

The Child You Didn't Dream Of

Benjamin faced many problems. His mom tells how he brought her peace of mind.

by [Priscilla Gilman](#) April 10, 2011



Courtesy of Priscilla Gilman

Priscilla Gilman's son Benjamin, seen here at two years old and beginning to spell the word "school."

After a quick hello, the admissions director got right to business: “We have some concerns about how Benjamin did at his visit,” she said. “Really?” I replied. “We thought he did well. He had a good time.” She paused. “No. He didn’t do well.”

“What was the problem?” I asked. After some pausing and sighing, she finally came out with: “He seemed fixated on the magnetic letters and numbers. He didn’t answer the teachers’ questions appropriately or respond to the other children. We think he might do better in another school setting.”

I was polite while the conversation lasted, but I hung up the phone dismayed and a bit angry. How could that woman, that school—one that prided itself on a joyful, progressive approach to learning—not see Benj for the amazing, original, bright little boy he was? According to my husband, Richard, at the screening 2½-year-old Benj had in fact taken the magnetic letters and spelled out “Benjamin,” “flapjack,” and “Friday.” He’d then arranged the numbers in sequence from one to 10, calling out each one in an excited voice while beaming up into the teacher’s face. So what if he didn’t say “hello” or respond to the teacher’s offer of crayons? Sharing his enthusiasm about the alphabet and numbers was his way of being friendly. And if he hadn’t been as responsive to the other children as he could have been, there were plenty of good explanations for that. He’d just gotten out of the car after a two-hour ride into Manhattan. He hadn’t eaten lunch or had a drink since he left home. He’d never been in a room filled with strange children before. How dare those teachers demand sunny normalcy from him? He wasn’t a normal child. He was Benj, and if they didn’t want him, then I certainly didn’t want them.

But I wasn't only angry. I was also deeply worried. So after a day of lamenting the nursery school's inability to accept my son, I began to realize that the concerns the admissions director described had resonated with me. I typed some phrases about early reading and trouble answering questions into Google, and the first thing that came up was the American Hyperlexia Association's website. I read breathlessly about a syndrome I had never heard of, whose symptoms—precocious reading, an intense fascination with letters or numbers, difficulty in socializing and interacting appropriately with people—matched up so precisely with Benjamin that I was thunderstruck.

The website suggested that kids with hyperlexia composed an extremely small subset of kids with high-functioning autism or Asperger's. I'd thought of autistic kids as kids who flapped their hands, banged their heads against walls, and never spoke or smiled. Benj had made eye contact, he was very smiley, happy, and responsive; he'd laughed at us frequently and chattered gaily throughout the day. Why would we ever have suspected this?

Because he was so verbal—he talked all the time in an animated and expressive way and had a huge vocabulary—we hadn't worried much about his speech or his ability to communicate. There had always been an explanation for the lack of social exchange. A rationalization. An excuse. "He's not interested in small talk; he wants to cut to the chase." "He's just like his father: he'd rather read than chitchat." I read on, and realized that Benj had never used gestures to express his desires and feelings: no waving, no pointing, no shaking his head no, or nodding yes. I ran through all of Benj's language in my head. He'd developed single words precociously, at a little under a year, started speaking in many two-word phrases at age 2, right on schedule, and now was speaking in longer sentences, just as the parenting books had said he should.

But the more I read, the more I realized that most of Benj's spoken language was actually echolalia (repeating or echoing other people's language rather than creating spontaneous sentences). When he woke up in the morning or from a nap, he'd say, "Did you have a good sleep"? When he was ready for a meal, he'd announce, "It's time for supper/lunch/yogurt for you/Benj!" When he was upset, he'd say, "What's the matter?" It had seemed that he was almost giving us a prompt to ask or say these things to him, and we'd found it endearing. A lot of his phrases were very sophisticated—when he drank his juice, he'd often say something we'd taught him: "Cup of juice is not only tasty but also delicious!" and when we went outside at night, he'd sometimes say, "The moon is high in the sky and the stars shine bright," something Richard had once said to him. All of these phrases, I now learned, were "context-appropriate delayed echolalia." I remembered twice he had greeted a loving adult's "Hi, sweetheart!" with his own "Hi, sweetheart!" The Stop & Shop cashier and my sister had found this adorable. But what had once seemed charming and funny now seemed alarming.

