Arguing Over Why Johnny Can't Read

2.3 million U.S. schoolchildren are now diagnosed with learning disorders; controversial findings pin the blame on biology and suggest the problem could be even more widespread

If difficulty learning to read, write, or do math at expected aptitude levels were an infectious disease, American schoolchildren would be in the middle of an epidemic. About 120,000 students each year are tagged as "learning disabled," a number equal to all the Americans who contracted AIDS, hepatitis, and tuberculosis in 1994. There were 783,000 children with learning disabilities (LD) in 1976; by 1992–93, the last year for which full figures are available, the LD population topped 2.3 million. This is a costly epidemic, too: Public schools spend about $8000 a year on average to educate an LD student, compared to $5500 for an ordinary student, and the bills are estimated to be in the billions of dollars.

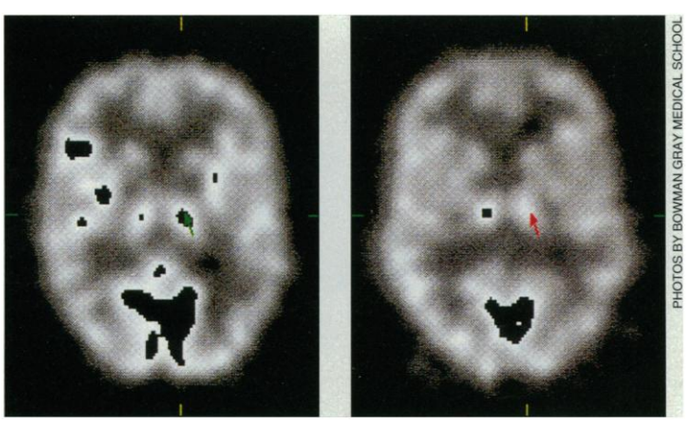
Yet despite the rising numbers, the definition, diagnosis, and basic scientific understanding of LD has remained remarkably elusive. There's no agreed-upon psychological test, no biomedically discernible problem, that characterizes LD. As a result, children are usually diagnosed as learning disabled when their reading or math competency lags significantly behind the level predicted by their IQ scores. (A low IQ score by itself does not denote LD.) Yet the size of the discrepancy between performance and IQ scores that merits the label varies from state to state—indeed, one "cure" for LD can be to move across state lines. Much of the diagnostic criteria "was set by policy, not by science," says Reid Lyon, a psychologist in the Human Learning and Behavior branch of the National Institute of Child Health and Human Development (NICHD). And special education, sometimes involving intensive reading programs that emphasize discerning word meanings from context, leads to only a 61% high school graduation rate nationwide, hardly the remedy with which to halt an epidemic.

Lyon thinks science now has something better to offer. NICHD has spent 10 years and nearly $30 million trying to decipher the underlying features of LD, and he and other researchers say they have traced aspects of the condition—such as a deficit in "phonological awareness," or the ability to decode words into individual sound units—to the level of the neuron and even to the gene. The researchers have begun to demonstrate that in poor readers, anatomical structures and activity levels in areas of the brain believed to be related to phonological processing show subtle abnormalities. Such abnormalities, they say, may appear in 20% of the nation's schoolchildren.

Together with data from years of school-based studies of reading performance, the scientists say, these findings strengthen the case for revising teaching methods nationwide. They want to replace current context-based reading instruction with "highly structured, explicit, and intensive instruction in phonics rules and [their] application to print," in the words of an NICHD report.

But skeptics charge that these neurobiological findings will actually make the LD muddle even worse. Observers argue that the mechanisms supposedly linking brain and behavioral differences are still sketchy—and differences in brain structures themselves provide no basis for identifying children for special services or devising new instructional methods, says Gerald Coles, a University of Rochester educational psychologist and author of *The Learning Mystique*, a 1987 critique of the LD concept. Marcus Raichle, a neurologist at Washington University in St. Louis and a pioneer in the use of magnetic resonance imaging to study brain functioning, agrees that such techniques tell little about the practical significance of brain differences between normal and LD readers.

