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## **DYSLEXIA UNMASKED – WHAT PARENTS NEED TO KNOW**

Prior to the current diagnostic manual (DSM-5) used by many clinicians to diagnose neurodevelopmental disorders and mental health disorders, dyslexia was the ‘elephant in the room’ nobody wanted to discuss, let alone diagnose. It was a ‘dated’ medical term.

Before 2013, most psychologists used DSM-IV diagnostic terms such as “Reading Disorder” and “Disorder of Written Expression” to diagnose individuals with reading or writing learning disabilities. I recall instances after communicating a “Reading Disorder” diagnosis or “Disorder of Written Expression” diagnosis having parents reply, “thank goodness it’s not dyslexia.” Since DSM-5 now endorses dyslexia as a legitimate clinical diagnosis, the elephant has finally left the room.

### **What is dyslexia?**

Dyslexia is a *Specific Learning Disorder (SLD)* affecting reading and spelling, and is found in 5%–15% of the population. It occurs when your eyes, ears, mouth and hands have problems receiving, storing and outputting alphabet letters, alphabet letter groups, words and sometimes digits. Some people think dyslexia means reversing letters, words and numbers. Some people with dyslexia do this, but most don’t. The core problem most people with dyslexia experience is difficulty identifying words automatically, sounding out words automatically (*decoding*) and spelling words correctly (*encoding*).

Although there are rare types of reading disorders, such as ‘Hyperlexia’ (an ability to read words and spell words adequately combined with poor ability to understand their meaning) and ‘Neglect Dyslexia’ (an inability to read on the left side of a page, usually the result of a head injury), Dr. Stephen Feifer describes four main types of dyslexia.

The most common type of dyslexia, named ‘*Phonological Dyslexia*’ or ‘*Dysphonetic Dyslexia*’, is basically a problem processing and remembering the sounds of words and word parts (phonological processing deficit). With this type of dyslexia, you over-rely on the visual aspects of words when reading or spelling. For example, your hand spells the word ‘video’ as ‘viego’ because your eyes think it is spelled this way. Sometimes you spell words with parts left out (e.g., ‘od’ for ‘old’), periodically you substitute word parts (e.g., ‘chan’ for ‘train’) and every now and then you add word parts (e.g., ‘joib’ for ‘job’). When reading words, you might read ‘broil’ as ‘boil’ because they look similar.

At other times the opposite happens. Your hand spells the word ‘stamped’ as ‘stamp’ because your ears and mouth think it’s spelled that way. Since you rely too much on your ears and mouth to spell words, you tend to spell words by how they sound. So while they sound right, they don’t look right and are spelled incorrectly. When reading words, you might read ‘begin’ as ‘beggin.’ This form of dyslexia is called ‘*Surface Dyslexia*’ or ‘*Dyseidetic Dyslexia*’, which is a problem processing and remembering strings of letters visually as word parts and whole words (orthographic processing deficit).

‘*Mixed Dyslexia*’, also known as ‘*Dysphoneidetic Dyslexia*’, a more severe and rarer specific learning disorder, occurs when you are unable to rely on your eyes, ears or mouth to spell words or read words. This happens because you not only have problems processing and remembering the sounds of words and word parts, but you also have difficulty processing and remembering strings of letters visually as word parts and whole words. Consequently, your word reading and word spelling have very unusual error patterns. You might read ‘novice’ as ‘axvices’ and spell ‘married’ as ‘mawrie’.

Finally, the fourth type of dyslexia is a reading disorder which limits your ability to understand what you are reading. This can be due to problems reasoning

with words and/or poor vocabulary knowledge. With this type of dyslexia, you can identify words automatically, sound out words well and spell words fine, but you have difficulty understanding what you are reading.

Your problem understanding what you are reading can also be due to difficulty holding information in mind while you are reading (working memory), and therefore you quickly forget what you just read. You need to reread text several times to understand its meaning.

### **What is it like having dyslexia?**

Having dyslexia as a kid is like running in a track meet at school with an ankle cast on, as an adult it's like driving a race car in 1<sup>st</sup> gear when every one else is in 5<sup>th</sup> gear; frustrating and demoralizing to say the least.

Many undiagnosed kids with dyslexia have poor self-esteem because they think they are dumb. Why? Most kids believe someone who can read words is smart and if a kid has trouble reading words they're not smart, which is false. In fact, to qualify for a dyslexia diagnosis, kids require at least average or higher intelligence. So, you can't have dyslexia unless you are '*smart*'.

To drive home this point, I tell kids during feedback sessions that some very intellectually disabled people with very low IQ's can read words easily, including difficult words, such as 'circumnavigation', they have never seen before. They have a form of hyperlexia whereby they don't understand words, but they can read them. Reading words and spelling words, low level mental functions, don't require a lot of brain power, but understanding words, a higher level mental function, does.

