

DEEP DIVE

# The children who leave autism behind

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*Illustration by Pep Boatella*

Alex, aged 10, bounds onto his bed to pose with his Aaron Rodgers poster, grinning as proudly as if he had recruited the Green Bay Packers' quarterback himself. Continuing the tour of his suburban New York bedroom, he points out his Packers-themed alarm clock, his soccer trophy, his Boy Scout trophy and then the big reveal: a homemade foam box in Packers green and gold.

"Mmm, very nice," I say. Alex grins — part shy, part sly — as he turns it around to show me the message on the back: "Jets stink."

Even though he seems to be an entirely ordinary boy, there's something unusual about Alex: He once had autism, and now he does not. There was a time when Alex's parents didn't know if he would ever speak in full sentences, let alone joke around with a stranger. His autism, they suspected, might prevent any such future.

Alex's parents began to worry about him before he was even 1 year old. He wasn't learning to sit, crawl or stand as his fraternal twin brother was. Even more striking was how much less social he was compared with his brother.

"Alex was an expressionless child," says his mother, Amy. (Alex and Amy's names have been changed to protect their privacy.) She remembers a friend trying in vain to get Alex to laugh — jumping up and down, gesturing wildly, making silly faces. "His brother would be in belly laughs, and Alex would be just glazed over," Amy says.

Their pediatrician, suspecting autism, recommended early intervention. When Alex was only 9 months old, his parents arranged for speech therapy, physical therapy and other special education services. Alex was formally diagnosed with autism when he was 2. He had all the hallmark symptoms: He avoided eye contact, he didn't respond to his own name, he wouldn't point to communicate what he wanted, he was obsessively interested in letters, numbers and animals. Like many children with autism, he had intense reactions to certain sensations, and mundane procedures such as getting a haircut were traumatic — the feel of the scissors on his neck made

him writhe and scream.

In the wake of the diagnosis, Alex's father struggled to picture a future that was anything but bleak, says Amy. But she was more optimistic, putting her hopes in an intensive program of behavioral therapy. Alex made steady progress — first in one-on-one therapy that required as many as 25 or 30 hours a week, then in therapeutic preschool and elementary schools and, finally, in a mainstream classroom. This year, his developmental pediatrician, autism specialist **Lisa Shulman**, judged that he no longer meets the criteria for an autism diagnosis.

Today, Alex is funny, gregarious and obsessed with sports. He is keenly self-aware and socially tuned in, chattering about the status hierarchy on the school bus and explaining that scoring soccer goals only occasionally is actually better than scoring in every game, because then it feels more special to high five your teammates.

Most children with autism will forever have the disorder. But a handful of studies in the past three years indicate that for reasons no one understands, a minority of children, like Alex, shed the core symptoms necessary for an autism diagnosis. Shulman, who runs a large clinical autism program at Albert Einstein College of Medicine in New York City, says most of these children face residual learning or emotional problems. "We still consider these kids as having had a wonderful outcome," she says. "But they don't get off scot-free." Only "the minority of the minority" breeze through each new challenge life brings them — the book reports in elementary school, the social minefields in middle school, the expectations for independence in later adolescence and adulthood.

## History lessons:

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The notion of recovery from autism is both tantalizing and fraught. (Even the term 'recovery,' with its connotation of illness, is controversial, and many researchers avoid it.)

In 1987, University of California, Los Angeles psychologist Ole Ivar Lovaas reported that half of young children who were treated for at least 40 hours per week with a type of autism therapy called applied behavioral analysis, or ABA, **became "indistinguishable" from other children** by the time they finished first grade. His finding drove support for **early, intensive intervention** for

children with autism.

ABA, first used as a treatment for autism in the 1960s, relies on principles of learning theory, including prompting and rewarding desirable behaviors such as social interaction and minimizing behaviors, such as repetitive movements, that interfere with learning. Many forms of autism therapy are based on these principles. Alex's therapists, for example, used a modified form of ABA to teach him basic aspects of social communication such as meeting another person's gaze, pointing when he wanted something, and mimicking actions such as waving.

Traditional ABA and newer variations **have been shown to significantly improve** children's cognitive and language skills, and adaptive behaviors.

