

Book's stories offer hope to families dealing with invisible disability

By Melinda Sacks
Special to the Mercury News

DYSLEXIA

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Even after more than 200 interviews, the stories continue to amaze author Shirley Kurnoff.

There is the little girl who would come home from first grade crying because she couldn't read the books her peers read. Today, at 28, she is getting her doctorate in psychology to study the condition that made her childhood so hard.

There is the University of Maryland junior who couldn't remember a word he'd read as an elementary school student but who today works as an archaeological research assistant and is considering the Peace Corps after graduation.

The list is endless -- bright kids who struggled to the point of desperation during grade school but didn't give up. Kurnoff's new book, "The Human Side of Dyslexia," highlights their battles and their eventual successes.

College kids share secrets for making it through a class with heavy reading and note taking. Parents tell of tricks they used to educate without alienating their children's teachers. And siblings reveal their feelings about growing up in households sometimes torn apart by the trauma of dealing with dyslexia, an invisible disability.

The book focuses on the success stories of people who have overcome dyslexia. It also makes clear why all of us should take an interest in the disorder that makes learning to read, write and spell so difficult for nearly 20 percent of the population.

"If you don't have someone in your immediate family with dyslexia, you don't have to look far," says Alexa Culwell, CEO of the Schwab Learning Foundation in

San Mateo, where thousands of parents find help in understanding and coping with dyslexia every year.

"If you think you don't know anyone, you just haven't looked carefully, or you're in denial."

Culwell says it doesn't surprise her that people interviewed for Kurnoff's book were more comfortable using pseudonyms to protect their privacy. The stigma of dyslexia is still powerful, parents and kids say. "When your child can't read or write at the age of 8," explains one mother, "the first thing people think is he's either stupid or lazy."



"My goal is to make the parents' journey less painful and more lighthearted." -
Shirley Kurnoff,
Author

Now understood to be the result of what scientists call "faulty wiring of the brain," research has recently shown that this lifelong, inherited condition may be linked to four chromosomes.

Webster's New World Dictionary defines dyslexia simply as "the impairment of the ability to read." Misconceptions about the disorder abound. The ideas that only males are dyslexic or that dyslexia is a visual disorder that makes people see letters and numbers backward have been disproved, and great progress has been made in early detection and teaching methods.

"There's no need for these kids to end up in the justice system consuming taxpayer money if we were properly educating them in the first place," Culwell argues. "When society doesn't care or take responsibility for these kids, you end up paying a lot of money and the social toll is huge."

Kurnoff, a 1995 graduate of Stanford University with a master's in education, wrote her book partly because, as the parent of a dyslexic daughter, she had looked for a

book about the subject that wasn't dry and clinical. When the Monterey-based mother couldn't find one, she decided to write her own, embarking on two years of interviews, many of which took place in the Bay Area.

"My goal is to make the parents' journey less painful and more lighthearted," she says. "If you are a student, the stories will show you some ways to cope. As a sibling, they will show you a caring way to understand your brother or sister. This book will give you encouragement and de-emphasize the negativity that comes with learning differences." Sarah Steffan is a 19-year-old Cal Poly-San Luis Obispo sophomore who grew up in the Bay Area. Steffan's little brother is six years younger. Although Steffan was a top student who read early and sailed through school, her brother is dyslexic and found reading painfully difficult.

"I would look at him in grade school still working on letters and realize at that age I was reading chapter books," she says. "There was a lot of stress in our house. He was stressed about school, and it didn't help his ego. I was

doing fine in school, and it was hard for me, too, because my parents didn't want to praise me in front of him since it made him feel worse. My mom came to me last year and apologized for how hard it must have been for me."

Like many of the siblings interviewed by Kurnoff, Steffan became protective of her brother. "If an adult would ask him, 'What does this say?' or he was in some situation where he had to read something, I'd step in just to be a buffer. It's made me a much more tolerant person. Now, if someone in one of my classes reads slowly or spells wrong, I don't automatically think they are dumb. I appreciate that not everyone has the same strengths."

Feeling stupid is one of the most painful side effects of dyslexia, says Caroline Bailey, 27, who grew up in San Francisco and attended Peninsula schools. Bailey, who is a student at the University of Southern California, is happy to use her real name for this story, because she wants people to know that being dyslexic doesn't have to limit one's life plans.

"I really wanted to be normal more than anything else," she says. "I got teased constantly. It started because I couldn't read, and that would make me cry. Then I'd get teased for being a crybaby. I was in a special class at school, and I got teased because other kids knew it was different."

But Bailey was tenacious. She'd stay in at recess to spend

IS YOUR CHILD DYSLEXIC?

The warning signs below are sometimes indicators that a child needs to be evaluated by a professional to find out whether he or she is dyslexic.

PRESCHOOL AGE

- Child speaks** later than most children
- Trouble** making speech sounds
- Slow** vocabulary growth
- Difficulty** rhyming words
- Problems learning** numbers, letters, days of the week

GRADES K-4

- Slow to learn** connections between letters and sounds
- Consistent** reading and spelling errors
- Transposes** number sequences, confuses signs for plus, minus and times

- Problems** remembering facts
- Trouble** remembering sequences and telling time

Source: Information provided by Schwab Learning

OVERCOMING OBSTACLES

Some famous and inventive people have overcome dyslexia to find extreme success:

- Charles Schwab**, investor
- John Chambers**, CEO of Cisco Systems
- William R. Hewlett**, co-founder, Hewlett-Packard
- Paul J. Orfalea**, founder and chairperson emeritus, Kinko's Inc.
- Jay Leno**, host of "The Tonight Show," NBC
- Craig McCaw**, chairman & CEO of McCaw Cellular Communications; chairman & CEO of Teledesic
- John Lennon**, musician

extra time on an assignment. She worked harder than her peers. "The thing about learning differences and dyslexia is it can be so different from one kid to another, and it's much more complex than most people think," says Chuck Bailey, the father of Caroline and her brother, John, who are both dyslexic.

"My wife, who is a special education teacher, knew from when they were 2 or 3 that something was amiss, but it took me much longer. I had this idea that you had to rely on grit and just tough it out. I had very high standards. When I finally accepted it in my gut, it helped a lot. Things still aren't perfect, but we've come a long way."

FINDING OUT MORE

Here are some resources for finding out more about dyslexia.

Shirley Kurnoff will be at the Stanford Bookstore Art Alcove at 7 p.m. at 519 Lausen Mall at Stanford University on April 16 to sign "The Human Side of Dyslexia." For more information on the event, call (650) 725-6136, extension 359. The book can be ordered online at www.edyslexia.com, or through major bookstores.

Schwab Learning, a free information and resource center for parents and kids, supported by the Charles and Helen Schwab Foundation, 1650 S. Amphlett Blvd., #300, San Mateo, Calif. 94402; www.schwablearning.org.

"**Misunderstood Minds**," a PBS documentary on learning issues, aired Wednesday as part of "The Developing Minds" library. These videos are based on the work of Dr. Mel Levine, founder of the All Kinds of Minds Institute. For more information on the tapes, call (800) 949-8670.