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An Interview with Don M. Winn: Dyslexia

Aug 5, 2019 by
Michael F. Shaughnessy *Education Views Senior Columnist*

Michael F. Shaughnessy –

1) Don, first of all, can you tell us a bit about yourself and your education and experience?

First of all, I am severely dyslexic, and I went to school in the sixties, when very little was known about dyslexia or how to help dyslexic students. After a very traumatic and difficult time in public school, compounded by my parents' divorce, I dropped out of high school. I ended up, thankfully, at the Texas Rehabilitation Commission. I had heard that one could get help with tuition to a trade school through the program, so I submitted myself to the evaluation process.

My expectations were along the lines of training in woodworking, metal fabrication, or some other trade, but my case worker was stymied at the results of my testing. I remember he said, "Why do you want to go into a trade? You have real academic aptitude!" Although I had struggled mightily with dyslexia in public school, and my dyslexia certainly hadn't gone away, the testing process revealed a strong affinity for computers and the technical world, and at fifteen years of age, I became a college student.

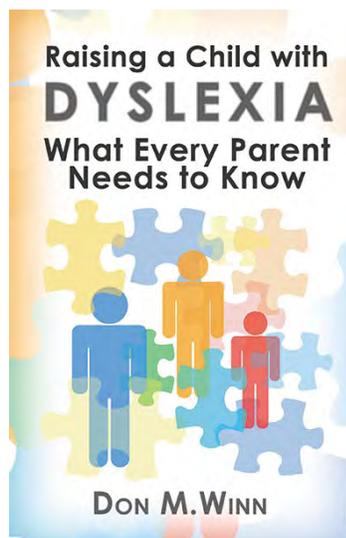
I began my education in Austin, Texas, studying business and computer programming, and later continued my education in Tulsa, Oklahoma. I worked in the technical field for over thirty-five years, first as a computer programmer, and finally managing a team of computer professionals for the State of Texas.

2) Now what about your own experience with dyslexia?

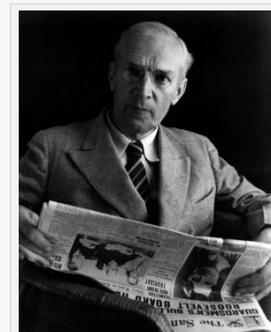
I felt like a normal, happy kid until I entered first grade. I liked to run, play, climb trees, ride my bike, go exploring, and in general do all the stuff the other kids in my neighborhood enjoyed doing. But on the first day of first grade, my whole world collapsed into itself, as if it had been sucked into a giant wormhole from a sci-fi show. In the space of a seven-hour school day, everything changed for me. I simply could not figure out how to do the things the teacher asked me to do.

Memorizing the alphabet, that long sequence of 26 unrelated letters, plus their sounds; reading and writing my integers; holding a pencil the way she wanted me to hold it; following instructions that had multiple steps or those that involved directionality; and so much more eluded me even though I was trying my very hardest to comply.

My brain struggled to make sense of the fact that everyone else in my class could do these things with seeming



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ease and efficiency. I didn't understand why I could not.

I felt like a duck out of water—I didn't belong, and I became very anxious. It was like everyone was moving at a fast-forward speed, and I couldn't raise my hand and say, "Stop! Slow down! I don't get this! I can't keep up!" Deep inside, I knew that day that there was something very wrong with the way my brain worked and things went downhill from there.

Though I didn't have the words to describe it at the time, I now realize that both the speed with which information was presented and the manner in which it was taught were not a match for my processing abilities. I flunked first grade and was part-way through first grade a second time when a special ed teacher who had taken an extension course on dyslexia recognized my symptoms and suggested that I might be dyslexic.

Once I had the label, the only thing that changed was that I now spent an hour a day with the special ed teacher to help me with reading. Unbeknownst to me, my parents, or the teachers in my life, I also had dysgraphia (trouble writing), dyscalculia (trouble with math, numbers, and learning/doing things in sequence), and some dyspraxia (trouble with coordination of muscle movements needed for multiple tasks).

Additionally, a SPECT scan later in life helped me understand that I not only had the "normal" inherited type of dyslexia, but my situation was complicated by "traumatic dyslexia" resulting from a traumatic brain injury.