Critics also object to the researchers' narrow focus on the neurobiological "final common pathway" presumably underlying learning problems, arguing that LD's complex social, economic, and environmental antecedents deserve equal weight in educational policy planning. And even if the neurobiologists are right, dropping 20% of the school population into special education classes would strain that system to the breaking point, says Kevin Dwyer, assistant executive director of the National Association of School Psychologists: "We need to avoid coming to grand conclusions with less-than-complete data."



PHOTOS BY BOWMAN GRAY MEDICAL SCHOOL

Reading problem? Arrows in these brain images point to the left thalamus of a normal reader *(left)* and a dyslexic *(right)*. There are higher activity levels in the normal reader's thalamus *(dark areas in PET scans)*.

The growth of a problem

The current disarray that defines LD begins, appropriately, with its definition. Students identified as dyslexic, who make up about 80% of the LD population and have been studied much more thoroughly than those with other categories of learning disabilities, typically have difficulty matching the letters in written words with the corresponding speech sounds, or phonemes. Students with math disabilities or "dyscalculia," on the other hand, have trouble naming and comparing numbers and performing mental calculations. Both groups—which often overlap—also have IQs which lead their teachers to expect higher achievement, making the "discrepancy diagnosis" the current hallmark of LD. What these children don't have is anything else obviously wrong with them to account for their learning problems, such as visual or hearing handicaps, emotional disorders, or mental retardation. (About 25% of LD children also have attention-deficit hyperactivity disorder, considered a separate medical condition.)

The looseness of this definition is one reason that the LD population has swollen so dramatically since parents' groups convinced Congress to officially recognize the conditions as a disability in 1968. By 1978 LD had already outstripped all other categories of disabilities recognized under the Individuals with Disabilities Education Act, including speech impairment, mental retardation, and physical handicaps.

Neither parents nor scientists were

pleased with this situation. Parents' advocacy groups like the Learning Disabilities Association of America (LDA) saw the population expanding without any concomitant growth in knowledge about causes or treatments. And scientists attacked the legal definition of LD for diagnosing by exclusion of other conditions and by IQ discrepancy rather than through a positive, theory-based method. The discrepancy model, they asserted, fails to tag children who perform poorly in reading and score low on IQ tests; although they may encounter many of the same frustrations as LD children do, these students are classified as generally underachieving, and therefore receive no specialized out-of-classroom instruction. In response to this discontent, Congress decided to put some new money into learning-disabilities research.

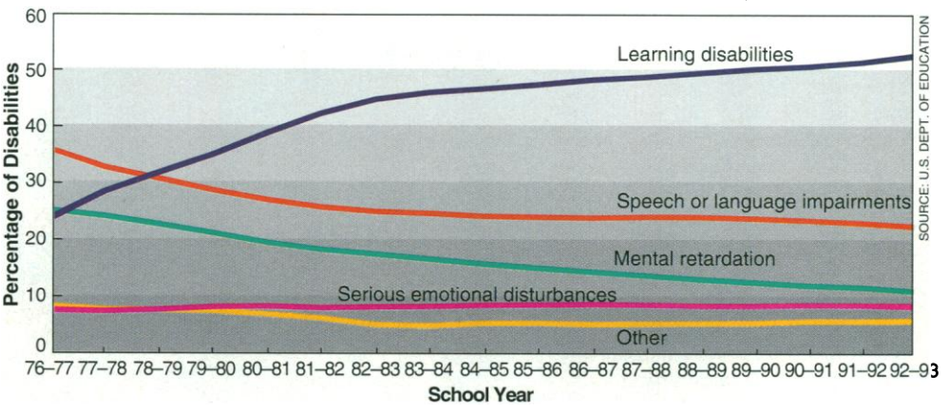
In 1985 legislators directed the National Institutes of Health to review research activities in the area. The outcome of that review was the creation in 1987 of a network of Learning Disability Research Centers (LDRCs), since funded through NICHD to the tune of some $29 million. The network's goal, according to Lyon, is to improve knowledge of the epidemiology, etiology, diagnosis, and treatment of LD; in short, to develop the study of LD into a respected scientific discipline. And according to investigators in the network, it has done just that.

