Dyslexia: Health, Literacy and Medical Libraries

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Key Topics

Definitions and Prevalence
Dyslexia Over the Lifespan
Consequences of Untreated Dyslexia
Health Literacy
Awareness and Lessons Learned--ALA
Evidence-based Reading Instruction
The Matthew Effect
Dyslexia and Librarians
DYS = DIFFICULTY
LEXIA = LANGUAGE
What is Dyslexia?

- Term for person with unexpected difficulty learning to read (and write and spell)

- Usually the problem is very specific to reading

--Professor Mark Seidenberg, UW-Madison
Dyslexia
National Institute of Child Health & Development (NICHD)

- Neurobiological

Brain changes are seen with educational treatment

Image courtesy of Eden, G. Georgetown University
“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.”

1 in 5 have some degree of Dyslexia—mild to severe
Dyslexia
National Institute of Child Health & Development (NICHD)

- Deficit in **phonological component of language**

- Unexpected in relation to other cognitive abilities and the provision of effective classroom instruction.
Dyslexia
National Institute of Child Health & Development (NICHD)

- Difficulties with accurate and/or fluent word recognition
- Poor spelling and decoding abilities
Secondary Consequences

- Untreated Dyslexia may result in:
  - Reading comprehension problems
  - Poor reading experience
  - Less growth of vocabulary
  - Decreased background knowledge

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What is Dyslexia?

- If society did not require reading, the person’s impairment would go unnoticed!

--Professor Mark Seidenberg, UW-Madison
But...our society **does** require reading, writing and spelling
What Dyslexia is NOT

- NOT about letter reversals or “seeing backwards”
What Dyslexia is NOT

• NOT a general learning problem
• NOT due to lack of motivation
• NOT rare
Left untreated, dyslexia may lead to...

- low self-esteem
- behavioral problems
- anxiety and depression
- delinquency
- aggression, and withdrawal or alienation from friends, parents and teachers.

http://www.mayoclinic.com/health/dyslexia/DS00224/DSECTION=complications
Lost Potential

“There is a 27% drop out rate of students with learning disabilities; that is more than twice the rate of the general population... lost potential... problems with substance abuse and juvenile justice problems... one can go to prisons and see that... the majority of inmates lack reading skill.”

James Wendorf, Exec. Director, National Center for Learning Disabilities
Suicidal Behavior

“In our study, poor readers were 3 to 6 times more likely than typical readers to consider or attempt suicide and 6 times more likely to drop out of school. ...Educators and parents should be aware of the risk of suicidal thoughts and behavior among adolescents with reading problems.”

-- Stephanie Sergent Daniel, PhD
Interview in ScienceDaily (Nov. 3, 2006)
How can we work together?

Health Professionals and Librarians

- Promote early identification of dyslexia
- Promote screening for adults
- Provide equal access to vocabulary and background knowledge
- Coordinate support from clinics, hospitals, schools and libraries
Who might be dyslexic?

- A little girl who loves listening to stories...
- An entrepreneur who sells KINKOS for $2 billion and considers himself a non-reader...
- A young guy just out of prison...
- A physician, teacher, architect, mechanic, artist, clerk, politician, librarian...
Signs of Dyslexia

- Family history of reading or learning problems
- Early: late speech development, difficulty with rhyming, letters and sounds
- School years: trouble sounding out words, difficulty with spelling, avoids reading
- Adults: slow, effortful reading, lack of fluency

Yale Center for Dyslexia & Creativity
http://dyslexia.yale.edu/EDU_signs.html
Sea of Strengths

- Curiosity
- Imagination
- Ability to figure things out
- Gets the gist of things easily
- Good understanding of new concepts

http://dyslexia.yale.edu/EDU_signs.html
Multiple Barriers

- Health settings
- Schools
- Justice system
- Libraries
Barriers in Health Settings

Physicians are not routinely trained to identify risks for dyslexia.

Screening is not standardized.

Access to neuropsychological testing is not readily available.

Lack of insurance coverage.
Barriers in School Settings

A few states require early screening and services--Wisconsin does not

Massachusetts requires teacher training in evidence-based reading instruction--MA ranks #1 in reading (NAEP, 2009)

Too often, schools do not specifically acknowledge dyslexia
In Wisconsin...

