

Dyslexia, Health, and Literacy

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What is Dyslexia?

Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge

—National Institute of Child Health and Development and
International Dyslexia Association (2003)

- Specific—certain skills are very difficult to acquire
- Neurological—persistent in nature—fMRI studies confirm that different areas of the brain are activated for children and adults with dyslexia during various reading and language tasks
- Difficulties with accuracy and/or fluency in word reading (reading aloud is effortful, though accuracy may improve over time)
- Decoding (difficulty sounding out words that is inconsistent with education level)
- Spelling problems
- Phonological processing deficits (discriminating, manipulating, and associating sounds with print)
- Language based (word finding and naming difficulties)
- Unexpected related to other abilities (average or above intelligence)
- Possible secondary difficulties in reading comprehension (using less efficient parts of the brain leaves less mental energy for thinking about meaning)
- Possible reduced reading experience, vocabulary and background knowledge (can be avoided with intervention)

How common is dyslexia?

“Dyslexia may be the most common neurobehavioral disorder affecting children, with prevalence rates ranging from 10% in clinic and school identified samples to 17.5% in unselected population based samples in the U.S. and other countries.”

—Lyon, Shaywitz, and Shaywitz. *Nelson Textbook of Pediatrics*, 2007.

In other words, even with the more conservative numbers of 10%, we all connect with people who have dyslexia every day—whether we know it or not. In a busy medical practice, a health care provider may interact daily with 3-4 kids or adults with some degree of dyslexia. In every classroom there are 2-3 students with dyslexia.

“Dyslexia is one kind of language-based learning problem that can fall anywhere on the spectrum of annoyance to severe limitation...It is more common than any other kind of learning disability. And, it responds to expert, informed instruction—the provision of which remains our greatest challenge.”

—Moats. *Perspectives on Language and Literacy*, Winter 2008

What does dyslexia look like in health settings?

- It could be a young boy who no longer wants to go to school...
- It could be a brilliant entrepreneur who sells KINKOS for \$2 billion and still considers himself a non-reader...
- It could be the young guy just out of prison who has no job opportunities because he dropped out of school and can't read...
- It could be the well-dressed mother who nods politely but doesn't understand the directions on her discharge sheet...
- It could be a physician, teacher, nurse, veterinarian, architect, mechanic, engineer, artist, postal worker, grocery clerk, or politician...

Dyslexia is a common reason an individual struggles with literacy, though multiple factors influence literacy and health literacy.

CLUES TO DYSLEXIA BASED ON DEVELOPMENTAL STAGE

Yale Center for Dyslexia and Creativity

www.dyslexia.yale.edu

Preschool Years

- Trouble learning common nursery rhymes
- Difficulty learning to name letters of alphabet
- Unable to recognize letters in own name
- Mispronounces familiar words
- Doesn't recognize (or enjoy) common rhyming patterns (cat, mat, bat, rat)

Kindergarten and First Grade

- Reading errors that show now connection to sounds of letters on the page—puppy instead of dog because there is a picture of dog on the page
- Does not understand that words come apart
- Complains about reading or disappears when it is time to read
- Cannot sound out even simple words (at, ran, it, dog)
- Does not link letters and sounds well

Possible Strengths—curiosity, great imagination, ability to figure things out, eager to learn new ideas, good at grasping new information, surprising maturity, larger vocabulary, enjoyment with solving puzzles, talent at building models, excellent comprehension of stories read or told to him or her

Second Grade and Up

Reading

- Very slow in acquiring reading skills (beware of developmental lag theory)
- Reading is slow and awkward
- Trouble reading unfamiliar words, often making wild guesses
- Doesn't seem to have a strategy for reading new words
- Avoids reading out loud

Speaking

- Searches for a specific word, ends up using vague language such as stuff or thing
- Pauses or hesitates frequently when speaking
- Confuses words or sayings that sound alike, such as tornado for volcano, get your feet wet instead of getting cold feet
- Mispronunciation of long, unfamiliar or complicated words
- Seems to need extra time to respond to questions