Searching for a cause

"NICHD has assembled a critical mass of investigators and made the study of learning disabilities into a science," contends child neurologist Bennett Shaywitz, who, with his wife Sally, a behavioral pediatrician, established the first LDRC at Yale University's Center for the Study of Learning and Attention. In studies progressing inside and outside the LDRCs, researchers are using functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) scans to watch activity levels of cells in various areas of the brain. Several of these studies have focused on the thalamus, a double-egg-shaped structure deep within the brain that mediates sensory input to the cerebral cortex. It functions like a telephone switchboard, taking incoming signals from the eyes, ears, and other sensory organs and routing them to different areas of the brain.

PET and fMRI studies of 60 randomly selected normal-reading and dyslexic adults have led neuropsychologist Frank Wood and colleagues at Bowman Gray Medical School to conclude that activation levels in the thalamus are different between the groups. Wood asked subjects undergoing a PET scan to watch letters and nonletter shapes (like "R" and "Я") projected on a screen and to press a button whenever a real letter was shown. Subjects who scored in the bottom 10% of the population on a standard reading test had less activity in the left thalamus, Wood discovered.

Additional support for the role of the thalamus in LD comes from separate studies designed to build a picture of phonological processing in the brains of normal readers as a prelude to future studies of dyslexics. Both the Shaywitzes at Yale and cognitive neuroscientist Paula Tallal at Rutgers University in New Jersey have identified another brain area, in the prefrontal cortex, as crucial in speech-sound processing. But Tallal's work also indicates that this processing relies on rapid and precise timekeeping in the brain, a role known to be played by the thalamus.



Growth area. More than half of all schoolchildren classified as disabled have learning disabilities. Eighteen years ago, the proportion was around 25%.

High-tech imaging techniques aren't the only tools that have homed in on the thalamus; the knife of the neuroanatomist has also come into play. In a study reported last August in the *Proceedings of the National Academy of Sciences*, Albert Galaburda, a neurologist at Beth Israel Hospital in Boston, and two colleagues examined tissue sections from the medial geniculate nuclei (MGN), small bumps on each lobe of the thalamus that process inputs from the auditory nerves. The researchers found that neurons from the left MGN in five dyslexic brains were, on average, smaller than those from the right MGN, an asymmetry that was not detected in the brains of seven control subjects.

The final realm in which NICHD-funded research on learning disabilities has attracted widespread attention is that of the genome. Family studies initiated in 1973 and twin-pair studies begun in 1982 by behavioral geneticist John DeFries and colleagues at the University of Colorado LDRC are yielding evidence that reading disabilities not only run in families, but may be linked to genes in a specific region of chromosome 6.

DeFries' lab has tested over 300 pairs of twins in which at least one twin is dyslexic. In a study described last year in *Science* (14 October 1994, p. 276), DeFries, geneticist David Fulker, and four other collaborators described evidence for a possible quantitative trait locus (the location of the suspected gene or genes) in exactly the same region in both the twins and the nontwin siblings. Behavioral geneticist Robert Plomin of Pennsylvania State University says the study provides the first evidence for the localization of a single putative gene for any complex behavioral characteristic to be replicated in two independent samples.

These developments also have their boosters outside the scientific community. Candace Bos, president of the Division for Learning Disabilities of the Council for Exceptional Children (CEC), notes that "it's reassuring to be able to say that there is initial evidence for a genetic and a brain-functioning link. Now we can move on ... to look at specific interventions." Says Sally Shaywitz: "Now that we know this is a phonological deficit it can really guide the public."