Some children given these intensive treatments improve more than others. But Lovaas' claim that half of young children who receive intensive ABA therapy would "recover" was clearly an overstatement. And clinical psychologist **Catherine Lord**, an autism expert at Weill Cornell Medical College in New York City, says those promises did damage. They set up parents to believe that if they just followed the 'right' therapy, they could make their child's autism disappear. "There's just no evidence of that at all," she says. Today, autism is generally considered to be a lifelong condition.

Nonetheless, in the modern history of autism studies, researchers noticed that some children — estimates vary widely, from about 3 to 25 percent — seemed to lose the social and communication impairments and **repetitive behaviors** that define autism. But they often assumed either that most of those children had been misdiagnosed and never had autism to begin with, or that they continued to have autism with less obvious symptoms.

It wasn't until a February 2013 study, led by University of Connecticut clinical psychologist **Deborah Fein** and published in the *Journal of Child Psychology and Psychiatry*, that researchers once again began to seriously consider the possibility of **recovery from autism**.

In her clinical practice, Fein says, she occasionally saw children who had made "surprising, remarkable progress" — so much so that she couldn't help wondering whether there was something unique about their early histories. In 2009, she began looking systematically at children in her own practice and elsewhere, identifying 34 young people between 8 and 21 years who had achieved what she and her colleagues labeled an "**optimal outcome**."

To be included in this group, the children had to have had a verified early autism diagnosis and no remaining autism symptoms. Fein also excluded ambiguous cases — for example, those who had never had a language delay or who were still receiving special education to address social or communication impairments.

Although the members of this group are similar to their typically developing peers in their

communication, facial recognition and language abilities, Fein wondered whether they might differ in subtle ways. To find out, she and her colleagues have conducted a series of follow-up analyses. One analysis suggested that some young people in the optimal outcome group are slightly more socially awkward than their peers — but they are perceived as more likable than those who either never had autism or who still have autism but are high-functioning. Another analysis revealed **a few minor differences in language**. But Fein’s group has found **no deficits in executive function** — a broad class of cognitive skills that includes abilities such as controlling impulses and emotional reactions, shifting attention between activities, and planning and organization.

More evidence that some children can outgrow an autism diagnosis followed. In a 2014 study in the *Journal of Child Psychology and Psychiatry*, Lord and her colleagues **reported results** from 85 children with autism they had followed from age 2 through 19 years. The team found that of the 32 children in the study who do not have intellectual disability, 8 — all boys, and just 9 percent of the original 85 children — no longer met diagnostic criteria for autism by age 19 and required no extra support. (Six of the eight boys in this “very positive outcome” group retained their diagnosis until they were at least 14.)

Fein’s and Lord’s studies don’t offer many clues as to why some children outgrow their autism. Those in Fein’s optimal outcome group had slightly milder social symptoms in early childhood than did their peers whose autism did not change, but their early profiles were otherwise largely the same. Similarly, Lord and her colleagues found that children who later lost their diagnosis were no less impaired than others at age 2.

## What changed:

Early access to treatment may have something to do with these outcomes: In an analysis last year, Fein’s group found that, on average, children in the optimal outcome group had received **earlier and more intensive therapy** than children who kept their autism diagnosis. About 40 percent of children in the optimal outcome group received ABA therapy between ages 2 and 2.5, compared with only 4 percent of children who did not lose their diagnosis. In Lord’s study, all eight children who no longer met autism criteria had received treatment by age 3, compared with only half the children who continued to have symptoms.

Because neither Fein’s nor Lord’s studies randomly assigned children to receive early intervention or not, it’s impossible to say whether or how much the therapy plays a role, however. “Most kids are not going to make this dramatic progress and lose the diagnosis, even with the earliest, most intense services,” cautions Fein.

In Alex’s case, treatment certainly seemed to help. When he was 3, he entered a therapeutic

preschool that emphasized social interaction, and he blossomed there. One day Amy took him to meet a classmate at a playground. When they arrived, Alex couldn't immediately see the child in the crowded park. "I remember him saying, 'I lost my friend. That makes me sad,'" Amy says. "That was an early revelation that he recognized and cared about another peer."

By the end of second grade, the director of Alex's elementary school, a therapeutic school for children with language-based learning problems, assured Amy she thought he was ready for a mainstream classroom. Later, he joined a regular education classroom at a public school with strong special needs programming. A Monday-afternoon socialization group strengthened skills such as initiating conversations and compromising with teammates.

