

A Condition Rightly Named: Why *Dyslexia* Is a Useful Term

by Diana Hanbury King

The International Dyslexia Association (IDA) was founded as the Orton Society in 1949 in honor of Samuel T. Orton, M.D., a neurologist whose early writings on the diagnosis and treatment of reading disabilities sparked scientific inquiry in medicine, psychology, and education. Dr. Orton's term for the disorder he observed was not *dyslexia*, but *strophosymbolia*—a term he coined from the Greek to mean *twisted symbol*. In 1950, when I was teaching at Sidwell Friends School in Washington, D.C., this was the term we used, though, among ourselves, we shortened it to *strophies*.

At that same school, in 1949, Anna Gillingham, who had worked with Dr. Orton, had established the Problem Prevention Program. With the help of the kindergarten teacher, she screened all the kindergarteners. Tests administered included those to test laterality, as well as auditory, visual, and motor skills—similar to the Slingerland tests that were developed later. Those students she deemed “at risk” were then placed in one of the several first grade classrooms. The children in the

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at-risk group were taught using her approach: a multisensory and phonetic method, with cursive writing from the beginning. Students were not taught to print. The various elements of the language were introduced step by step, beginning with the easiest and the most frequent. This group of students was kept together through the fourth grade. The cost? —only the training of four teachers. When these children were tested at the end of fourth grade, they scored on par with their peers in reading skills but were somewhat better at spelling. More importantly, they never had to experience failure or to perceive themselves as different or stupid. Of course, the success of this intervention was dependent on early diagnosis and labeling the risks that the children's symptoms presented.

The term *dyslexia*, though coined by a German ophthalmologist in 1887, came into use later. There are several reasons for using this useful label. Like all terms coined from the Greek, it is recognizable in any language. While individuals may differ in the manner and extent of their dyslexia, there are sufficient criteria to make dyslexia a clearly identifiable syndrome. Thus, it is a term useful to teachers, psychologists, and others involved in education, inasmuch as it calls for specific kinds of teaching.

Alternative terms in vogue these days, such as *auditory*, *visual*, and *fine-motor processing disorders* of various kinds, skirt around the problem the child is having and delay setting the path to remediation. At best, the student is parceled out between the speech therapist, the occupational therapist (in the case of handwriting problems), and the reading teacher. Parents are often misled into treating what is misperceived as the problem and wasting both time and resources. For instance, parents may decide their child needs eye exercises and colored lenses if the problem is perceived to be visual. Others might think “the problem lies in lack of upper body strength.” Some have tried computer devices that turn up the volume, speed up word recognition, or slow down speech. While these forms of remediation are successful commercial ventures and may even produce a temporary benefit, they are neither the best nor the most effective form of intervention. Effective remediation must include a total approach under the guidance of a trained teacher.

Other terms, such as *learning disability*, or *specific language disability*, are too vague to be of any use. Some students, such as Colin, find these terms demeaning, “As for the term *learning disability*, I bristle at it. I could be anything—it incorporates anybody marginal.”

One of the arguments against using the term *dyslexia* is that we should avoid giving children labels. Alas, left unlabeled, children are quick to label themselves. Elliot, bright and gifted, came home from first grade crying, “I'm the dumbest kid in the whole first grade!” Others might accept a teacher's evaluation. “I guess I'm just lazy or careless.” Consider the experience of Emerson Dickman, an attorney and the current president of IDA:

I am dyslexic. I was left back in the first grade because I couldn't learn to read....this teacher also used the EIF approach to teaching reading—Embarrassment Is Fundamental. She was actually surprised that I had just as much trouble reading in front of the class as I had trying to read at my desk. As a result, until I was 40 years old, any kind of public speaking resulted in inordinate anxiety and embarrassment. Teachers called me “lazy and unmotivated” to my face. I began hating school. They told my parents: “He needs a fire put under him,” or, “Put a bomb under his butt.” I learned to hide in the back of the room. I wanted to be invisible.” (Dickman, 2004).

Too many students go through much of their lives puzzled about themselves with scars in their self-esteem, until eventually a friend makes the diagnosis. Eileen Simpson, the psychotherapist, struggled with her dyslexia and was finally diagnosed in

Continued on page 18

her twenties, not by a psychologist, but by the poet John Berryman. Many parents of students with dyslexia share a similar experience. During my many years of meeting with parents to discuss the difficulties their sons or daughters were experiencing, at some point during the conversation, one of the parents would suddenly realize that the problems that have been plaguing family members, even themselves, does have a name.

