



## Princeton group says it's hard to get children's Dyslexia treated or even recognized

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By **Wendy Plump/For The Times**

**PRINCETON** — The group of parents sitting in a board room here were part of a hard-luck fraternity even before they decided to start their new statewide advocacy group, Decoding Dyslexia.

They had been meeting for years in local coffee shops to discuss how their children weren't reading anything by first grade, couldn't spell their names, couldn't remember sounds, couldn't match rhyming words, couldn't distinguish left from right, didn't have a dominant left or right hand, couldn't get their shoes on the correct feet let alone tie the laces — and they weren't getting support in their classrooms.



Andrew Miller/For The Times

Stacy Manzari gives Pre-Algebra instructions to her student Carter Mosner, 14, of Princeton during class at the Cambridge School in Pennington, where education is offered for students K-8 who learn differently on April 29, 2011.

And all along they were being told, there is no such thing as dyslexia.

"There are districts here and all around Mercer County that will tell you that dyslexia doesn't exist," said parent Liz Barnes, who grew up in Lawrence. "Well, it exists. My husband is dyslexic as well as my daughter. One in five people — not just kids but all people — have some form of it."

So together with other parents in the region who are experiencing the same frustrations, Barnes, Andrew Karulich of Pennington and Edward Bray of Learning Ally in Princeton formed the group Decoding Dyslexia last October. There are already 18 members, and more are sought. Membership is open to all.

Through their advocacy, these parents hope to spread the word that dyslexia doesn't readily fit the common misconceptions that dyslexics read backwards or reverse letters like "b" and "d." Instead, they said, it is a complex learning disability with its own set of interventions that work best when administered early.

Now they just have to persuade the school districts of that.

"Dyslexia falls under the umbrella of 'specific learning disabilities.' It's a clinical diagnosis," said Bray, the director of government relations for Learning Ally, a national nonprofit educational association that is providing free meeting space to the advocates from its Princeton location. "It's one of the classifications that qualifies a kid as learning disabled, but schools don't go any farther than that.

"And the frustration of parents is, they've done the research. They can say, I know of a more discrete diagnosis for my child and the interventions that work well. But they're not always listened to. It's getting the school to say 'yes' that is the problem."

Dyslexia is a language-based disability of neurological origin that affects both oral and written language skills, according to the International Dyslexia Association. Those who are dyslexic can and do learn, but they need a targeted program of multisensory interventions to help them with their language skills — one that provides sound- motion- and sight-based cues. Dyslexia and other learning disorders like it cannot be cured and often present lifelong challenges. It has a strong genetic predisposition.

By way of illustration, Bray described his daughter years ago when confronted with the task of writing sentences for her vocabulary homework. Imagine that she wanted to write the sentence, "The cat jumped over the fence," he said. By the time she figured out how to spell out the first word — agonizing over the simple fact of writing t-h-e — she would forget what she had intended to write next.

Dyslexics, these parents said, do not interpret words as words. Instead, the marks on the page look simply like a jumble of meaningless lines.

Now 13, Bray's daughter is largely receiving the help she needs, but only through an endless process of advocacy with her school system, Bray said. Barnes and Karulich have had to move their children to the Cambridge School in Pennington, which specializes in severe learning disabilities — and has a steep price tag attached. It is the only New Jersey school that offers a program targeted enough to help their children learn, they said.

"The simplest way to describe dyslexia is that it is a different wiring in your brain," said Karulich, who moved to Pennington with his family because the services in South Jersey, where they lived until recently, are ineffectual. Karulich and his wife have four young children. Three of them have dyslexia — as does Karulich's wife.

Like the other parents, Karulich grew tired of hearing that his eldest daughter was lazy or not trying hard enough in school or allowing her focus to waver.

"These kids are all working at 200 percent just to get through this," said Karulich. "I'd get her off the bus and she'd have this glazed-over look. They're overwhelmed with the day. And when I'm told by a man at her

school that dyslexia doesn't exist, I think, 'I can't even have a conversation with you.' These are the people I'm being asked to rely on."

Decoding Dyslexia is advocating specific goals. The first step is simply educating the public about dyslexia and correcting some of the misconceptions. The second is serving as a resource for parents of dyslexic children throughout New Jersey.

"A lot of parents don't know what to ask for and they're waiting for the educators to guide them," said Barnes. "But the educators aren't necessarily educated about it. We want people like us to have somewhere to go from day one as opposed to wasting multiple years to get there."

Third, Decoding Dyslexia wants to enact legislative changes so that dyslexia has a common definition enshrined in the state code for "the learning different." That way, Barnes said, the educational system will need to codify a set of interventions for this specific disability.

"Dyslexia affects your ability to read," concluded Bray. "If you can't effectively read you cannot be prepared for college and a career. We have to address this issue now, when they're young. Because otherwise we're going to take upwards of 20 percent of the population and effectively exclude them from those preparations.

"These are our individual stories. But our individual stories in aggregate," he said, "start to make a very dramatic impact."

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