If I had to pin down the one thing that created the most difficulty for me over the years, it was the lack of information leading to understanding, accepting, and coping with my dyslexia. My teachers never explained things to me, my parents never had a single discussion with me about what was going on or what we could do about it, and most importantly, there was no one I could talk to about my fears, feelings, and frustrations.

About ten years ago, my wife and I started a mutual mission to make a project of understanding dyslexia, learning all we could about current science, teaching methods, genetic involvement, and emotional and educational techniques to help dyslexics cope with the fallout of their condition.

We took a huge leap forward in our quest at an early screening of the 2012 documentary *The Big Picture: Rethinking Dyslexia*. I had never before seen such a comprehensive and relatable depiction of all the things I had been struggling with since first grade. Viewing this documentary had a profound impact on both myself and my wife. I finally understood myself in a way I never had, and now realized that I had a tribe. And although my wife has a background in biochemistry, psychology, and genetics, prior to viewing the documentary, she was completely unaware of the breadth and scope of the effects of dyslexia.

3) A paramount question—is there, in your mind a difference between a "learning disability in reading" and "dyslexia"?

Absolutely. Learning disabilities in reading can comprise multiple scenarios, only one of which is dyslexia. There are any number of ways a child's ability to interact with the printed word can be impaired or challenged, and that's why testing by an experienced diagnostician is crucial. Only a clear determination of the specific type of print disability a child has will lead to effective remediation, and targeted emotional support so the student can understand, accept, and cope with his situation.

4) Real tough question—at what age or grade can we make a diagnosis of dyslexia with any kind of confidence?

Thankfully, there are early warning signs that savvy parents can watch for, starting in infancy. Numerous testing modalities are proven to be diagnostically accurate starting as young as eighteen months of age. I provide a comprehensive list of current testing methods, broken down by age group and diagnostic focus in my upcoming book, *Raising a Child with Dyslexia: What Every Parent Needs to Know*.

5) Don, we hear a lot about "struggling readers." Is this a good term to use or are these kids possibly dyslexic?

The term, "struggling readers" is a good descriptor for any situation in which a child is not reading at grade level. I find that its very inclusivity is helpful, because it focuses parental and educational attention on the needs of any child that requires diagnosis and accommodation. In every child's life, there is such a small window of time during which they must learn to read well, so the sooner the difficulty pops up on the radar, the better it is for the child.

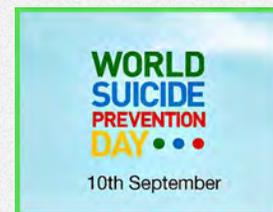
I strive to raise awareness of all struggles to read so that parents know what to watch for and can get help for their child as early as possible. The only way to be certain whether the problem is dyslexia or something else or perhaps a combination of factors, is to get professional evaluation for the child. Telling the child's pediatrician what they have observed is a great place for parents to begin the process.

6) Obviously vision and hearing problems and repeated otitis media needs to be ruled out—anything else?

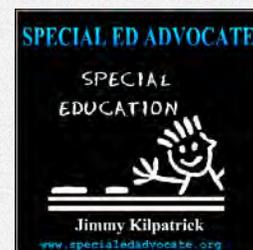
One of my wife's favorite brain researchers, Daniel Amen, MD, urges all parents to be aware of protecting their child from head injuries. Even a little bump on the head, Amen states, can completely change a person's life, including their ability to process new information and learn. Even when there's no family history of dyslexia (it's highly heritable), a concussion, fall, or other brain injury can cause traumatic dyslexia or any number of other

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learning challenges. I

if a child suffers a head trauma, he or she needs to be evaluated by a neurologist, and any professionals involved in the child's testing need to be made aware of the extent of the trauma and area(s) involved.

7) I guess a major question—how much help does a child with dyslexia need—at elementary, middle school and high school, and where should it be provided?

While every child's dyslexia experience has its unique aspects, there are a couple of common denominators: the need for extra time for completion of assignments and the need for a multisensory learning environment. Then the variables enter the equation: Did the child have a good pre-literacy foundation before he or she entered school? How severe is the child's processing challenge? What type of dyslexia does he or she have? Is there also dyscalculia, dysphonia, dysgraphia, or ADD/ADHD? Is the child on the autism spectrum? Is the child 2E, or twice exceptional, meaning challenged in one or more areas, while also being gifted in another? Every one of these factors must be assessed, and then a plan of accommodation(s) must be determined and put into place.

