





In 1972, with the publication of 'A Child Called Noah,' **Karl Taro Greenfeld's** kid brother became the national face of autism.

But nothing—
not experimental
private schools, not
special diets—ever
drew the boy out.

Now, thirty-seven
years later, Karl is still
trying to understand
who his brother is

A MIDDLE-AGED MAN sits by himself on a patch of brown lawn, just outside a run-down house in South Central Los Angeles. He seems neither to miss company nor show any eagerness to seek it. If you greet him, he will not look at you nor turn in the direction of your voice.

Noah is a client of California's Regional Center for the developmentally disabled, his life indifferently recounted in seven horizontal feet of files containing psychiatric-progress notes and client-location sheets and social-discharge summaries and psychological evaluations. His story is told there in starker terms than in any of my father's books—including the acclaimed *A Child Called Noah*—or in my mother's writings or in my memory. There, in the state system for the developmentally disabled, he has been a client, a ward, passed from institution to institution, damaged, hurt, roughed up.

Noah's adulthood came on too fast—he was just 13 when he was first institutionalized, 17 when he went to the first of a succession of group homes, 22 when he began a fifteen-year stay at the Fairview Developmental Center, a state institution—and his has been a harder life than I like to think about. When friends ask after Noah, it is too complicated to explain the details and nuances of his suffering. The facilities where he has ended up, the careless caregivers, the cruel housemates, the abusive psych techs (as the junior-college-trained assistants working with the developmentally disabled are called), have left Noah grizzled, gaunt, angry, defensive, and lost. To spend time with Noah is to confront the uncinematic reality of madness. There is nothing quaint or charming about raving, violent lunacy, about a man in torn, ragged clothes banging his head against a concrete floor, scratching himself, spitting, pinching. I have to be honest—he is not charming, not to me, not anymore. He is a grown man and a heavy burden, prickly, hard to love, disinclined to please, quick to lash out. I feel guilty that I don't love him, and that culpability causes me to act as if I do love him.

That the system failed Noah is beyond a doubt. But of course, Noah failed the system first. You can't ask the world to provide for those who have effectively turned their backs on it. And Noah, as a low-functioning autistic adult, is rejection personified. Help him, offer him a snack he likes, a pat on the back, a cool drink on a hot day, and he will as likely grab your hair or scratch your arm as smile. He wasn't always like this, of course; he used to be more gentle, occasionally loving, but so much of that affection was abraded through years of harsh surroundings. He learned, the hard way, that you strike first and ask questions later. The clients at some of his group homes learned to be wary of him, while

others got the better of him and sometimes had their way with him.

Noah doesn't speak. A high-functioning, criminally inclined autistic, or a perverted caregiver, can take advantage of that. I spent my adult life knowing terrible things were happening to Noah yet somehow averting my attention just enough so that I could go on, so that I could answer "Noah's okay" when people asked, because answering that my brother may have been raped, more than once, takes the conversation out of the realm of small talk.

I DON'T KNOW NOAH. He is, I suspect, unknowable. Yet he remains the center of my life.

I hate him for that.

If I could, I would never write about him, speak about him. I would tell anyone who asked that I was an only child.

Yet he's my brother.

I dread the phone calls that come from my parents: He has attacked another client. He's bitten one of his psych techs. He has been beaten up. He has a black eye, a chipped tooth, another unexplained scar. Those calls remind me. They make me feel helpless, because Noah is helpless.

I want to have hope. I read the books and articles about autism, the alleged scientific breakthroughs, the inspiring family stories, and they are all, ultimately, about hope. But then the reality of Noah intrudes and I struggle to feel a similar sense of possibility.

I don't feel sorry for myself. And I don't feel pity for Noah, though he is in every real sense pitiful. To feel pity for Noah and not anger would be letting him off too easy, I tell myself, would somehow be unfair to him. His autism doesn't preclude him from being just as responsible for his own circumstances as

any of us are. That is a philosophical gimmick I employ, to believe that Noah has somehow chosen his life, not consciously but biologically, which is even more ineluctable.

Even as I tell myself that, I feel the reality of Noah intruding and the weight of worrying about him returning. Unless I am willing to walk away, to just close my heart to him, then understanding why he is where he is is as useless as figuring out the exact temperature while you're freezing to death. It's information, but it's just not helpful.