"Some of our kids do amazingly well, but they still need help." Developmental pediatrician Lisa Shulman.

Another person who eventually left his diagnosis behind has a similar story. Jake Exkorn was a chatty, active 1-year-old who gradually lost interest in other children, then stopped responding to his name and finally stopped speaking. At age 2, he was diagnosed with autism. For the next two years, he spent more than 40 hours a week in therapy, relearning the skills he had lost: how to clap and wave, how to make eye contact, how to play with other children.

At first, Jake merely imitated his therapists or his parents, spurred by the promise of an M&M or an Oreo. But once Jake developed spontaneous language, his mother Karen Siff Exkorn says, "it was like someone hit the fast-forward button."

By the time Jake was 4, a friend watching him at a birthday party remarked that he seemed just like any other preschooler. His mother had him re-evaluated, and the doctor said that not only did Jake no longer meet criteria for autism, but he had none of the residual behaviors that sometimes persist. The doctor said he was a rare case of "full recovery."

When Jake started kindergarten, his parents told the teachers about his autism history so they could keep an eye out for any lingering difficulties. But soon they stopped worrying — Jake did fine. By the time he reached middle school, no one there guessed he once had autism, says Exkorn, who in 2005 published "The Autism Sourcebook," a resource guide for professionals and parents of children newly diagnosed with autism. This September, Jake starts college at the University of Michigan in Ann Arbor. He says he doesn't remember much about having autism — though he does remember the M&Ms.

## Losing autism:

Some in the autism community object to the very notion that autism can or should be left behind. Autism “is intrinsic to who we are — it’s the hardware, not the software,” says Carol Greenburg, a professional special education advocate in New York and an editor of the “**Thinking Person’s Guide to Autism**,” a book and blog offering practical advice and perspectives on research, education and other topics.

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Greenburg says that in most, if not all, cases of apparent recovery, people have not actually lost their autism, but rather have learned coping mechanisms that allow them to “simulate a non-autistic persona,” even in formal assessments. But “passing” in this way takes enormous energy, as both Greenburg and her 14-year-old son know from personal experience. “All autistics are forced into a position where we have to use that energy to create an appearance of normalcy rather than to actually function,” she says. “I don’t want either me or my son using that energy trying to look ‘normal.’ I want us to use it trying to accomplish goals that we have set for ourselves.”

Brain imaging seems to support the idea that losing the behaviors necessary for an autism diagnosis doesn’t necessarily mean the brain has ‘rewired.’ In an unpublished study, Fein and her colleagues found that when performing a language task, young people in the optimal outcome group have patterns of neural activity in some brain regions that more closely resemble those of their peers with autism than the patterns of typically developing individuals. The finding doesn’t negate the idea that those children’s autism has faded, Fein says: After all, the disorder is diagnosed based on clinical observations of behavior, not based on brain scans. But, she says, “the brain functioning is not normalized. It looks like they might be compensating.”

**Ari Ne’eman**, president and co-founder of the **Autistic Self Advocacy Network**, argues that losing an autism diagnosis deprives people of the opportunity to be part of the autism community, and that adults in this situation often sense that they’re somehow different, but can’t make sense of the feeling. In other cases, children may reject their own history. “If your whole life your parents have looked at autism as something that was this scary thing that, thank goodness, was no longer associated with you, that’s a hard thing,” Ne’eman says.

Karen Exkorn says she’s convinced that’s not how Jake feels. “He embraces his past and can talk about it,” Exkorn says. They are both certain that for him, autism is part of the past. But she

says she understands why it seems hard to believe. “I’m not sure if I would have believed that full recovery was possible — if we didn’t have a son who fully recovered.”

For many children, loss of the diagnosis can be a double-edged sword. Many **continue to have persistent difficulties**, such as attention deficit hyperactivity disorder or language-based learning issues. “Some of our kids do amazingly well, but they still need help,” Shulman says. Some of these deficits might not show up right away. Problems with attention might not emerge until first grade, when children are expected to sit still, for example, and language-based learning difficulties may not become apparent until the third or fourth grade, when children are expected not just to read, but to read in order to learn.

