

Putting the D in to the IEP: Why Advocating for a Child with Dyslexia is so Difficult

Kelli Sandman-Hurley, Ed.D.
Co-Founder of the Dyslexia Training Institute

Advocating for a child with dyslexia or suspected dyslexia can be tantamount to moving a cruise ship with a piece of string and your teeth. But if you pull hard enough and you give the ship enough fuel to move, you can make progress. Once you set sail the whole ordeal will be worth the struggle. So, why is it so difficult to get appropriate services or even recognition of a problem from most schools?

“Dyslexia is a broad term that covers a lot of different issues.” If I had a dime for every time I heard this mantra that has been adopted by countless participants at IEP meetings, I would have a lot of dimes. I have to admit, I have had to control my smirk when I hear this mantra and wait for my turn to set the record straight. The fact is the opposite is true. Dyslexia has a very narrow definition and only includes those students with a phonological processing problem (www.interdys.org for a complete and official definition). It can be identified with the correct battery of tests that are correctly interpreted.

Solution: Be prepared for this response and do your homework. Bring FAQ sheets with you about dyslexia, ask them about their training in dyslexia, and ask them what they think dyslexia is and how they came to this conclusion and do so in collegiate manner – it’s an academic conversation not an accusation. Dyslexia is so hotly debated that is important to remain calm in order to truly teach the team about it. Be prepared to compromise and pick your battles. If they seem to understand the underlying cause of the reading/spelling trouble and seem willing to provide the appropriate strategies, then accept the label Specific Learning Disability. Last but certainly not least, remind them that dyslexia is listed as one of the conditions under Specific Learning Disability. This is where the humor comes in: Dyslexia is too broad, but it is listed as one of the eligible conditions. Specific Learning Disability encompasses every learning disability but it is not too broad? Do you see why I am smirking now? Silly, right?

“We don’t test for dyslexia.” If testing has been done by a School Psychologist or outside professional that includes the following areas: phonemic awareness, phonological awareness, oral reading, silent reading, spelling, and cognitive ability, then they usually have enough information to determine the root cause of the reading problem. However, they often lack the expertise to parse it out of the data and instead rely on visual or auditory processing problems. So, why not go ahead and call a duck a duck? It is covered under IDEA after all. This is where a dyslexia advocate can hit a brick wall if they are not careful.

Solution: Have an independent professional with expertise in dyslexia read the testing and determine if they see scores that indicate dyslexia. If so, request an Independent Educational Evaluation (IEE) from someone who is trained in dyslexia. Contrary to popular belief, this does

not have to be a psychologist and they are wonderful if trained, but it can be a professional with an Ed.D. or equivalent. The most important qualification is their understanding of dyslexia. But do your homework and make sure their reports will hold-up in an IEP. Also, make sure that person is willing to come to the IEP to explain their report. This can go a long way for an advocate in just getting the student qualified for the services they need.

“We will provide the appropriate instruction in the resource room.” Any advocate’s next question would be, “What does that instruction look like?” More times than not, the answer will include ‘small’ (I’ve seen ‘small’ groups as big as 5 kids) group instruction using a district-adopted textbook. The problem here is very significant when it comes to true intervention. To truly help a person with dyslexia, the instruction needs to be individualized (as it should be in an IEP) and it needs to start from the beginning. Many students will begin an IEP mid-year and they join another group, this is not going to be beneficial in most cases. There is a bigger problem which is the training of the teacher. Students with dyslexia need teachers who are trained in the Orton-Gillingham approach and are capable of using a program that is based on that approach. Don’t get me wrong here. I love teachers and I love schools, but this is the cornerstone of a good program for a student with dyslexia. Herein lies the biggest challenge for a dyslexia advocate; how to get the child the appropriate intervention.

Solution (most of the time): Again, doing your homework is key here. Bring research or be prepared to cite research that makes the case for one-on-one instruction in an Orton-Gillingham-based program. Be sure to know which programs are more effective and widely used. (Wilson and Barton are both effective). When school districts state the program they are using is based on the Orton-Gillingham approach call the publisher and verify that this is true – it usually is not the case. Some schools will have appropriate programs that they did not offer until you specifically ask for it and when they do then you are in luck. The next step is to make sure the teacher is properly trained. Don’t be intimidated to ask for his or her training and credentials – it is essential to the student’s success. When schools do not have the appropriate intervention it is time to make the case for outside tutoring. This is where things get sticky. As a dyslexia advocate you need to be realistic about how far you can take a case. If you have enough evidence that the student was not identified early enough or had been denied an IEP previously, you can request Compensatory Services and sometimes your case is so strong that this is relatively easy and sometimes this is the end of the road for the advocate the beginning for an attorney.

“We won’t test him because he is getting A’s and B’s” While it is true that the student seems to be passing or even excelling in school, the truth may be that he is working four times as hard and four times as long on his homework than his peers. This may work in the earlier grades, but as school get harder and begins to get text-heavy, this student will begin to struggle. Many schools will argue that because they are not struggling they do not need extra help.

Solution: If a student has received Prior Written Notice (PWN) for the reason above, you can do two things: Begin to document how long it takes the student to complete work, collect writing

samples from first drafts through final drafts, observe the child in the classroom then collect what he did in class. Once you have collected your data, approach this school with new information in a compelling letter and resubmit a request for assessment. You can supplement this letter with a meeting with the Principal to show them your data. Secondly, if you believe the student only needs accommodations to be successful, you can request a 504 instead of a full IEP. Again, expect resistance but offer examples of how this would help. Data is imperative this case.

I became an advocate because my students and their parents were so defeated by the time they figured out what was causing the school struggles and they did not where to go next. I knew there was a niche in this area. I went through the training to become a Special Education Advocate and thought I was going to save the dyslexic world. What I encountered was a world of misinformation amidst well-meaning and caring teachers and administrators. It is very difficult to be a dyslexia advocate, but it can be done. With a little finesse and a whole lot of preparation mixed with some sugar, it can be done. Just ask Zachary, who is now receiving services paid for by his school and thriving.



Dr. Kelli Sandman-Hurley is the co-founder of the Dyslexia Training Institute (www.dyslexiatraininginstitute.org and www.dyslexiadr.com.) She received her doctorate in Literacy with a specialization in reading and dyslexia from San Diego State University and the University of San Diego. Dr. Sandman-Hurley a Certified Special Education Advocate assisting parents and children through the Individual Education Plan (IEP) and 504 Plan process. She is an adjunct professor of reading, literacy coordinator and a tutor trainer. Kelli is trained by a fellow of the Orton-Gillingham Academy and in the Lindamood-Bell, RAVE-O and Wilson Reading Programs. Kelli is the Past-President of the San Diego Branch of the International Dyslexia Association, as well as a board member of the Southern California Library Literacy Network (SCLLN). She is a professional developer for California Library Literacy Services (CLLS) as well as a Literacy Consultant for the San Diego Council on Literacy. She was awarded the Jane Johnson Fellowship and the Commission on Adult Basic Education (COABE) scholarship. Kelli has presented at numerous conferences as well as provided professional development for k-12 teachers. She is currently working on her book, Putting the D in IEP: A guide to dyslexia in the school system.