Growing Up Dyslexic: A Parent’s View

Wendy Donawa

In those morning moments between sleeping and waking, before consciousness has sent all the monsters of chaos and alarm slithering back into their ooze, I see very vividly that the central impulse of my life is to make things safe for my children. I also understand that this is impossible.

What an illusion safety is! How beyond our control! It’s silly to buy anything more than term insurance, whether in the large political sphere or in our own small lives. Always the beast slouching toward Bethlehem. Parents say of their children, “Oh, I only want them to be safe and happy”—as though this were not an enormity. Such hubris—“only!” Safe and happy! And yet most of us go through our daily routines as though we could mandate security. We think: I will give them vitamins, read them bedtime stories, teach them to look both ways, and the monster will not get them.

But the beast comes in the night, even to my careful friends. Among their children I count one brain tumor, one malignant sarcoma, one suicide, one motorcycle accident, two deaths by fire. One friend’s beloved and talented daughter is a schizophrenic bag lady; one girl needs a liver transplant.

Yet on we go, setting goals, building our methodological card houses. As though our routines have some magical efficacy; that willing will make it so; that in teaching, our small models of order will reflect out into the world.

Much of my energy over the last 15 years has been devoted to negotiating a safe passage for my dyslexic son. This has been my journey, too, and the discoveries I have made are at the heart of all the educating I have done since.

The Island, like many postcolonial societies, inherited England’s caste-sustaining education system. Efforts to “Caribbeanize” it have made it, if anything, more hierarchical and elitist, more rigid and punitive. An entrenched distrust of creativity ensures that the unusual, original, or unconventional will, as they say here, “boil down to a small gravy.”

My Gabriel was an ebullient, outgoing toddler, demonically hyperactive, but that was my problem, not his. He could go for 20 hours without sleeping and didn’t sleep the night through until he was 3. Though I staggered through those years in a fog of exhaustion, my reward was to witness the emergence of a delightfully quirky intelligence, an unpredictable imagination. Although I poked fun at myself for sounding like a doting mother, I was convinced he was gifted.

By the time Gabriel was 7, he had become clumsy, overweight, withdrawn, and depressed. He was a chronic bed wetter; he was barely able to read. A bewildering contradiction to me: He was affectionate, articulate, and well-behaved at home, but friendless at school; the picnics and birthday parties went on without him. He had an excellent vocabulary and lots of mental furniture from his insatiable appetite for listening to stories. We went straight from nursery tales to the Narnia Chronicles.

At age 9, he was still barely reading, and his writing was an illegible scrawl. He couldn’t use scissors or tie his shoelaces, couldn’t tell time or get the alphabet or months of the year in order. He hardly spoke at school and would slump, staring into space, for hours. He was unbelievably disorganized and in constant trouble for losing or breaking things. Every week the class-rank bulletin was posted on the
board; by the end of the term there were 12 or 13 lists with his name at the bottom. But at home, he was working out a plan for nuclear disarmament, and we’d started on The Lord of the Rings.

Island schools are very competitive, and the last 2 or 3 years of primary school are a desperate scramble to prepare for the exam that every child writes at age 11, which will determine where, or if, he or she will go to secondary school.

With this always in the back of my mind, I tried to intercede. The nicer teachers tried to persuade me, kindly, that I had a slow learner. The less kind said that his vocabulary showed he was clearly shamming and that a sound thrashing would improve his attitude. On one Parents’ Day, his class teacher snapped, “Surely you realize how backward he is! Look at this! Just look at it!” as she went, à la tossed salad, through the rest-like chaos of his desk. Other proud parents departed with cheerful children, bright posters, neat folios. Gabriel sat slumped in the car, subdued beyond tears. “It must be very embarrassing to have me,” he said.

He didn’t seem to hear when I spoke, but his hearing tested all right. The general consensus was that I was a pushy expatriate mother wanting special concessions for her backward child. Gabriel’s pediatrician, whose remote but benevolent stance was that he would “come along” in time, tried to put me on tranquilizers.

That was the same year in which one day Gabriel declared that The Lord of the Rings was more than just a story, that it was really about important ideas, and he could tell because the language was very noble and glorious. It was the same year he tried to get his class to tell their parents to boycott Barclay’s Bank, which had holdings in South Africa. It was the year he was the only child in his class without a gift at the Christmas party, although one child had brought a gift for each classmate except Gabriel. This was the year he decided he’d be better off dead.

I abandoned career, family, everything, somehow wrangled a 5-month sabbatical, and fled to Canada with him, to British Columbia, where I had relatives and where, in another life, I grew up. It was April; I had 5 months to find out what was wrong and fix it. I didn’t know where to start, and I knew nothing about learning disabilities.