- Dyslexia is not identified routinely.
- Inconsistent policies and procedures exist throughout the state.
- Teachers are not required to have training in evidence-based reading instruction.
- When identified, a Wisconsin dyslexic is unlikely to be provided effective reading instruction.
Legislation in Wisconsin 2009-2010

- **ASSEMBLY BILL 584**
  Dyslexia screenings required annually for pupils in grades K-2 and selectively in grades 3-5

- **ASSEMBLY BILL 583**
  Reading specialist and special ed. teacher: supplementary exam required for license issuance or renewal

  Bills died in Committee.
Low Health Literacy Costs...

- Between $106 BILLION to $238 BILLION annually to the U.S. economy
  

- Up to $7.6 BILLION annually in Wisconsin

  http://www.madison.com/wsj/topstories/444955

---John A. Vernon, PhD
Literacy Skills and Health

“Literacy skills are a stronger predictor of an individual’s health status than age, income, employment status, education level, and racial and ethnic group.”

Your physician has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.

-- Barry Weiss, MD

“Reading problems are not outgrown, they are persistent.... Without identification and proven interventions, virtually all children who have reading difficulties early on will struggle with reading when they are adults.”

Children of the Code: Excerpt

- Health and health care (2 min; 16 sec)

http://www.childrenofthecode.org/Tour/c1/health.htm
Library staff generally exhibited the same lack of knowledge about learning disabilities as the U.S. population in general.

The most common misconception of library staff was that people with learning disabilities are intellectually disabled.

(Intellectual disability was not the term used when the survey was published in 2001.)
Services and programs for people with disabilities are perceived as peripheral to the library’s mission, rather than a necessary and integral part of its programs and services.
Many librarians miss the connection between learning disabilities and key areas of concern:

- information access
- technology
- literacy
Most attention to disabilities focuses on “bricks and mortar” fixes for people who are deaf, blind or have mobility difficulties.

--ALA Roads to Learning, 1996-2001
Diversity isn’t just about race, language or culture

“As far as how we think about, talk about, depict and serve people with disabilities, we’re back in the 1950’s or 60’s.”

--Audrey Gorman.
“On My Mind.”
Undetected or untreated learning disabilities have been found in 60% of adults with severe literacy problems.
Deficits in reading skills are the most common forms of learning disabilities.

People with learning disabilities are generally of normal or above average intelligence.
People have learning disabilities all of their lives.
When the learning disabilities of young criminal offenders are addressed, their recidivism rate is 2%.
People with learning disabilities can learn to compensate for their conditions.
“Although the world is full of suffering, it is also full of the overcoming of it.” -- Helen Keller

Helen Keller and Anne Sullivan. 1897. http://hdl.loc.gov/loc.pnp/cph.3a15420
Evidence-based reading instruction

Slide courtesy of Guinevere Eden, D.Phil.
Multisensory Structured Reading Instruction

- Helen Keller and Anne Sullivan
- Orton-Gillingham
  - Dr. Samuel Orton (1879-1948)
  - Anna Gillingham (1879-1964)
- Sample of programs based on O-G
  - Project Read
  - Wilson Reading System
  - Lindamood Bell
- Emerging programs
  - RAVE-O
MSL Programs

- Multisensory
  - Visual
  - Auditory
  - Kinesthetic
  - Tactile
- Sequential
- Explicit
- Cumulative
- Learn to mastery

Content is complex.
“Teaching reading is rocket science.”
--Louisa Moats, Ed.D
Keira Knightley, Patrick Dempsey, actors
Carol Greider, PhD, Winner of the 2009 Nobel Prize in Physiology or Medicine
Bruce Jenner, 1976 Olympic Champion & Narrator of Demystifying Dyslexia
Barriers at the reference desk and in the medical community
The Matthew Effect

--Keith Stanovich

“The word-rich get richer, the word-poor get poorer.”