I VISIT, HE RECOGNIZES ME. He knows me. Sometimes, rarely, he hugs me, or lets me hug him. Frequently, he spits at me or tries to pinch me. His spitting is perfunctory; he makes the sounds of spitting but there is very little saliva actually launched. It is a warning gesture, an attempt to establish territory—don't come too close—a gorilla beating its chest, a dog baring its teeth. He is a man—it is still shocking to think of him as a man, a corollary to society's habit of referring to all autistics as "children," as if somehow they never grow up. They do, and Noah looks his forty-one years, with his receding hairline and thinning black hair, his graying facial stubble, the slight radiating of wrinkles beginning at the edge of his brown eyes. His hands and forearms always seem scabbed, self-inflicted scratches and cuts. He bruises his forehead from banging his head against walls and picks up other bruises, scrapes, and scars. The damage helps to make him look more wizened than I. His greeting gaze also contributes; it is a skeptic's squint. Prove it, he might be saying,

► **Karl Taro Greenfeld (left) and his brother, Noah, in a moment of calm and ease, back when the family lived under one roof.**





prove it. I make the first move. As I said, I always try to hug him.

Sometimes, when he's happy, I get the hug back. It is one-armed, brief. He is going through the motions.

I cannot think of any other human relationship that would continue with so little positive feedback from one party—those whose parents suffer from severe Alzheimer's or who have had loved ones suffer traumatic brain injuries know this sense of visiting, of loving, and getting so little in return. But Noah knows me. He has a memory, perhaps of those decades we lived together.

What does he make of his own childhood? A distant sense of warmth, a vague idea of more comfort than versus discomfort now? He lived with us, my mother and father and me, in a home—a family, that has to mean something, right?—where, at the very least, he had to know he was loved. He would have felt that, wouldn't he? Despite all the literature explaining the emotional distance of the autistic, they are human in the sense that they can feel good and bad based on how they are treated. It is terrible to say this, but a dog knows love, so Noah must, too. But does Noah share the almost universal memory of the familial cocoon, his mother's embrace, his father's lap, being carried, hugged, lifted up and away from danger and into safety?

I believe he does, because when he sees our parents, his reaction is often so different from when he sees me. He is more likely to hug them, even to bend his head forward so that they can kiss him on the forehead. Our parents—my

The two of them, my old parents, slightly hunched, carrying their little bags of Noah's favorite goodies, California rolls and rice crackers and guava punch. My mother lays out a napkin, opens the plastic supermarket sushi container, and then Noah tears into it, stuffing his mouth with crab and avocado and rice and looking warily around, lest someone would take away his food. He leans forward, his elbow around his meal, the way I imagine a convict would in prison. He doesn't understand, or believe in, delayed gratification. And his years in and out of group homes and facilities have further reinforced the notion that if something is good, now, then take as much of it as you can. If he is in a good mood, he will then hang around for a while. Perhaps we will take a walk with him or a short drive. He will bob his head slightly and smile, a wide, open-mouthed, cheek-creasing, eye-muscle-relaxing expression of uncomplicated joy that is as real as smiles get—Noah doesn't lie. He will say, "M-m-m-m-m-m-ommy," and then expect the reward that is always forthcoming when he uses a word.

As my father says, when Noah is in a good mood, you feel like you've won the lottery.

AS A CHILD AND THEN TEENAGER, my feelings about Noah evolved from sibling love to, finally, angry indifference. Noah and I once played together. He was 2, and I was a year older. We wrestled, and I tickled him. He responded in a high-pitched giggle, halfway between a baby's gurgle and a child's laughter. I can't remember ever playing with him again. Noah stayed forever a baby, profoundly retarded, always dependent, never very communicative. And my role changed, much too early, from playmate to steward. There was barely any sibling rivalry. There were no battles to be fought. He would always be the center of attention. I was treated as a sort of supporting player. Because my father had written a trilogy of books about our family with Noah as the title character, I would often be asked what it was like having an autistic brother. I never figured out how to respond. The answer I always gave—that I had never known any other life or any other brother—seemed cryptic and somehow unsatisfactory.

By the time I was a teenager, I used to take bong hits on the back porch when I was left in charge of Noah; he literally couldn't tell on me. He would be sitting in the den or the living room, chewing on furniture, twiddling a rubber band, humming in his repetitive monotone. Those repeated consonants—*muh-muh-muh-muh*—as steady and droning as the chirping of a cicada, were the soundtrack

He recognizes me. He knows me. Sometimes, rarely, he hugs me, or lets me hug him. Frequently, he spits at me or tries to pinch me.

father is now 80, my mother in her late seventies—surprise me with their deep reservoir of love for Noah. Their loyalty astonishes me, and sometimes I have thought that it is their weakness.

