. If you hear anything that states otherwise, do not accept it. Instead present them with the IDEA definition of Specific Learning Disability (SLD) that includes the qualifying condition of dyslexia. A state cannot supersede IDEA and eliminate dyslexia from the definition of SLD. They just can't. Again, ask them this, "Would you please send me the written policy that supports your stance that you do not use the term dyslexia or that the state/district/school does not acknowledge dyslexia." It is no longer the 'd' word; just use it and use it often. Dyslexia, dyslexia, dyslexia...there I said it, now your turn.

'I am not sure what you are concerned about Ms. Smith; Joe is doing great in his classes.'

Is he really though? Have you asked him how long it takes to study for a spelling test or read a chapter in his social studies book? Can he spell those words two weeks later? How many times did he write that paragraph in his journal? Don't you think his oral vocabulary far exceeds what he writes for you? When you are reporting a fluency score to me, is this a hot read or a cold read? Is this a grade level passage?

Yes, most kids are average, as are most of us, but if you know your kid is not average yet he or she is performing in the average range, you do not have to accept it. Also, what if it is taking the student 4 hours every night to stay average...is that a problem? I think so. This is the great marginalization of these kids with dyslexia. IDEA does insinuate that schools have to take into account (again, take into account, not maximize) the student's potential when creating plans for those children – the basic floor of opportunity standard is being slowly chipped away, and that's a good thing.

I lay awake at night and wonder which bit of rubbish the parent succumbed to in the belief that the school personnel were the experts. What ended up happening to the child that provoked a desperate email and office visit? Yes, you just might upset the school and as one of my clients recently said 'get the stink eye' for making waves, but does that really outweigh the lifelong benefit of getting the correct services?

Let's face it; there is a laziness factor here. I am not privy to any super-secret information and then have top-secret clearance to share it with you. Sure, I am good at condensing it and making it accessible (and hopefully putting a smile on your face every now and then with a quip), but any school personnel could google dyslexia and learn quite a bit in one to two hours.