Clearly, none of my childrearing or teaching strategies had worked, but I had a very fragile little boy on my hands and decided that until I had a plan, I had to simply remove every bit of stress I could. I followed his pace: We ate when he was hungry, we went on walks, did the museums. I read to him by the hour. And, instead of the spoiled monster I’d been warned about, Gabriel became more alert and responsive, his behavior less erratic. His “deafness” almost disappeared. But this didn’t solve any long-term problems. I followed every lead I could turn up, and nearly opted for a behaviorist, convinced he could recondition my boy. But there were bad vibes and I backed off. I put Gabriel in a neighborhood school, only to have the teacher call me in on the second day with a list of bizarre and disruptive behaviors she had observed. She advised a full assessment. I didn’t know what that was.

Finally, with 2 of our 5 months gone, I found a psychologist who turned out to be literally a lifesaver. This was the first adult who had not dismissed as nonsense my conviction about Gabriel’s brightness. She confirmed, after testing him, that his conceptual thinking and spoken language skills were in the superior range, and she also identified dyslexia. She understood his despair and my anguish. She showed me the bizarre effects his perceptual disability had on his life, and how we could begin to work out compensatory strategies.

I still had a bitter lesson to learn, for I’d been driven by the conviction that when we pinned down the problem, I’d fix it. I hadn’t entertained the possibility of anything else. Our wonderful psychologist stressed that I must accept the reality that this was a permanent neurological condition. I cried all over her desk, thought I’d never be able to stop. Ten years later, it’s still hard; little lumps of acceptance are still stuck in my craw.

I told Gabriel that all his difficulty and sadness had been our fault, not his. That we’d find ways to help him learn. That the psychologist had proved he was a very smart boy. I explained the mechanism of his learning disability, told him that Edison and Einstein had had learning disabilities. A tear slid over his cheek. “And all this time I thought I was mentally retarded,” he said.

My own despair and frustration were replaced by a sense of urgency, and by the conviction that Gabriel’s self-esteem must be rebuilt and academic competence acquired by adolescence if he was to emerge a whole person. And, of course, we had a specter of the Eleven-plus exam 2 years ahead of us.

In hindsight it seems a tidier scheme than it was at the time, but our successful efforts basically boiled down to three strategies:

1. Remove the negatives and stressmakers;
2. Break every piece of information into its smallest components;
3. Find something at which he could really excel.

Removing the Negatives and Stressmakers

It was clear that the usual practice of letting a child learn from the consequences of his or her actions was not appropriate here. With his developed sense of space and time, Gabriel lived in a world of terrifying confusion and uncertainty. That his room looked like a Neanderthal midden, and that in dress and demeanor he often resembled a refugee, were not character faults, but a function of his disability.
Every few days, I asked, "How's the log?" Sometimes it took him several weeks to lose the whole lot, and meanwhile he could even help out kids who lost their pencils.

Fortunately, he had a warm-hearted, grandmotherly teacher that year, and the rigidity of the traditional classroom environment was balanced by her concern and affection. Although somewhat nonplussed by the newfangled assessment I'd brought back, she was willing to make some concessions. Gabriel's father built three study carrels for the classroom. Gabriel was better able to focus his scatterbrained attention without seeming to be singled out, and the other children thought it a perk to work in a carrel.

Because of his erratic eye tracking, Gabriel couldn't copy work accurately from the board, or even from book to book; 76 could end up 67, 79, or 97. His teacher reduced his life-tension just by being willing to write down his homework assignments.

At home, I dictated problems to him; if he didn't have to copy, he could do math faster in his head than I could on paper! We worked out an effective, if tortuous, technique for essay assignments: Gabriel dictated what he wanted to say; I wrote it down verbatim. I read it back; he made verbal corrections. When he felt it was finished, I dictated it to him and he wrote it down.

**Breaking Down Information Into Its Smallest Components**

This part should be subtitled "How I Acquired the Biggest Flashcard Collection in the Western Hemisphere."
The heavy workload imposed by the Island's primary school curriculum and the unattractive and often outdated texts would daunt any pupil; they were added burdens to a child with a learning disability.

I read Gabriel through each text and through each day's assignments, putting every fact, every diagram, on separate flashcards. These were grouped with elastic bands, each subject in a box. It made review of huge quantities of information less overwhelming. The system worked well, and we used it well into high school.

I tried putting his texts on tape because he focused so much better when listening, but he lost the tapes as fast as I could make them.