My father walks in shuffling steps, his hands in his jacket pockets, a captain's hat or baseball cap on his head that Noah always makes him remove. My mother is shorter; she was never more than five feet two, and in her eighth decade I believe she has lost an inch or two, and she has grown wider in the middle. When Noah was at home, she was slender, as narrow as a prepubescent boy; all the running after Noah kept her a flyweight.

of our house, a regular reminder of Noah, of the problem of Noah, the question of Noah. What do we do with Noah?

When Noah was 13, he was as tall as my mother. My father, already in his fifties, was soon diagnosed with a heart problem; he has since had open-heart surgery. Both of them felt they couldn't take care of Noah at home anymore, that it had become a matter of their survival or his. Noah's peers at the day-care center had already begun disappearing into the abysmal state institutions or—for the luckier ones—group homes. My parents reluctantly admitted that they needed to find a place for Noah, a process that meant a year of looking before finally choosing a group home in the Valley.

When we arrive, we are shown the room—four beds, three along one wall and the other in the corner, and two windows with vinyl drapes—that Noah will share with three other boys. My parents sign some paperwork and show the staff how to use the rice cooker they are donating so that Noah can still eat his favorite foods. My mother has sewn labels into all his clothes, prepared a huge stack of *gyoza* dumplings; then they are given an additional stack of forms to sign, including one that allows for the use of aversives—slaps, spankings.

It wasn't forever, my father believed, as if he had packed his son off to a military academy for some discipline. But he knew. He already knew, that this felt wrong.

My mother was crying.

Noah bounced on a leather sofa, disinterested, and then he reclined on his elbow. He didn't know this was forever; he didn't even know he wasn't coming home with us.

We left him sitting there. He waved to us, a weak, indifferent, limp-wristed gesture. Good-bye, like he didn't care.

Driving away felt like a crime.

A FRIEND OF MINE who also has an autistic brother asked me about guilt. I reflexively told her I didn't have any, at least not about Noah.

"Bullshit," she said.

I thought for a moment. We were walking down Broadway in New York City and stopped at a corner. "I guess you're right," I said.

I'd never thought of it before. I assumed I just felt sorry for Noah, that I would do what I could to help Noah. Actually, it made me tired thinking about Noah. There were no solutions. I had resigned myself to that so long ago, I didn't even remember ever thinking there might be. So I built this static model of Noah = Problem and tried to leave it unexamined, because there were no answers, right?

Yet she was right; I did feel guilty when I thought about Noah. Why was I here, normal, speaking, writing, talking, living a life, and Noah was always twice imprisoned, in

his mind and in an institution? It wasn't fair, but that wasn't my fault. I don't believe I suffer from some version of survivor's guilt. The guilt has to do with a practical matter: Couldn't I be doing more? Shouldn't I be visiting more often, calling up his caregivers, fighting for his rights in the various supervisory and medical hearings that are held to determine his fate? Instead I traveled the world, spending decades getting as far as I could from Noah: New York, Paris, Tokyo, Bangkok, Ibiza, Hong Kong. If he could talk, then we could have spoken on the phone; he could have told me he wanted to see me. (What the hell do brothers talk about, anyway? Even though I have one, I realize I have no idea.)

So his silence allowed me to wander away, to stay gone, leaving Noah in the hands of my parents, who never suggested I should stay closer because of him. Who are reluctant to even remind me that Noah will be my problem as well. We've talked about it, but never so specifically that a schedule is discussed.

My father has said he doesn't want me to feel burdened, that it's not fair that I should live with this obligation. How is it, then, that I feel it is as inevitable as hair graying? Because it is assumed that I will take care of Noah, that my parents will go on for as long as they can, and that they are already faltering, forgetting appointments to meet with his doctors, losing the list of medications Noah is taking. Here is how implicit the whole arrangement has become: During a recent visit, as my father realized that of my two daughters, the elder, Esme, has a more gentle disposition than her more lawyerly younger sister, he said to me, "If something happens to you, then I think Esme would take care of Noah."

So then at what point is the guilt imparted to Esme? And will she ever feel that she's doing enough?

