Getting Past Denial

The author's son Louie calls this drawing "Pressure," and he said it's how he feels about his learning disabilities and his life—confused, a little at loose ends and happy.

by Martha Randolph Carr

THIS IS A CAUTIONARY TALE, not just for people who have no real idea of what a learning disability is and probably suspect the whole thing is an overindulgent scam, but also for any parent of a child struggling mightily through school. The timing is particularly good because of the ongoing debate about redesigning the federal law that governs how children with learning disabilities must be treated in public schools.

Last March, I sat in a nondescript room, at a set of long folding tables shaped into an L and ringed by plastic chairs, and asked officials at Godwin High School to please test my son, Louie, then a ninth-grader, for any possible learning disabilities. It had taken me 15 years to get to that meeting and while I didn't know it yet, I was going to learn as much about myself as I would about Louie.

I explained carefully, and repeatedly, that I didn't expect them to find anything seriously wrong. I assured them that whatever accommodations Louie might need, if any, would be simple.

Louie and I make up our entire family unit. He is a tall, creative 16-year-old whose wild curly hair makes him easy to find in a crowd. Almost from the time he was born, I've raised him alone. There have always been family members nearby, but nearly all of his milestones—the scary croup when his tiny chest heaved in and out, the visit to Santa when Louie said, "You know, I think he recognized me from last year," or the time he dyed his blond hair a flaming red—have been witnessed by just the two of us.

Early on, I learned to relate only the happy stories to friends or family because anything short of happy brought an avalanche of advice I didn't want and could rarely use. I chalked it up to TV talk shows, which seemed to make people feel that it was their obligation to tell me exactly what I should do without ever asking me what I'd already tried.

When Louie was in first grade it became obvious to me that he was having difficulty reading. To avoid labels being placed on my young son, I did what I thought was best: I started reading to Louie. Every book he came into contact with, whether for school or for fun, I read to him. To keep him entertained while I read, I created funny voices or made comments about the plot lines that I found particularly far-fetched. Through elementary and middle school, Louie grew into a thoughtful, intelligent, articulate boy who earned mostly Bs, but who had trouble comprehending the little he could read. No one else knew, and Louie and I rarely talked about it.

His reading difficulty was the only problem I saw, and I accepted that everything else was fine. I told myself that I was doing the right thing because Louie might feel bad about himself if he thought there was something wrong and because mainstream colleges wouldn't accept a kid with learning disabilities.

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Fortunately, time and high school caught up with both of us.

Louie's workload in ninth grade became so large that I couldn't read everything to him, and Louie was becoming too independent to want me to. He also was starting to fail in more ways than I realized. I knew that I had to find help, which led me to my request for testing and my pronouncement that Louie was in need of only a little help. But I still hadn't allowed myself to look at the depth of his disability.

John Ribble, a soft-spoken gentle man who is responsible for testing most of the students in the Henrico County system, called me for a meeting after only the first round of tests. He held out Louie's answers and said that, based on these first tests, Louie had a more acute problem than I had indicated. He pointed to one answer on a timed test that required more speed as it went along. Toward the end of the test, Louie had indicated that May was a day of the week. He hadn't had enough time to puzzle over the words. Ribble looked at me, still surprised, and said, "No one ever misses that question."

He pulled out old standardized test scores for Louie going all the way back that showed wild inconsistencies. He said the tests and Louie's school record suggested my son was not only "visually processing impaired" (Henrico County's official term for dyslexia), but that he likely had attention-deficit/hyperactivity disorder, and was suffering. Ribble pointed out this possibility again and again, mostly because I denied it firmly every time he said it. "I'd know if he was struggling that much," I protested. "I'd be able to tell."

But I hadn't. I had ignored the clues because I didn't want to see them. Besides not being able to read much, Louie was habitually disorganized, couldn't absorb instructions that went on for very long, and was easily distracted by sound or movement. All signs of AD/HD.

When I told Louie about the diagnosis, he didn't look hurt or confused. Instead, his face relaxed and he shouted, "You mean I'm not stupid?!" I was so taken aback that I started to cry. Louie said, still very relieved, "Were you worried, too?" I cried harder.

By denying the truth to myself and thus keeping it from Louie, I had left him with the only other plausible answer he could come up with as to why he always worked so much harder than his friends and didn't get the same grades.

Ribble had called me in early because he had sensed that I was part of the problem. For all the parents who battle with lawyers and school administrators to get their children the tools they believe are necessary to make progress—and there are thousands around the country—here was a public school system trying to do the right thing, trying to bring the parent out of denial.

To reinforce his findings, Ribble had polled Louie's teachers and found that Louie had recently stopped turning in most of his homework, which meant he was outright lying to me. He tapped the grade sheets with all the zeroes and said it again. "Louie is giving up." Finally, I stopped talking and began listening.

I sat through Louie's first IEP meeting—the beginning of the process to design the "individualized education program" called for under federal law—in somewhat of a daze. Over the next few months, we mapped out a plan to address Louie's weaknesses and bolster his strengths. Most importantly at the time, the school offered to pay for Louie to become a member of Recording for the Blind & Dyslexic, an organization with more than 90,000 CDs and books on tape in its library. The initial fee was $75, and for $25 a year Louie can use the service for life.

Perhaps the hardest thing I did, though, was to take a long look at my own behavior. While I had done many things right, I had fallen into the trap of trying to make Louie conform to my own definitions of learning, instead of being open to the idea that he would have his own path. I thought about all the years I had not helped Louie to look clearly at himself and knew that had to change immediately.

Now Louie is taking responsibility for himself, with accommodations both at home and at school that are geared toward making him independent and more confident in his ability to figure out the hurdles.

Louie is naturally talented in the visual arts, which is common among a lot of kids with dyslexia, though no one can say exactly why. To inspire him, I arranged for us to take a tour of the new arts building at Virginia Commonwealth University. Our guide was the retiring head of the department, Myron Helfgott, whom I had told beforehand of Louie's learning disabilities. Helfgott made a point of telling us of a talented recent graduate who had such severe dysgraphia that he couldn't write at all, but had found his way nonetheless and thrived.

I had been wrong—there are mainstream colleges that will take students with even severe learning disabilities, as long as the students know what accommodations they'll need and prove they can keep up. In other words, keeping Louie from learning about himself and getting help would have been the biggest factor in keeping him out of a college.

Recently, Louie got his first report card of his sophomore year. I tried to look both congratulatory and empathetic as I waited for him to tell me how he had done. I didn't want him to think I didn't expect much. Nor did I want him to conclude that I wouldn't be happy with whatever he had achieved. A tricky balance.

Louie had made the honor roll. A wave of relief came over me. Louie had stapled his report card down the middle to keep it open, and it already looked a little ragged. "You've been carrying it around?" I asked. "Yeah," he said, trying to sound casual. "How about if I frame it?" I said, trying to do the same. "Yeah," Louie said. "That'd be good."

Louie and I take everything day by day, a good lesson in general, and we occasionally share a laugh over a misstep, such as his recent repeated use of the word "arousal" rather than "aerosol" in the draft of a paper. And best of all, because I am now able to see and celebrate who Louie really is, so is Louie. Louie is happy, at last. ■

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