Connecting cause and effect

Not everyone, however, is ready to make the leap from these studies to educational policies. Observers such as the University of Rochester's Coles believe that many of the assumptions underlying DeFries' work and the other studies are flawed. "Truly substantial research would look at brain structure and function, but it would also look at the cognitive processes involved when children are learning to read and at the full set of social experiences related to learning," Coles says. But the current studies, he continues, stop at the anatomical level and may not even say much about that: "To extrapolate from all of this current scientific ambiguity and speculation to diagnostic instruments and school policy is a non sequitur."

Coles takes particular issue with Galaburda's work, saying the Beth Israel scientist has not documented whether the deceased subjects in his studies had really suffered from dyslexia. "There is virtually nothing at all in the research to demonstrate that these brains are indeed the brains of dyslexics," he com-

plains. Further criticism comes from a surprising corner: NICHD's Lyon. "The anatomical studies are going to be tough to interpret. The topography of brain structures is as variable as are our faces," he says. Lyon also notes that Galaburda was unable to control for the gender, handedness, or health problems of his autopsy subjects, all of which could have had independent effects on the anatomy of their brains. "The good science started with structural anatomy, but it's not going to elucidate much beyond telling us where to look with our functional-imaging machines," says Lyon.

Galaburda responds that, while they were alive, the people he studied met the "standard diagnostic criteria" of discrepancy between measured and expected reading achievement. "I stand confident that as more and more data are acquired on the brains of dyslexics, our findings will be replicated," he says. As to the charge that brain topography is ambiguous, Galaburda acknowledges that "individual variability in unusual brains is a major issue" in both anatomical and neuroimaging studies, but says that computerized imaging techniques allowing many subjects' brains to be "homogenized" in artificial composites will help alleviate this problem.

Coles, however, thinks neither this nor the prized fMRI, PET, and other neuroimaging studies will alleviate anything. "The technology has obviously grown more sophisticated, but that doesn't eliminate the fundamental conceptual problem of distinguishing between causation and correlation," he says. Demonstrating a difference in brain activation between normal and learning-disabled readers, as Wood did, does not prove the difference is responsible for the disability, he points out.

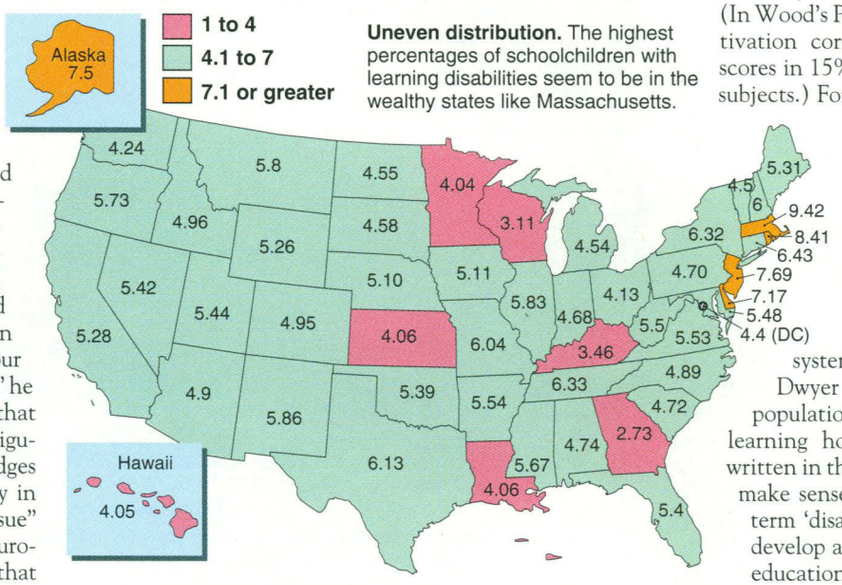
Again, other LD researchers admit that such objections carry some weight. Tallal of Rutgers goes so far as to say that many neuroimaging studies resemble "modern-day phrenology." She says that "just because we are looking at the brain [while a subject is] reading or listening to music doesn't mean that is what the brain is actually doing. The spots that we see activated might be integrating tasks across large domains of the nervous system." Neurologist Raichle adds that a dyslexic would probably employ very different cognitive strategies—and neural circuitry—from a normal reader in performing the test, so comparisons of neural activation are difficult.