It is ironic that in the 1970s, my father played the heavy when autistic parents were gathered to discuss their issues. Twice he appeared on Tom Snyder's *Tomorrow Show* to advocate euthanasia for the severely retarded and autistic. He did this, he said, to highlight how little was being done by the state and society for those afflicted, "to dramatize the plight of those afflicted." In truth, he was unable to stop worrying and hand-wringing over Noah, constantly fretting over his lousy schools and his indifferent teachers. I now see my parents' devotion to Noah as a strange kind of sacrifice, a masochistic cycle they saw no way out of. As a parent, I feel the great sucking force on my love and spirit emanating from my daughters; how could I ever turn my back on them? But if it were survival, I ask myself, if it were them or me, would I still sacrifice everything so that they might feel a little better?

But Noah never required one massive decision, to institutionalize him or keep him at home. It was a gradual process during which every day a small decision was made to keep him home, if only for one more day. "We keep thinking of finding a place for him," my father wrote. "We know we have to start the long weaning process. But how hard it is to wean oneself from a six-and-a-half-year test of love." Yet my mother and father were resolute in keeping him home. What it came down to for them was this: Our home was the best place for Noah, even though Noah was the worst thing that could happen to a home. It was a mistake, yet it was the only humane course. And my father used to tell me that he talked and wrote about killing Noah because that meant he could never do it, that the confession and motive were already there, on tape, in his books, so he could never get away with the crime.

But I was a different matter. I had never talked about it with anyone, had never written such a thought down. I think about this sometimes when I visit Noah now. I could stage the same sort of accident my father wrote about—take him out on a boat and push him overboard. Noah can barely swim. His symptoms include frequent jerky movements and erratic behavior. He would be more likely to fall overboard than stay on the boat. And then the problem would be solved, and that way, if something happens to me, then perhaps poor Esme or Lola won't have to spend their middle years bringing sushi and fruit to her crazy uncle.

He will be even more grotesque by then; the severely autistic don't groom themselves. Noah is far more likely to pick up a stray piece of trash or make sure all doors are securely closed or put any cups into the sink. He likes his surfaces pristine, even if that means picking up a piece of dog feces. This symptom is described in the *Diagnostic and Statistical Manual of Mental Disorders*: "inflexible adherence to specific, nonfunctional routines or rituals." (Noah, by the way, scores a perfect 16 out of 16 on the *DSM-IV* test for autism; 6 is good enough for a diagnosis. He excels in autism.)

Why would anyone pretend that he is anything more than a freak, a broken human, a sick animal, kept alive by the taxpayers and despite himself? I can see him that way, too; I am guilty of the same rationalizations, particularly when I need to justify my going months without seeing him.

My mother, who has very little artifice, once said, "People like Noah, they die if no one goes to look in."

So I make the trip, the drive down the 10 freeway to La Brea and then down La Brea to Chesapeake and the little house by the recycling center where he resides now in a supported-living environment.



I SUSPECTED, even before I boarded the planes and rented the cars, that there were no cures for my brother's affliction. Yet the television news kept broadcasting stories of hope. A boy in Evansville, Illinois, whose parents had staged an intensive, immersive intervention when he was diagnosed at 18 months, now responded to the newscaster's questions in the same evasive, smiling manner as would any other 6-year-old; a famous actress put her son on a gluten-free diet and then wrote of his remarkable return to normalcy; the families on *The View*, on *60 Minutes*; the revelations of new therapies, medicines, treatments, interventions.

But as I have come to realize, there are no adult autistics featured in any of this media coverage. The pathos of the child who for the first few months of his life appears to be developing normally and then, in the words of so many of the memoirs and hope manuals, "regresses" or "vanishes" makes it seem as though autism is a tragic affliction that snatches children but ends there.

And yet there's Noah, my 40-year-old brother, an adult autistic and living proof of the obvious: Autism is not a terminal disease, so these autistic boys and girls are likely to become autistic adults. But where are the well-funded programs and research papers and longitudinal studies ascertaining the state of adult autistics?

I have phoned representatives of the numerous autism advocacy groups that have arisen over the past decade, looking, I suppose, for reassurance that my brother still has some kind of chance, that with all these happy endings, with all this money and focus and research—with Oprah!—Noah won't end up a member of a lost generation of autistics. What I have found out is that the focus of these organizations is relentlessly toward the children. There are plenty of studies being done to benefit adults with Asperger's, the highest-functioning part of the autistic spectrum, but next to nothing to help low-functioning autistic adults.