### **How to explain dyslexia to your kids.**

Keep your explanation simple, using kid-friendly messaging. If they are very young (6-9), they don't need to know their formal diagnosis, but they need feedback about their reading/spelling challenges. You can say something like:

“You have a smart brain that has many roads to learning. Your brain’s road for (e.g., doing math, playing hockey, building lego, playing the piano, making friends...) is straight and clear, which is why (e.g., math, playing hockey, building lego, playing the piano, making friends...) is really easy for you. Your brain’s road for learning to read words and spell words is more curvy, and has a few rocks in the way. Your resource teacher/tutor will help you straighten the road and clear the rocks so reading and spelling will become easier for you.”

If they are older (10+) begin having the ‘dyslexia conversation’ by discussing what it’s like having dyslexia and letting them know there are many successful and famous dyslexics (e.g., Albert Einstein, Richard Branson, Jim Carrey, Jay Leno). As mentioned previously, it is essential they understand having at least average or better intelligence is required for a dyslexia diagnosis.

Another point to consider in your discussion with your child/teen is to remind them successful people overcame at least one or more obstacles during their life journey. Dyslexia is simply one obstacle needed to plan their road to success.

In my private psychology practice, the kids I worry about most are the straight ‘A’ students who easily navigate through school without having to face academic obstacles. Because learning is easy for them, and they don’t have to work through challenges, they are at risk of failing to develop the resilience needed to handle major obstacles later in life. Since most students with dyslexia have to work much harder than their non-dyslexic peers to maintain positive grades, they most likely have learned coping skills needed to better position themselves to handle later life challenges.

### **What can be done?**

Since dyslexia is a ‘brain-based’ neurodevelopmental disorder, it is not curable; however, it is effectively treated with evidence-based treatment programs. It is also managed with assistive technology and learning accommodations, such as extended time for assignments/exams, a reader for tests/exams and access to audio books. Some local school boards offer evidence-based effective treatment program in some of their schools, such as ‘*Empower Reading*’ which helps many students with dyslexia, although not every student with dyslexia responds to

this program. Some students also receive excellent support from resource teachers at their schools, although the quality and availability of this service varies widely from school to school.

Alternatively, there are local private tutoring/instruction services available to assist kids with dyslexia. Some offer evidence-based treatment programs based upon the Orton-Gillingham approach, such as the Barton Method, the Davis Method, the Wilson Program (e.g., The Open Door, Dyslexia Solutions), while others offer one-on-one individual sessions with experienced special education teachers based on the student's assessed needs and learning support history.

Your role as a parent is to advocate for your child's learning needs. To do this effectively, you need to fully understand your child's learning strengths/weaknesses, the nature of their diagnosis, the recommendations best suited to advance their educational needs and what type of supports and programs are available at your child's school. Knowledge is power, and a comprehensive psychoeducational assessment provides you with the evidence (knowledge and power) needed to help your child's school staff understand his/her learning needs.

A former politician once said, *"There's what you know you know, what you know you don't know and what you don't know you don't know."* One challenge as a parent is to find out 'what you don't know you don't know' about school resources, policies and procedures beneficial to your child's learning needs. A useful question to ask at teacher conferences is: *"What do I need to know about resources/policies/procedures available for my child at your school I don't know?"*

Every child with learning needs is entitled to an Individual Educational Plan (IEP) to specify which accommodations/modifications are needed to support their learning needs. Many children with diagnosed exceptional needs may require formal identification through the Identification, Placement, and Review Committee (IPRC) process, which is a legal procedure available to ensure your child's school board meets your child's learning needs through accommodated programming, modified programming, resource teacher assistance and, in some instances, special class composite placement.

Children with exceptional learning needs may qualify for a Special Education Allotment (SEA), which is an Ontario government funded program to provide school-aged children and adolescents with computer hardware/software equipment. The local school staff complete an application form with a statement from a qualified professional indicating the equipment is *essential* for the student to access the curriculum.

Qualified professionals include: psychologists or psychological associates, physicians, audiologists, speech-language pathologists, augmentative communication therapists, optometrists /ophthalmologists, occupational therapists and physiotherapists.

Having worked as a school psychologist for many decades, I have no doubt the public and private school systems have several dedicated staff willing to do everything possible within their limitations to support kids with exceptional learning needs. Both systems have their pros and cons, but each work best with direct parent involvement.

I hope this brief article is informative and helpful in better understanding dyslexia, how to share information with your kids and what can be done to support them.

**SOURCES:** Dr. Stephen Feifer, Dr. Nancy Mather and Dr. Virginia Berninger.



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