- Good readers read
- Poor readers avoid reading
- Poorer readers read less and learn less from reading
Finding information
Search terms

- Dyslexia
- Specific learning disability
- Learning disabilities
- Reading disability
- LD
- Developmental reading disorder
- Learning disorders
- Learning difference
Related topics

- Attention Deficit Hyperactivity Disorder (ADHD)
- Dyscalculia
- Dysgraphia
- Executive function
- Gifted/twice exceptional
National Institute of Neurological Disorders and Stroke (NINDS)  http://www.ninds.nih.gov/disorders/dyslexia/dyslexia.htm

National Center for Learning Disabilities  http://www.ncld.org/

International Dyslexia Association  http://www.interdys.org/

Learning Disabilities Association of America  http://www.ldanatl.org/

National Institute of Child Health and Human Development  http://www.nichd.nih.gov/

National Institute of Mental Health (NIMH)  http://www.nimh.nih.gov/index.shtml
Fact sheets
Bibliographies
Research on multisensory structured language instruction programs


See also websites: LD Online, Reading Rockets and Wrightslaw
Support & Advocacy in Wisconsin

- Learning Difference Network
  http://sites.google.com/site/learningdifferencenetwork/

- Wisconsin Branch of the International Dyslexia Association
  http://www.wibida.org/

- Wisconsin Literacy
  http://wisconsinliteracy.org/
  Health Literacy Wisconsin
  http://www.healthliteracywisconsin.org/

- Wisconsin Reading Coalition
  http://sites.google.com/site/wisconsinreadingcoalition/
Accommodations

- Time
- Accommodations do not simplify the material to be learned, but only the effort required to learn it.
- Utilize diverse and informative materials in multiple media & adaptive technologies.
- Know your patron’s learning profile.
Assistive Technology

- Wisconsin Public Library Consortium
  http://www.wplc.info/welcome.html
- Wisconsin Regional Library for the Blind and Physically Handicapped
  http://dpi.state.wi.us/rll/wrlbph/
- Disability.gov
  http://www.disability.gov/education/assistive_technology
- RFB&D (Recordings from the Blind & Dyslexic)
  http://www.rfbd.org/
- TechMatrix
  http://www.techmatrix.org/Home
3 great, new documents—
but no word of dyslexia

- Health Literacy Universal Precautions Toolkit

- National Action Plan to Improve Health Literacy

- Healthiest Wisconsin 2020
What librarians can do:

- Re-examine how we do reference interviews
- Build collections and include multimedia formats
- Think about access: directions, call numbers, etc.
- Consider aspects of universal design
- Partner with other libraries and literacy groups
- Raise awareness
Questions?

- What materials are available and accessible for:
  - medical practitioners
  - parents, teachers and tutors
  - individuals with dyslexia (all ages)

- Do you have information on:
  - dyslexia
  - evidence-based multisensory reading instruction
  - dyslexia organizations and community resources
Related Early Literacy Programs

- Reach Out & Read
  - MDs prescribe literacy
- Get Ready to Read
  - Screening Tool
  - Information for librarians
Start a collection...

**Overcoming Dyslexia**

A new and complete science-based program for reading problems at any level

*Sally Shaywitz, M.D.*

*Co-director of the Yale Center for the Study of Learning and Attention*

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**Parenting a Struggling Reader**

A guide to diagnosing and finding help for your child's reading difficulties

*Susan L. Hall & Louisa C. Moats, Ed.D.*

*Authors of Straight Talk about Reading*
For beginning readers...

- Promote **multisensory** approach to songs, finger plays, rhymes and movement
- Provide information on the **early signs of dyslexia** and the **importance of early intervention**
- Build collections with **decodable books**
Authors with dyslexia write books for kids...
“My father was an angry and impatient teacher and flung the reading book at my head.”

--W.B. Yeats
“I won a Pulitzer Prize for playwriting, and I grew up having trouble reading.”

“I write in libraries, almost because I have the sense of wonder about all these other people who sit and read.”

“I’m not going to be able to read a book with small print or a lot of print. It helps if it has really dark print.”

--Wendy Wasserstein
author of The Heidi Chronicles
“Even though I couldn’t read quickly, I could imagine things faster than some other people who were stuck thinking sequentially. That helped me in solving complex business problems. I could visualize how things looked at the end of the tunnel.”

-- Charles Schwab
“Librarians do change lives.”

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