One spring day in 2007, I boarded a plane for Seattle, to attend another major conference that drew together the various arms of the autism establishment: the geneticists seeking a cause, the behaviorists seeking better therapies, the epidemiologists looking to explain prevalence, the neurologists looking to understand etiology. At these gatherings, too, were the parents. They were the ones who leaned forward, spoke loudly, pleaded. They were shabbily dressed compared to the doctors and geneticists; years of living with an autistic boy or girl had forced spartan sartorial choices—rough, durable fabrics, hair tightly coiffed, no dangling jewelry that might be pulled or twisted or yanked by an unruly and angry 12-year-old. I knew these mothers and fathers, recognized in them my own parents' reduced lives.

I did not attend to find empathy or consolation. I was there to gather information about studies and programs for adult autistics. Amid 450 papers and presentations and three dozen talks given by the elite academics and specialists covering autism, only two dealt with low-functioning adults.

Of course, the great autism-industrial complex want to believe that by treating children, they are heading off the next generation of autistic adults. In reality, the success rate for these early-intervention programs is still far lower than the glowing media reports would lead one to believe. These conferences, for all the good intentions and hard work of the experts, are still selling short-term solutions to high-functioning kids, the easiest-to-treat segment of the autistic population. Where, I always find myself wondering, does Noah fit in to this?

He doesn't. He was a lost boy then, and he is a lost grown-up now.

AT ONE CONFERENCE, I stand before a great man, a smart, charming geneticist with understanding eyes. "How old is your brother?" he asks. "Is he verbal? Where does he live?" I explain and immediately realize that he has already slotted me into the category of "concerned family." (It is novel that a sibling is here instead of a parent, but that, too, will soon become common enough as this current, swelled cohort of diagnosed autistics ages into adulthood.)

He tells me how sorry he is. It is heartfelt, but the squint of his eyes catches me off guard when I realize that he sees me as a figure to be pitied. I want to show him that I am not, that I am full of life and not chained to my unfortunate brother, so when he asks how long I am going to be in town, I tell him I am leaving early the next morning, to fly to Las Vegas to see a highly anticipated prize fight. The geneticist detests boxing, he says, those blows to the brain. Terrible. Terrible.

I am left standing, feeling foolish.

Later he will address a vast hall, speak on the state of genetic research into autism, regret that the search is entering a more complex phase. The great genetic hope of so many in the autism community, that we would find a straightforward location on the genome for autism and be able to more quickly diagnose and maybe prevent it, was now gone. The geneticist seemed almost

► Noah Greenfeld (seen here at age 38 in a photo taken by his father) was institutionalized as a teenager. He now resides in a supported-living home in Los Angeles.

contrite as he summed up what everyone in the room already knew, that "autism is not an easy disease." It may not be one disease or condition at all, but merely a collection of behaviors and deficits stemming from a range of rare mutations. All of us can answer yes to at least one or another item on a checklist of autism symptoms listed in the diagnostic criterion—are you occasionally "preoccupied with parts of objects," do you have "non-functional routines or rituals," do you have an interest that is "abnormal either in intensity or focus"? Any one or even several of these proclivities means nothing. Too many and you are autistic.

That is where the research is pointing. It is a fascinating idea, this concept that autism is not a disease at all but a trait that is expressed everywhere in the genome. Sort of like being Asian. You can't really find the gene that makes people Asian. It is expressed everywhere in the genome.

What does this mean for boys like Noah? Yes, treatment strategies have evolved since Noah went through Dr. Ivar Lovaas's UCLA program, but there has been no revolution. Intervene earlier, with more intensity, with greater focus. That is the sum of it. There are dietary therapies, yet for every child who benefits, another shows no improvement. Perhaps if Noah were born today, his diagnosis would have been earlier and discrete trial intervention would have started sooner. Would a few seasons' head start have transformed him?

Early intervention is now the accepted and recommended course, with the diagnosis made, if possible, at 5 months. Are "normal" children being caught up in this early-diagnostic dragnet? Of course. How many of them are among the miraculously "cured"? We will never know, but it can't hurt to start early. What we do know is that all autistic children grow up. And I wish, I really do, that they will all miraculously recover.

But I know, I really do, that not all of them will. ❌

From Boy Alone: A Brother's Memoir, by KARL TARO GREENFELD, to be published this month by HarperCollins.