



George's Place

Autism swept him off to a secret world. Could his grandmother find a way to meet him halfway?

GEORGE, MY GRANDSON, is one of those little boys you can't get enough of. He's slender and blond, fine-boned, and dead-on beautiful. There was a time when he couldn't get enough of us, either. He chatted, he paid attention, and whatever the current joke was, he got it.

Then, when he was around two, something changed. He began to love watching the eternal curves of a spinning electric fan. He loved the play of his own fingers in front of his eyes. His glance shifted over to the middle distance. He wouldn't look us in the eye. He pretty much decided against talking.

The Thanksgiving of the year he turned three, we couldn't ignore his behavior anymore. During dinner, a big friendly affair for our family, George ran through the rooms, charting his own course, occasionally flopping his hands in front of his face, laughing delightedly. He did this for hours, all the while

seemingly oblivious to the rest of us.

The family had known for a long time that something was not "right" with George. We all kept saying, or maybe it was more hoping, that it was nothing. Because wasn't George so endearing? And he so loved to laugh. But he did make those "guah-guah" noises. He did

flap his hands. Then, a short time after that dinner, someone at George's day-care said the word. Autistic.

I think my daughter knew before her husband. But he was the first to just say it. "There's something wrong with our son." That's when we all finally allowed ourselves to admit it. There was something wrong. But what?

It's extremely difficult to get a diagnosis of autism. Doctors don't want to bring up the subject; they don't want to be the ones to give the bad news. So they gave George hearing tests and IQ tests, EEGs, and more appointments, and more tests, until it was confirmed: my beautiful grandson was autistic.

After the diagnosis, we had so many questions. And no one could answer them. I had done my research, but that just brought up more questions. Autism was first recognized in 1943. From the 1950s to the 1960s, doctors blamed the mothers. They were accused, because of

Grandparenting



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a theory promoted by developmental psychologist Bruno Bettelheim, of withholding love from their children. (If that man weren't already dead, I swear I'd kill him, then sentence him to ten thousand years in hell for each tear he made those innocent mothers shed.)

Today, there is still no clear explanation for what causes autism. But one school of thought suggests early intervention is a child's best hope. Many behaviorists recommend 40 hours a week of behavioral therapy, minimum. They say if you don't get to these kids by age six, they'll be lost to you forever.

That's easier said than done. The first symptoms often don't appear until the child is around 18 months, and it usually takes at least another year for people to figure out what's going on. Add to that a regrettable lack of specialists and therapists (the only ones who can make the diagnosis), and the years are lost. Meanwhile, there's your beautiful grandson, running aimlessly, not talking, not meeting your eye.

Once the final diagnosis is made, there's the question of education. Most states, in theory anyway, are committed to giving each and every child an appropriate education, according to his or her needs. They're supposed to provide individualized education for autistic or otherwise disabled children. State-funded organizations called regional centers (in most states) fill this function. In many cases, however, they don't have enough funds to do it properly. My daughter was tormented by the fear that George would be dumped, warehoused in a classroom full of deeply troubled and disabled kids, and that the time when he should be getting treatment would be frittered away. Everything depended on the school's mandatory Individual Education Plan (IEP). We had been forewarned that the center would want to spend as little money as possible, and we were prepared.

Our first formal IEP meeting was agony. Four of us—my daughter, her husband, her sister, and I—attended.

There was a physical therapist who had evaluated George. A psychologist from somewhere. A couple of other women who had reports on George, and a speech therapist. Our family had brought a tape recorder. Notes were taken. Tears flowed.

We listened as they read all of their reports: George had almost no speech, a vocabulary of about a hundred words, most of which he hated to use. He had no muscle tone. He was skinny as a rail. He couldn't or wouldn't take directions. After four hours of passionate argument, we managed to get some of what George needed. He ended up in a public special-ed nursery-school class.

As I look back on that terrible time now, I see that—in addition to fighting for what we knew George needed—we were doing the only thing we could have been doing, playing our parts on cue: my daughter crying a mother's tears, her husband being as masculine and stoic as he could, my older daughter trying to maintain some dignity and control on

behalf of us all (as she always does), and me with a grandmotherly smile plastered on my face, because things were going to be fine. Weren't they?

I think of myself as an agnostic, or at least a person who doesn't believe in a storybook God who keeps tabs on us all. During the nights before and after the IEP, I railed at the God I didn't quite believe in, not for my grandson, who through it all was sunny and uncomplaining, but for his mom, one of the finest human beings on this earth, who, with her dear husband, was going through the tortures of the damned.

About a year after my grandson's diagnosis, the four of us—he, his parents, and I—flew to Chicago for an autism conference to find out as much as we could about what we were dealing with.