The situation is compounded by the fact that there are no national standards for what goes into a good plan of individualized education. Each school district makes their own determination, and even those standards can change. Parents have a steep learning curve to gain traction in the processes involved in tailoring an educational strategy for their child. The acronyms describing these testing and accommodation processes are enough to make one picture a giant bowl of alphabet soup!

I also can't stress strongly enough how vital it is that parents immerse themselves fully in educating themselves about their child's challenges. Any accommodations made by the school district are only a part of effective support and remediation of the child's dyslexia. The home environment must be tailored to the child's needs as well, and the way parents communicate with their child about his or her challenges, the various strategies and coping skills the family chooses to embrace, and providing emotional support all fall under the umbrella of creating a safe, loving home.

8) Often parents feel they need an advocate or even an attorney to help them. Your thoughts?

Many parents do choose to get professional help in their journey. Some parents may feel intimidated when talking to highly trained educational professionals and prefer to have a representative act or speak on their behalf. Others have had issues with the refusal or cessation of accommodations for their child and must appeal the situation to a higher authority.

The worst-case scenarios actually involve lawsuits, but my hope is that by making available the information on dyslexia, its early warning signs, testing, and accommodation, that fewer families will see these types of escalations in their child's FAPE, Free Appropriate Public Education.

9) In your mind, what are the biggest challenges facing parents and also teachers in terms of working with students with dyslexia?

We don't live in a perfect world, and so most parents don't know that education and building a foundation for literacy in their child can literally begin in the womb. An astonishing number of parents have never even heard of pre-literacy, and therefore also don't know how to help their child build their own pre-literacy foundation. Most parents also have no idea what developmental markers indicate the need for a conversation with their child's pediatrician about testing and diagnosis.

Then there are the emotional complications families encounter. Seeing your child struggle, not knowing why, then getting a diagnosis of dyslexia brings up a lot of feelings for parents that can present challenges. Parents need to process and cope with any fear, sadness, frustration, grief, or other strong feelings so as not to cue their child to respond negatively to his or her diagnosis. If mom and dad think the diagnosis is a tragedy that means Junior or Janie won't be able to become a good reader or learner, then that's what the child will believe as well.

The barriers teachers face are arresting as well. Although the data on multisensory teaching methods (adding kinesthetic and tactile learning aspects to the usual visual and auditory teaching methods) have been around for decades, there is not a single higher learning institution that teaches new educators these methods as the educational norm.

And here's the thing: these methods aren't just best for the dyslexic student but they can enrich the learning of all students! And while the United States government subsidizes some continuing education for the nation's teachers, those who wish to get certified in multisensory instruction methods must pay out of their own pocket to do so.

I have real compassion for teachers. They have such a hard job! I can't imagine how difficult it must be to have a room of twenty or thirty students, each with different strengths, needs, learning styles, and challenges. Teachers must not only strive to teach the whole class but must also write regular reports on any students in their class who have qualified for specialized instruction and accommodation, must implement those strategies, and must meet with parents and school officials who determine what next steps are needed for each student.

And for those maverick teachers out there who have the courage to stand up to the bureaucracy of the

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educational system and its “we’ve always done things this way” mentality by embracing the science of learning, I also have the deepest respect. It’s not easy to buck the system, but it’s the students who benefit from their courage!

10) Where can parents and educators learn more about dyslexia?

My new book, *Raising a Child with Dyslexia: What Every Parent Needs to Know* will be available in October of 2019. It offers a comprehensive approach to dealing with the challenges of dyslexia in the family and at school. Understanding the importance of early detection, testing, working with a child’s school, investigating possible behavioral issues, appreciating the role of social and emotional learning, recognizing the strengths of dyslexia, embracing advocacy, and much more is covered in this user-friendly guidebook. While the writing took me many months to complete, this book has been in the works for over 53 years—ever since I became aware of my own dyslexia and the needs it presents.

I’ve often wondered how my life and the lives of other dyslexics who did not receive adequate accommodation, support, and understanding would be different had we all gotten the help we needed during our most formative years. With the knowledge that’s available now, there is no reason why any child with dyslexia needs to experience this level of hardship ever again.

My website, <https://donwinn.blog/>, also offers a plethora of information categorized by subject in my blog archives and will feature announcements about the availability of the new book in printed, digital, and audio formats.