One of the most painful things about these discoveries was that they made me feel that all the things I'd considered unique and special about Benj were instead uncontrollable manifestations of a disorder. He was not unusual; he was typical, ordinary, a classic case. He didn't have an interesting mind; he had faulty wiring. He didn't have a distinctive personality; he had a syndrome. His jubilant recitations of Robert Frost's "Fire and Ice" and "Nothing Gold Can Stay" and word- and note-perfect renditions of *The Sound of Music*, *West Side Story*, and *Oklahoma!* were not the result of a love or appreciation for poetry or music but rather a mindless parroting.

His animated recitation of scripts from *Between the Lions* and *Sesame Street* was not a dazzling display of his powers of memory as much as it was “perseveration” or “video talk.” His seeing letters everywhere—in the shape of his food (a string of spaghetti was an S) or the curve and lines of a piece of jewelry (little earrings of mine were T’s)—wasn’t perceptive or imaginative; these were ominous signs of obsession. His not responding to questions or not turning his head in response to a voice wasn’t a sign of single-minded focus on an engrossing activity so much as it was an inability to engage with the outside world. His early reading wasn’t “just like his mom”; his perfectionism wasn’t “just like his father.” Both were symptoms, items on a checklist, pathologies. In my darkest moments, I saw Benjamin as a textbook case, an embodiment of a syndrome rather than a distinctive individual.

My sense of disenchantment was greater because I’d had such unabashedly romantic expectations for my son’s childhood. Growing up in New York City among writers and artists, I’d experienced childhood as a whirlwind of imagination and play, and later, as a student and scholar of the romantic poet William Wordsworth, I’d embraced Wordsworth’s view of children as imaginative, intrepid, playful, and a source of refreshing honesty, authenticity, and meaning.

It was the loss of hope that so devastated me in those early days. “Am I even allowed to have dreams and hopes and anticipation for his life?” I wondered. When did hope become fantasy or denial? And what risk was I taking if I allowed myself to hope and then those hopes weren’t realized? I didn’t want to set my son up to fail. I didn’t want to make my goals for his progress too lofty or my dreams for his future impossible to fulfill.

There is nothing less romantic, literary, or lyrical than the language of pathology, diagnosis, symptom checklists. As I read through these checklists over and over again, I was struck by the harshness, the crudeness of the terminology. Benj had a speech disorder, sensory-integration dysfunction, severe gross and moderate fine-motor delays. He needed OT (occupational therapy), PT (physical therapy), SLT (speech and language therapy), SIT (sensory integration therapy). These harsh, ugly words and bland, cold acronyms soon became as familiar to us as the brush, comb, and mush from *Goodnight Moon* in our discourse about Benj.

Richard and I began to do tons of “therapy” with Benjamin ourselves—hours and hours of speech games and physical exercises. I bought a small trampoline for him to practice jumping on, a big inflatable ball for bouncing on, kicking, and throwing to build muscle strength, endless canisters of Play-Doh and bottles of bubbles, a step stool to practice stepping up and down, beanbags to squeeze and throw at targets. I began to keep a “speech journal” of every single thing Benj said and in what context. To develop his language skills, we’d ask him to put things behind, next to, in front of, on, under the table or the chair. We’d model choice-making and turn-taking for him: “Daddy, do you want the red book or the blue book?” I’d ask. “The red one, Mommy,” Richard would reply, ostentatiously taking the red book from my outstretched hand. Every time we spoke, it felt like an act of intervention. I became hyper-aware of everything I said and did around Benj, trying to model for him the correct phrase or reaction, calling his attention to me so he could learn from my example. “The book fell!” I’d cry; “I’m hungry,” I’d say, swinging the refrigerator door open with exaggerated force. And although Benj initially either ignored or resisted us, we held our ground and coaxed him into trying. Within a few months, he had made enormous progress.