Who of us can forget the scene in the film *Dyslexia: The Challenge and the Promise* in which the cabinetmaker, Nick Cortula, learns that he is dyslexic? As he tells it, the psychologist said, “‘In the first part of the test, which was reasoning, you scored in the 99th percentile.’ And I said, ‘Does that mean that I’m intelligent?’ And she said, ‘Of course.’ And I started to cry. I cried because all the time I struggled and had no one to tell me, I was getting the signal that I was dumb.” (*Dyslexia: The Challenge and the Promise*. The New England Branch of the Orton Dyslexia Society.)

A relatively new politically correct term is “persons with dyslexia.” It creates a problem because it immediately establishes a negative connotation. We do not say “persons with intelligence” or “persons with creativity;” instead, we call them “intelligent” or “creative.” So why not call a person “dyslexic”? Certainly they are unlikely to introduce themselves as “I am a person with dyslexia,” but will simply say, “I am dyslexic.”

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Whereas in the past the term *dyslexia* had a negative connotation, much of the general public is now better informed. People no longer associate the term with stupidity, nor do they suspect people of using it as a “cop out;” instead of being prejudiced, they are interested and often want to learn more.

Colin, the successful artist mentioned earlier, was diagnosed in elementary school. He never knew a time when he was not dyslexic, and he has long described himself as dyslexic. Colin is quick to identify himself in any context where it might benefit him, for example, as an apology when someone wants him to put something in writing. He regards it as a red badge of courage, and says, “I am what I am both because of it and despite it.” He continues, “It’s been years since I ran into somebody who didn’t know the term, but they usually don’t understand the full impact of it. People have said to me, ‘If you don’t remember names, just try harder.’” He adds, “As I get older, I compare myself to those around me...they certainly had a better playing field in the beginning, but haven’t done any better. I’ve excelled far beyond them. A friend of mine, a nuclear engineer, hasn’t read a book since high school; I have read over four thousand...many on tape. One is reminded of Margaret Rawson’s Rose Valley School study, where she found that by

any measure of success, her former dyslexic students outstripped their peers.”

Dr. Orton called his book, *Reading, Writing, and Speech Problems in Children*, and, as far as the general public is concerned, that title says it all. Kay Howell tells me she has no difficulty explaining dyslexia to five-year-olds: *dys* means problems and *lexia* means words, so *dyslexia* means problems with the words you speak, the words you hear, and the words you see. These young children are pleased that they have a name for it. Katherine Schantz, head of Delaware Valley Friends School, shares, “It’s just such a meaningful term and the kids understand that their brain works differently and feel relieved.” Most of the longer definitions, promulgated by members of the medical profession or research scientists seeking grants, complicate matters unnecessarily.

A geneticist friend of mine, Brenda Sladen, believes that many inherited traits have persisted because they provide an advantage for survival. For instance, she long puzzled over color blindness (now known as red-green insensitivity) until she discovered that in World War II, reconnaissance pilots were selected from this population because they were not fooled by camouflage. Thus, in primitive times, they would have seen the animal hiding in the dappled shade. In explaining dyslexia to somewhat older students, I point out that during the eons before people had to learn to read or write, dyslexics were, because of their strengths—especially their keen powers of observation and creativity—the leaders of their tribes. Thus, any group with dyslexic members would have had an edge on survival.

Those of us who have worked longest and hardest with children of all ages are the ones best equipped to judge the subject of labeling. As Wendy Sweeney Canning remarked, “We have got to stop mincing words and dancing around it!” Dyslexia is not some rare condition—it may affect up to 20% of the population, and it is found in all classrooms. Sixty to eighty percent of the students in Special Education programs are dyslexic. Drake Duane and Paula Rome in *The Dyslexic Child (1981)* estimated that there are more dyslexic children than all of the other handicapping conditions combined. Very few states recognize children as dyslexic. Other states fight hard to avoid using the term. Eileen Perlman, when training teachers in the public school of New York, is often not allowed to use the term so she has to describe the condition instead. All classroom teachers need guidance on how to use the term, most particularly those in elementary education.