At seminar after seminar, we heard about theory after theory. Autism may have a genetic component, it may be the result of very intelligent people having



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** Biochemical disease-free survival

¹ John P. Long, et al., Five-year retrospective, multi-institutional pooled analysis of cancer-related outcomes after cryosurgical ablation of the prostate. *Urology* 57 (3), 2001.

² Paschal RE, Colberg JW, Surgery, brachytherapy, and external-beam radiotherapy for early prostate cancer. *Lancet Oncol* 2003; 4: 233-41.

³ The most commonly reported side effects of prostate brachytherapy are short-term urinary or obstructive symptoms within the first few weeks after the implant procedure.

Grandparenting

children together. It may have something to do with alcoholism or depression running in families. We heard that autistic kids seem to absorb toxic pollutants, especially mercury, from the environment; that the increase in cases during the past 10 years may have come about by the greatly increased numbers of vaccines babies receive and could have something to do with a preservative used in those vaccines, thimerosal, a mercury-based compound. The latter is a charge the drug companies deny.

Listening to all this, I felt almost unbearable anger. Here at the conference were hundreds of respectable, well-educated, law-abiding citizens—good parents, devoted grandparents. And here's this disease that affects two to six children per thousand and is growing at a rate of 10 to 17 percent a year. I wondered if anyone was listening.

* * *

At that time, only one person in American public life had openly addressed autism—Representative Dan Burton, a Republican from Indiana whose grandson is autistic. Burton demanded and held congressional hearings, and he squawked like the devil when special interests were able to slip a proviso into the Homeland Security bill that would have exonerated drug companies from liability. He talked to hundreds of people. He got a standing ovation. He's a hero to the autism community.

I'm glad my daughter and son-in-law asked me to go along to this conference, this noble, hit-or-miss quest for knowledge. I'm honored to be of some use in all this, if only tangentially. But later, when a friend asks me what it was like, I can only answer, "Have you ever been to a four-day funeral?"

* * *

George is five years old now. Kidding on the square, I can say to my daughter that her son has a life anyone might envy. He goes to kindergarten in a special-education class. He has speech therapy two afternoons a week. He takes gymnastics (for autistic kids) and loves it. He and his parents traipse out on Saturday



To learn more...

Autism Society of America
800-328-8476; www.autism-society.org

**National Alliance
for Autism Research**
888-777-6227; www.naar.org

The Autism Coalition
914-935-1462; www.autismcoalition.org

**Families for Early
Autism Treatment**
916-843-1536; www.feat.org

morning to social-skills class. George has been to the zoo and the circus.

And the training—that behavioral therapy we heard about at the beginning of this process—tends to work. His 10 hours a week—along with school, gym, dietary changes, and huge amounts of love—have changed his life dramatically. Every situation is different, of course. The infrastructure of care for these children is still jerry-built, shaky, desperately underfunded, and changing. But behavioral therapy for George comes in the shape of four or five cheerful professional women who take turns sailing into his house each weekday afternoon jabbering at him, trying to get him to jabber back.

I don't like to talk about what all of this costs: the school district and regional center split the cost of behavior therapy; health insurance covers some medical services. George's extended family picks up all the rest, which runs into thousands of dollars. I won't talk about the time all of this takes to arrange. Or the heartbreak, all over again for all of us, when George bursts into scalding tears and cannot tell anyone what's wrong with him. I can't talk anymore about what my daughter and her husband have gone through. It should be enough—it has to be enough—that George is happy.

* * *

Still, George is my delight. When it's my night to baby-sit, he strides in dressed to the nines, wearing a stylish backpack. He allows me a fleeting smile, puts up

with being hugged, and lopes over to his books and blocks. He's beautiful. He's hard to get. He's delicious.

My grandson stacks the blocks, counting, up to 30. Then he counts backward. He has the most beautiful, piping voice. He loves to hide and be found. When I get tired of playing, he'll say, "Oh, come on, Grandma!" But talking is not his strong suit. Often, he'll sing. It's a sound like no other. When he's watching *Snow White and the Seven Dwarfs* for the hundredth time, he hums along happily when the prince sings, "One song, I have but one song...."

I try to get him to talk, and to follow along when I read books to him. He's polite. He goes along with it for a while, but really he'd rather be scoping out the electric fan or galloping through the house, capturing his shadow against a white wall, or trying to. His favorite pastime is still to throw my necklaces on the carpet. Then do it again. Finally, he comes and sits down by me and smiles. He strikes a wise pose with his chin in his hands. He says, "Hello, baby!" He's some of the best company in the world.

It's a cosmic dance, I guess. I'm clomping around on the ballroom floor, he's two-stepping in clouds. The important thing, however, is that we're dancing together. ■

Carolyn See is the author of Making a Literary Life: Advice for Writers and Other Dreamers (Ballantine Books, 2003) and five novels. Her book reviews appear on Friday in The Washington Post. Her next novel, Jerusalem, is due out in 2005.