But then we moved to Poughkeepsie, N.Y., where I'd accepted a job teaching in the English department at Vassar, and Benj had to adjust to a new home, begin working with new therapists, and go to school for the first time. He had a very rough start at school, but through daily conversations and emailing with the staff, we figured out ingenious ways to reach Benj through his strengths and to use those strengths to address his weaknesses. I found myself often overcome with admiration for Benj. For his courage, his perseverance and determination, his openness to instruction. For, as his teachers put it, "the way he bravely accepts the little challenges he's given every day (putting his coat on a hook or getting a friend to help him remove his smock)." When I thought about what was actually going on in Benj's brain and nervous system, it seemed incredible how well he was doing. How difficult must every single day be for him? He was always teachable and willing to try. And when he was happy, no one was more incandescent.

Because of his physical limitations and sensory sensitivities, I'd feared that Benj would never be an adventurous and carefree child. But one afternoon the spring he was 5, Benj came home after a long day at school tanned, filthy—dirt and grass stains covering his clothes, paint on his fingers, forearms, elbows—with skinned knees and bruised shins, exhausted and happy. Maybe he wasn't climbing trees or skating with abandon across frozen ponds, but he was going down the slide and finger painting; he was becoming more comfortable getting messy and disheveled. And he was learning to express feelings and connect with others: "I had fun at school," he said, leaning his body against mine, "but I missed you, Mommy!"

The intervening years have had their challenges and rewards, and nine years after the discovery of Benj's hyperlexia, my life is entirely different from what I'd once dreamed it would be. I'm divorced, but have a very amicable co-parenting relationship and a supportive friendship with Richard. I left academia. My two boys are very different from what I'd expected my children would be like. And my life is so much richer and more satisfying than I could ever have possibly imagined.

Benj has put me in touch with my deepest sense of what's truly meaningful. A partial list of the milestones and moments of triumph that have mattered most: Benj pats his crying baby brother on the head and says, "It's OK, James;" drinks from an open cup without spilling all over himself or screaming in frustration as the juice dribbles down his chin; says "yes" for the first time at 3½ years old; refers to himself as "I" for the first time at a little over 4; says "I love you" for the first time at 4½; swims the length of a pool unassisted, his little head bobbing determinedly above the water; writes a poem called "The Reading Boy" about enjoying "A good book/alone in his own private nook." I can't imagine obsessing over first-, second-, or third-tier schools, sports trophies, the perfect birthday party.

Twelve-year-old Benj still has many challenges. He can melt down if he loses a game, he has odd and obsessive anxieties, and tics like reciting surface during times of stress. He hasn't ever had unsupervised time with a peer. He continues to struggle with open-ended situations, abstract language, and unexpected events. There have been no easy solutions to the problems Benj and I have faced, and I'm sure there are obstacles and hurdles I can't even envision yet. What I do have is an abiding faith that we can ride out anything that is thrown at us. In one of the

wonderful ironies of my experience, little, controlling, rigid Benj has helped me to let go of my desire to follow a predetermined path and taught me how to surrender.

Benj has taught me so much more than any professor or class. While initially he seemed to contradict romantic ideas of childhood and parenting—he defied and rebuffed every expectation I had—ultimately he has reaffirmed, in a deeper and truer way, my romantic ideals. As Wordsworth wrote in “The Sparrow’s Nest”: “[He] gave me eyes...[he] gave me ears;/And humble cares, and delicate fears;/A heart, the fountain of sweet tears;/And love, and thought, and joy.”

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