Fifty-seven years ago, when I learned about the Sidwell Friends School program, I remember thinking that if it were adopted by all the schools in the country, there would be no need for tutors, nor for special programs—thousands of dyslexic students would learn to read and write painlessly, bright and creative minds would flourish, and there would be no stigma attached to the term *dyslexia*. Alas, it remains a dream. Despite all the evidence, phonological training remains a rarity, and dyslexia is seldom diagnosed before a child is 9 or 10 years old. No class in any middle school or high school in the

country is without its quota of illiterate and often angry or depressed students. Even worse, colleges are not training teachers either to recognize dyslexia or to know enough about the language to teach its elements in a structured, sequential, and multisensory manner.

In closing, I will share the text of a letter, reproduced here as written, from Sydney Rubin, a former student and recent graduate of New England College. It expresses as well as I can the importance of the term *dyslexia* for a person's self-understanding and ability to cope with this condition.

To most people the word *dyslexia* has implied meanings of difficulty reading, poor spelling and barely legible handwriting but to me the simple word means so much more. In fourth grade I diagnosed myself as dyslexic based on the similarities between myself and a professor who openly admitted, in fact laughed at, the fact that she is dyslexic. In fifth grade I underwent a full spectrum psycho-educational evaluation and was told that I had auditory processing deficiencies. Attempts were made to implement the suggested remediations but were inevitably dropped. In seventh grade I had another round of evaluations only to hear the same thing. My grades began to suffer almost as much as my self-confidence. I was being told that I was stupid, slow, didn't try hard enough and that I was lazy, at the time I really didn't fully grasp the meaning of those words but I couldn't understand why I spent 4 or 5 hours a night on my homework and still remained a C student.

In 10th grade I underwent another series of tests this time including an IQ test and my results would rock my world. I was told that I am dyslexic, finally I had a word for what was wrong with me. It was the most liberating feeling to finally know that there is an actual, understood problem with my learning. I began attending the Kildonan school and working with the wonderful Diana King, to whom I attribute my success. Diana helped me to understand that there is nothing wrong with me but there is something wrong with the way I had been taught. It was so foreign to me to begin working with writing handbooks to improve my handwriting but Diana insisted that it would help and of course she was right. Going back to square one was a hard thing to do but I see the success in myself and am so grateful that I have found out why I am so different and why learning had

always been a struggle to me. Having a simple word that relates all of my learning differences to others has helped me not only cope but also learn to laugh at myself when I misspell a word instead of criticize or be hard on myself. Knowing that I am dyslexic has helped me to be accepting of myself and my differences. I now know what a blessing my difference is, it helps me to think outside of the box and to be more creative with my answers. If I remember correctly and I am almost positive that I do the root of *dys* is down or bad, and *lex* is words so basically my understanding of dyslexia is bad words and its true a lot of the time my words come out wrong and without spell check I would never have made it out of college but for a word with such negative connotations I find it amazingly comforting and liberating.

Drake Duane, a neurologist and professor, remarked that he thought the reason the term *dyslexia* is not used more frequently is that it is regarded as a medical term. Perhaps that is a mistake, for the person most likely to notice the child's difficulty is the teacher. Roger Saunders used to say, "If the child is still reversing letters by Christmas of first grade, pay attention." He meant that the teacher should make sure the child is really learning to read—not merely memorizing the little books.

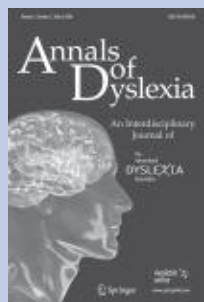
While the diagnosis may be "medical"—to quote Margaret Rawson—it is those of us in the educational field who are in the best position to make an early diagnosis. Certainly, if the Slingerland screening tests were routinely given at the beginning of the first grade year, teachers would be able to pick out those students who need an Orton-Gillingham approach. So it is, we would be better off were the term not relegated to medicine, but placed in education.

References

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Diana Hanbury King has been a member of the International Dyslexia Association since 1951 and received the Samuel T. Orton Award in 1990. She has spent a lifetime working with dyslexic students and training teachers. In 1955 she established Camp Dunnabeck, and in 1969 she founded The Kildonan School. Both programs are designed to meet the needs of dyslexic students.



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