But Tallal also points out that the neuroimaging studies are "getting better" and that their basic strategy is pragmatic: "If we had a more specific diagnosis for language-based learning disabilities, we could design more specific therapies."

Lurking behind these debates, however, is a far more basic objection—that the current studies fixate on a presumed neurological and genetic substrate for dyslexia while setting aside the influence of the family, classroom, and community, all of which affect how children grow and learn. Even malnutrition and environmental toxicity as possible causes of learning disabilities are "bad words" among NICHD-supported researchers, complains Audrey McMahon, a lay member of the scientific studies committee of the LDA. McMahon, who participated in the LDA's 5-year lobbying effort in the early 1980s to obtain increased congressional support for the scientific study of LD, says her judgment of NICHD's success today is "reserved. ... They haven't turned out to be as multidisciplinary as we wanted."

An overreliance on neurobiological markers concerns observers who fear it can be used to exclude, not to help. Says Daniel Hallahan, a professor of education at the University of Virginia, Charlottesville, "My worry with neuroimaging and PET scans and so forth is that you will have to have *x* amount of your brain affected to be considered disabled—that a single number is going to identify some kids as learning-disabled and other kids as not."

But DeFries sees the LDRC studies as a step toward removing ambiguity in the LD diagnosis. "A number of parents feel that their children should be getting extra help, but the school says no. If the parents could say, 'This child has a gene associated with reading disabilities,' that might help them qualify for special education."



Uneven distribution. The highest percentages of schoolchildren with learning disabilities seem to be in the wealthy states like Massachusetts.

SOURCE U.S. DEPT. OF EDUCATION

But what if it's true?

Indeed, the LDRC researchers emphatically deny that their work will cut needful children off from help. The Shaywitzes, Wood, and other researchers say the emerging diagnostic techniques are helping to confirm findings from conventional school-based surveys, such as Sally Shaywitz's 12-year Connecticut Longitudinal Study of over 400 randomly selected schoolchildren, that as many as 20% of all students have persistent difficulty with phonological processing. (In Wood's PET study, low thalamic activation correlated with low reading scores in 15% of the randomly selected subjects.) For cash-strapped school systems already struggling to cope with growing numbers of students with LD, that's a frightening prospect.

Some contend that such findings would mean scrapping the country's entire special education system. As school psychologist Dwyer puts it, "If 20% of the population has a dysfunction in learning how to decipher materials written in the English language, does it make sense any longer to utilize the term 'disability'? Do we not need to develop a system within the normal educational structure to make sure that all those different needs are met?" José Torres, a policy analyst for the National Association of State Boards of Education, voices a similar suggestion. He says his group favors an "inclusionary" approach in which all but the most severely disabled children would be taught in regular classrooms, and significant further expansion of the learning-disabled population would probably bolster this position.

That thought troubles a lot of professionals and activists in the LD field, who decry inclusion as a mere cost-saving move in a time of fiscal cutbacks. The CEC's Bos argues that full inclusion would mean ending the intensive instruction most LD students receive daily in resource rooms or separate classrooms. "The concern is that [through inclusion] they will lose all services except those that can be managed by the general education teacher who is juggling 30 other students," she says.

Potential conflicts over funding and curriculum are likely only to intensify debate as these studies of learning disabilities progress. And it's worth noting that no critic of the work has called for an end to the research. But they do plead for caution. "This research is still in its infancy," Dwyer says. "The scary part is for some people to assume that they already have the answers."

–Wade Roush