Digging into the charts of some of the children she has treated, Shulman found that of the 569 children diagnosed in her program in the last decade, 38, or 7 percent, no longer meet the criteria for autism. Of those, 35 continue to have emotional, behavioral or learning difficulties, and only 10 are in a mainstream classroom with no additional support. (Shulman does note that her study may overestimate the proportion of people who have persistent problems because those who are fine may stop visiting the clinic.)

Amy, Alex’s mother, sees hints of these lingering difficulties in her son, despite the stunning progress he has made. When he was a baby, one of the first clues that something was wrong was his poor motor development. Now, at age 10, he is all knees and elbows. He bumps a glass of milk, catching it just before it spills. He accidentally taps the edge of a plate of chips and scatters them on the counter.

These may seem like signs of ordinary clumsiness. But to his mother, they represent a persistent, if minor, problem with gross motor skills. In Alex’s Aaron Rodgers fascination, Amy sees not a typical adolescent interest in sports but an echo of his earlier fixation with letters and numbers. His thinking also retains some of the rigidity that marked his earlier years: He’s strongly averse to reading unless it’s about sports, Amy says, and “shuts down” if he can’t find a book to his liking.

These remnants of Alex’s past, Amy says, “remind us that while they may be a little bit more latent than they were, they’re still there, and they’re still part of who he is as he grows older.”

## Mixed feelings:

In fact, Amy says she is not confident that Alex has completely left autism behind. He still struggles in school, especially in reading comprehension and other areas that strain his still-immature language-processing skills. But he has learned coping and compensatory strategies that, at least for now, can convince teachers that he is understanding and processing information as any fifth

grade student should.

This leaves Amy with a fresh set of worries. Although she is grateful for Alex's many gains, she has mixed feelings about his losing the autism diagnosis — and the many sources of help that come along with it. "He just gets lost in a sea of other students because he's a sweet, compliant kid, and somehow in his crafting of his answers to the homework, making it look like he's on it — but he's not," says Amy. "My ongoing struggle with the school is making sure he doesn't fall through the cracks, and that becomes harder without an autism diagnosis."

In his fifth grade science class, for example, Alex was skimming through the assignments, and his mother became convinced that he didn't really understand the material even though he was keeping up. His science teacher didn't realize what was going on until Amy pointed it out.

Parents like Amy sometimes face another conundrum: whether and when to tell their children, or the rest of the world. Some parents see autism and everything that came with it — the anxiety and perseverance, the setbacks and successes — as a core part of their child's and their family's identity, something that cannot and should not be erased.

Jake's parents told him about his diagnosis when he was about 5. "I wanted him to find out from us," his mother says. "I didn't ever want him to hear from another family member at a family reunion." She says she also wanted to destigmatize autism: Why should it be a big secret? Jake took it in stride, she says. "It was as if we told him, 'You had the chickenpox and then you recovered.'"

Others say they worry that a history of autism will affect how friends or teachers treat their children, or affect college admissions, or damage their child's sense of self. Alex is aware that he gets extra help with reading, writing and social skills. But his parents have not yet told him about his autism, and Amy says she's not sure if or when they will.

But that's a question for another time. Today, Alex's parents are happily looking forward to their son graduating from high school, going to college and finding a fulfilling job. And they hope that as he grows, he'll form meaningful friendships and find love. "Sometimes it is amazing to think about his beginnings and to see this kid who has evolved into a very thoughtful, very self-reflective, socially aware child," says Amy.

Amy might never be able to think of autism in the past tense, and she might always worry whether Alex gets all the support he needs — but what parent doesn't? "I'm not sure any parents, of typical or non-typical developing children, can say there is an 'optimal outcome' in the end," she says. "We all try to develop and leverage our children's strengths, but in the end they are who they are destined to be."

Perched on a kitchen stool as he finishes a snack, Alex gamely entertains questions about what it



was like to move to a new school a couple of years ago. Making new friends was the hardest part, he says. "I had to stretch to do things that other kids were into so I'd have something to talk to them about." Luckily, he says, he figured out a key to social success: Minecraft. He's not the best at this game, just like he's not the best reader in his class. But that's okay with him. "I'm proud of me because I'm good at being me," he says. "I don't want to be anybody else."