School and Life

- Trouble with remembering specific dates, times, random lists
- Trouble finishing tests on time
- Extreme difficulty with learning a foreign language
- Messy handwriting
- Low-self esteems that may not be immediately visible

Possible strengths—excellent thinking skills, learning that is accomplished best through meaning rather than rote memorization, ability to get the big picture, high level of understanding when read to, surprisingly sophisticated listening vocabulary, excellence in areas not heavily dependent on reading and is more conceptual

Young Adults and Adults

Reading

- A childhood history of reading and spelling difficulties
- While reading skills have developed over time, reading still requires great effort
- Rarely reads for pleasure
- Slow reading of most materials
- Avoids reading aloud

Speaking

- Pronounces names incorrectly, trips over parts of words
- Difficulty remembering names of people and places
- Struggles to retrieve words, has “it’s on the tip of my tongue” moments frequently
- Struggles when put on the spot
- Spoken vocabulary is smaller than listening vocabulary
- Avoids words that are tricky
- Earlier oral language difficulties persist

School and life

- Despite good grades, may say or worry that others think he or she is dumb
- Penalized by multiple choice tests
- May sacrifice social life for studying
- Extreme fatigue when reading
- May perform rote clerical tasks poorly

Possible strengths—high learning capability, noticeable improvement when given extra time on test, excellence when focused on specialized area of study, excellence in writing if content and not spelling is important, original thoughts, out of the box, creative thinking, resiliency and ability to adapt

What can healthcare providers do for dyslexia?

- Appreciate that dyslexia is common, often hidden, and persists throughout life
- Understand that the way dyslexia manifests itself varies depending on educational opportunities, co-morbid conditions, and individual strengths
- Offer support, resources, and coordination care
 - ⇒ Speech/Language
 - ⇒ Occupational Therapy
 - ⇒ Ophthalmology
 - ⇒ Audiology
 - ⇒ Psychology
 - ⇒ Psychiatry
 - ⇒ Collaboration with Schools
 - ⇒ Etc.
- Take a good, age-appropriate family history

Dyslexia runs in families. Areas on multiple chromosomes have been implicated for transmission of this condition. Family history is a strong risk factor. Numbers vary based on the group studied, but an easy thing to keep in mind is $\frac{1}{2} * \frac{1}{2} * \frac{1}{2}$.

About half of kids with dyslexia have a parent with dyslexia. There are parents who are able to understand their personal learning struggles only after having a child diagnosed. Notable examples include financier Charles Schwab and author John Irving.

About half of parents with dyslexia have a kid with dyslexia and about half of siblings with dyslexia will have a sib with dyslexia. Discussing parent and sibling reading and learning problems is an opportunity for monitoring and early intervention for other family members. It is an opportunity to carefully tailor all interactions.

HOW AND WHAT WE ASK IS ALSO VERY IMPORTANT!

If I had been asked prior to my son entering kindergarten if anyone in our family had a learning disability, I would have quickly said no. Looking back there are relatives on both sides who had difficulties with school...but were never diagnosed with anything specific.

Details To Consider When Asking Kids About School

What are they reading?

Struggles or frustrations in school?

Reading, writing, or math problems?

Difficulty completing assignments on time?

Extra support from parents/teachers/tutors?

What are they good at?

Time spent on homework?

Spelling difficulties?

Avoidance of homework?

Worrying about school?

Health Literacy and Education are Inextricably Linked

Details To Consider When Talking With Adult Patients Or Parents

“...Routine screening is controversial. Some worry that it takes too long, embarrasses patients, and could stigmatize those with low literacy...physicians often perceive inquiring about reading ability as opening Pandora's box, releasing a sprawling, unwieldy problem that they haven't been trained to handle and that is beyond the scope of a 15-minute office visit...health care system does not help physicians who treat low-literacy patients. Some experts advocate an approach to communication similar to universal precautions...assume that all patients have a limited understanding of medical words and concepts, whether or not they have passable general-reading skills...organize their discussions with patients around three key points per visit and use a teach-back approach, asking patients to explain what they have been told.

—Marcus. NEJM. 2006.

Earlier is Better, But It Is Never Too Late To Learn

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