Reading went better when we used a page-sized "mask" with a line-sized slit cut out of it, so Gabriel's focus didn't wander all over. It was still arduous, though. At home, it was easier for me to do the reading. We kept up the reading aloud for pleasure and information; his favorite now was Ursula K. LeGuin.

The year of his Eleven-plus, I left my job. Even in retrospect, I am astonished at the ordeal of that exam and of the stupefying workload in the year preceding it. It says something about a society when its denizens are willing to put their children through so much pressure for a one-shot evaluation that pretty well fixes the children's social status for life. Middle-aged men don't say, "Oh, he graduated from X University," they say, "He's an old boy from HC" (the Island's Eton, its first-choice boy's school, which accepts about 3% of its applicants).

After Gabriel's precariously and hard-won improvement, I couldn't bear to see him dragged down again. During those months, free of my own work schedule, I picked him up right after school, and we'd go for a swim and relax. By the time we got home, he was refreshed; and we studied until supper and from after supper until bedtime. I shuffled flashcards in my sleep. We studied Saturday morning and took the rest of the weekend off.

In the end, Gabriel survived the exam and, to his school's utter astonishment and disbelief, got a perfectly respectable place in a mid-range grammar school. But the school was large, poorly organized, and already plagued by the violence that has since turned it into a "blackboard jungle." So,
when an opening occurred at a small Catholic boys’ college that I thought would provide a more structured and individualized atmosphere, I took it. Gabriel resented this bitterly, feeling I’d stolen the one proof he had that he’d made it in the mainstream. And who knows if he was right; I’ve soul-searched many times. The Christian Brothers who ran it were querulous, rigid, burned-out; there was a lot of bullying. But by dint of flashcarding and home reading, Gabriel did adequately.

The year he was 12, I was up in British Columbia again for 6 weeks. I brought Gabriel, and he attended a school for students with dyslexia. In 6 weeks, he shot ahead 2 years in his maths, and I had a vision of what he could accomplish in a school that could really teach him. When we returned to the Island, he finished the school year placing second in his class.

Finding Something at Which He Exelled

This was more easily said than done. Athletics involved coordination and stamina that Gabriel didn’t have. He played a fair game of chess, but that is hardly a 10-year-old’s road to popularity.

Perhaps I should have added a fourth criterion—giving him lead time for the initial learning process. He took forever to get the hang of something, and this was the phase at which he was ridiculed and rejected. But once he got it, he could hold his own.

In the end, an odd combination of things worked. He’d begged for a skateboard while we were still in Canada, and with misgivings, I got one. With no other kids around to comment on his ineptness, he spent days sitting or lying on it, pushing it around. He finally, gingerly, managed to scoot around with one foot on it. He persisted through the summer, battered and bandaged, finally becoming quite adept, losing weight, improving coor-

dination, and arriving back in the Island with a skill he could flaunt.

Dungeons and Dragons was another success story. Gabriel was intrigued by the game and received one in Canada as a gift. I hate games; this was not my favorite project, but by the time we went home, we could both play. Here his vocabulary and love of mythology served him well, and he acquired a little group of enthusiasts who would stay overnight, playing for hours. I’d never seen Gabriel concentrate on one thing for so long, and socializing within the constraints of a game with elaborate rules sustained some relationships, which developed into real friendships. Apparently I had the dubious distinction of being the only mother Dragon Master in the Island. Still, I was glad when they all learned the game so I could resign.

The biggest success was karate, about which I was initially very dubious. I found a small group for Gabriel to join, with varying ages and stages, so his clumsiness wouldn’t stand out. The instructor, a compassionate sensei, persevered as Gabriel stumbled about. Slowly, those three-elevens-a-week workouts had some effect; the excess weight turned to muscle, and a handsome little boy emerged. His stamina and coordination improved beyond my hopes; his self-esteem grew with each level he rose to. The constant repetition and discipline also improved his mental concentration at school. By the time he lost interest, 4 years later, he was a second-degree brown belt.

By then I was working again and finding that what I’d learned from Gabriel had made me a much better teacher. I now recognized all the Gabriels for whom there was no advocate, all the kids whose lives would be easier with extra lead time and less unnecessary stress. I now knew that nothing is unlearnable if it’s broken down into small enough steps—even King Lear for students without a grasp of standard English. Even in my college’s demanding syllabus, there was space to maneuver in a little more humanity. I’d seen how hostility and boredom can be a face-saving mask for self-doubt and despair.

It is strange how simple and self-evident the pattern seems in retrospect. But, of course, it wasn’t as simple as the remembering of it; it was always hard, with many setbacks, and I never knew how it was going to come out.

