

May 24, 2009

OP-ED CONTRIBUTOR

Growing Old With Autism

By **KARL TARO GREENFELD**

IN mid-2007, I set off to meet with geneticists, epidemiologists and doctors who specialize in researching and treating autism. I was seeking a novel therapy for my 42-year-old autistic younger brother Noah. I was also looking to discover how heightened awareness of autism — it is now among the most financially successful and mediagenic diseases ever, with hundreds of millions of dollars a year going to research, and regular press coverage — might have resulted in new and innovative programs for adult autistics like Noah.

Autism was already widely being described as an epidemic, affecting as many as 1 in 150 8-year-olds, according to the Centers for Disease Control and Prevention. We had come a long way since Noah got his diagnosis in the late '60s, the so-called dark ages of autism, when many pediatricians believed they had never seen a case, and so-called refrigerator mothers were mistakenly blamed for their children's withdrawn, antisocial condition.

But now, with autism described to me as “the disease of the decade” by Peter Bell, the executive vice president of programs and services for the advocacy group Autism Speaks, I thought perhaps there was hope, even for low-functioning adult autistics like Noah.

Noah has been my family's focus for decades. As a baby, he had been very slow to turn over, crawl or walk, and each subsequent developmental milestone was even more delayed as he grew into adulthood. My parents did everything they could for him, moving us from New York to Los Angeles in the early 1970s to be closer to a pioneering autism program at the University of California at Los Angeles, opening their own day care center for the developmentally disabled, even creating a one-on-one assisted-living situation for Noah — years before this became common — so that they could delay institutionalizing him.

I toured those state hospital systems with my parents when we started looking for a place for a growing-up Noah. Those were terrifying visits: adult patients wearing helmets and restraints, howling and hitting themselves. This was during the '70s when the scandals at state psychiatric hospitals like Letchworth Village in New York and Camarillo in California were making terrifying headlines. Clients at Camarillo were dying from neglect and improperly administered medications. We had to keep Noah out of that system for as long as we could.

Eventually, when he was 22, Noah had to leave home. He graduated from his special needs school on a bright, sunny Orange County day; he was beaming, handsome in his bright blue cap and gown.

But for the profoundly autistic, graduation is perhaps the saddest day in their lives. For those who cannot enter the work force, continue on to more education or find some sheltered workshop environment with

adequate staffing, there are few options. Far too few programs and resources are allocated for adults with autism.

Noah has been in and out of sheltered workshops, but these are always under threat because of state budget deficits. Noah has been asked to leave some programs because he was too low-functioning. For several years, we have been trying to find a day program where he might interact with others and perhaps perform some simple, menial job. We have long since given up any hope that he might continue in adulthood the behavioral therapies that are now considered standard for autistics; unless the family is willing to pay the bulk of the cost, there is very little out there for men and women like Noah.

For purposes of fund-raising and awareness-raising, autism has been portrayed as a childhood disease. The federal Department of Health and Human Services has characterized it as a “disorder of childhood.” There are practical reasons for this: early intervention has been shown to be the most effective therapy. The trend in autism treatment has been to steadily lower the age at which intensive intervention commences — as early as five months, according to some experts. Yet autism is not a degenerative condition; the vast majority of those 1 in 150 children who are afflicted will survive to adulthood.

As I spoke with the experts, I began to see that the focus on children had influenced not only the marketing of autism, but also research and treatment. It seemed the majority were interested in children only, the younger the better.

“The best time to look is at the early ages, when autism is developing,” Sophia Colamarino, vice president of research at Autism Speaks, told me a few months ago, explaining that was also where there had been the most treatment success. “I’m not making excuses, but that’s really why more research into adults with autism hasn’t been done.”

Low-functioning adult autistics are viewed with sympathy but not much scientific inquiry. No one has broken down how many dollars are actually flowing to adult autistics, but at the International Meeting for Autism Research in Seattle in May 2007, I counted more than 450 papers and presentations and three dozen talks on autism given by academics and specialists; of those, only two dealt with low-functioning adults, and neither included a cohort large enough to be statistically relevant.

The careful measurements of brain function, or dysfunction, were almost all done on children. A few cognitive and emotional development studies dealt with adults, but these were overwhelmingly focused on high-functioning autistics and people with Asperger’s syndrome.

Autism Speaks, the major sponsor of autism research projects, has not broken down the proportion of funds that go to adult-oriented research, but Mr. Bell, whose teenage son is autistic, laments that “it’s low, too low. ... We have to change the paradigm for those of us who have kids who are going to grow up and need more and better services.”

That change can’t come soon enough. Even with state-of-the-art early intervention — eight hours a day, seven days a week — many autistics will need support throughout their lives. The reality is that very few, perhaps only 10 percent, of those as severely autistic as Noah benefit from the current interventions to the point where they become functioning members of society.

If the current C.D.C. estimation of prevalence is correct, then there will be an awful lot of adult autistics who need lifetime support and care. Noah's life has been a grim study in how scarce those resources are. Without them, his behavior has regressed.

A recent "psychological and psychopharmacological" report by the California Department of Developmental Services said Noah exhibited a "failure to develop peer relationships, a lack of social or emotional reciprocity," and it described some of his "maladaptive behaviors" like "banging his head against solid surfaces, pinching himself and grabbing others."

"Noah may also," it noted, "intentionally spit at others, pinch or scratch others, dig his fingernails into others, and/or pull others' hair. He may bite, head-butt and hit others; throw objects at others, and hit/slap his head when he is highly agitated." He is a handful.

Now, imagine a few hundred thousand Noahs.

Karl Taro Greenfeld is the author, most recently, of "Boy Alone: A Brother's Memoir."

This article has been revised to reflect the following correction:

Correction: June 2, 2009

An Op-Ed article on May 23, about autism in adults, misspelled the name of the vice president of research for the group Autism Speaks. She is Sophia Colamarino, not Calimaro.

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