Adolescence

Adolescence brought a different chapter, and I don’t yet have the objectivity to see it in perspective.

The hard-won equilibrium of Gabriel’s school career ended when his school, without warning, closed. It was hard finding another school to take him, and he was finally put in the sixth (bottom) stream of the school I’d originally refused for him. His classmates were the troublemakers and nonachievers of the school, probably many of them with learning disabilities, too. The teachers barely made a pretense of teaching and didn’t bother to hide their disdain for this group.

Gabriel’s childhood depression and despair turned to anger and led to some dangerous acting-out. He skipped classes and went surfing. As class wordsmith, he became the leader and spokesman for the bad boys. Bad girls, older girls, fancied him. He stayed out all night, got into fights, went where people got shot and stabbed, was taken in by an older gang.

Gabriel’s longing for acceptance was not helped by his mixed racial heritage. I suddenly did not fit the heritage-image he desired, and his hostility and rejection were (and are) a painful repudiation of our former closeness. His aim in life was clearly to prove he was bigger, badder, and blacker than anyone. Oddly enough, the friends, the bad boys, most with no sort of guidance or support, liked me. They liked being nagged and cajoled and admonished and fed. I thought: I’d better get them on my side if that’s all the protection Gabriel has. I felt like den mother to Boyz in the Hood.
What a high for Gabriel! Swaggering into dens where danger and adventure dwelled, where no one had heard of dyslexia or cared about exams, where a fair-skinned mulatto stood out like a target but where his older, blacker, badder buddies would protect him. That year he finished exams with an average of 34%—and at that, was top of his class.

In desperation, we packed him off to a residential school for dyslexic students in New England. Gabriel finished his last 2 years of school at this excellent institution. It cost only slightly more than Harvard, but we decided that our college savings would be of no use if he didn’t finish school. Or didn’t live to college age.

He hated it. He hated me. A racial epithet aimed at a friend led to a fight; Gabriel pulled a knife and nearly got expelled. His visits home were hideous, as he crammed in all the high and dangerous living we had exiled him from. He got into a life-threatening situation I can hardly bear to remember, much less write out. We bled money. Finally, Gabriel went back to school. I got shingles.

He must have been a severe trial, even for professionals trained to deal with angry adolescents. To my sorrow, the staff were glad to see the last of him, but they did their job. And, at some higher level, Gabriel understood that his future lay in using what they could give him. He graduated with an A average and a high class standing.

He was accepted at a Canadian university with an excellent LD support program. What a triumph! What anxiety! We could hardly believe it. Gabriel had my picture on his desk! He kissed me goodbye in public! I indulged in a period of total euphoria before returning to reality.

From time to time I read of admirable families with problems far worse than mine, who cope with seriously disabled children, their own or adopted, or with children with multiple handicaps. Their faith and good humour never falter; their friends and relatives rally around. And I wonder what they know that I don’t, as I ponder the costs of loving a child with special needs.

Even on the least painful level, that of financial cost, there is the unending stream of lost thermoses, books, shoes, and glasses; the extra tuition; the jetisoned career. Later, schooling can be a mortgage-sized investment. Still later: the lawyers, the drugs, the smashed car. But the real costs are to the spirit: the sorrow of observing a child’s bleak despair, the anguish and alarm when that despair turns to rage.

Stress has dislocated us all. I couldn’t stretch my resources far enough beyond Gabriel to meet the family’s needs. My unequal attentions wounded his elder brother deeply. Perhaps he will never believe how I cherish his fine mind, his beauty, his integrity; perhaps he will never believe in them himself. Perhaps he will never forgive me. Well, he has made a life for himself in Canada, pursuing a career in which his talent is appreciated. We circle each other cautiously, treat each other carefully, like convalescents. I dare to hope for true friendship.

The boys’ father—himself a product of a dysfunctional family, and of a culture that views childrearing as women’s work—couldn’t take up the slack, not in those days. Now, scarred, weary, we attempt to splice our separate lives back together, to reconnect with the elder boy, to develop the stoicism and wisdom we will need on the turbulent ride that is Gabriel’s life.

Gabriel’s need to separate is overwhelming. He has joined the counterculture with a vengeance, reviles the establishment, dismisses his family, refuses the support offered by his university to students with disabilities, denies he has a problem. And yet, somehow, he has survived his first year, passed his courses.

As he sails his leaky boat over the horizon, I stand on the shore, knowing it is futile to shout advice, or blessings, or entreaties after him. My next task is to accept that I can’t build any more scaffolding for him, and must refocus my life.

I’ve done what I could.

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