An inconvenient child

My six-year-old son was suspended as a danger to others. His crime? A disability you could find in any classroom

Michael Graziano

A few months ago, my son, who is in second grade, went on a field trip. As the class assembled in the parking lot, a new child joined in. He had metal leg braces and difficulty walking. Nobody quite knew how to talk to him and so he was left by himself at the edge of the crowd. But my son seemed drawn to him. As the little boy in braces began to struggle up the steps of the bus, my son went over to help and then sat beside him. Throughout the bus ride, they talked together. According to the teachers, that new little boy soon seemed like the happiest child in the group. One of the most sociable children in the class had made friends with him, and that goes a long way towards building self-esteem when you feel isolated and anxious.

I'm very proud of what my son did. He showed compassion. He was still a new pupil himself, and he had suffered bullying related to a disability of his own. The way he was treated at his previous school was so horrible that he might easily have decided to pay it back rather than forward. But kids can be amazingly smart about how to treat one another. After all, it wasn't the children who bullied him at his old school. It was the adults.

Our son's movement problem emerged slowly – so slowly that we didn't notice at first. When he was five, he moved more like a three-year-old. He was happy and chatty, but he had difficulty writing, drawing, cutting, pasting, and sitting straight and still in a chair. Milk tended to spill an awful lot in his vicinity. His kindergarten teacher at his elementary school noted these difficulties, but the school decided he was in the normal range and didn't require any extra support.

The following year, he started first grade at the same school. In November 2012, we met with the first-grade teacher, who told us that our son's writing was a useless scribble compared with the other children's. He was at the bottom of the class. We were taken aback. Poor writing can have an impact on reading and on math. Why hadn't the teacher told us earlier? During math homework, our son seemed so anxious about the effort of forming each digit that he couldn't think about the question itself. And yet, apparently, he didn't qualify for any school occupational therapy to help with his writing.

A worse surprise followed a couple of months later (this is, among other things, a story of escalating shocks). At the start of 2013, my wife requested a meeting with the teacher to follow up on our son's classroom progress. We were braced for bad news, but we couldn't have prepared ourselves for what the teacher had to say. She brushed aside our concerns about writing and reading and math, and informed my wife that, for almost a month, since before the holiday break, our son had been 'touching himself inappropriately' in class.

The teacher's description was vague. She seemed extremely uncomfortable talking about the issue. When pressed, she explained that he never put his hands in his pants. He never opened his pants. He never exposed any part of his privates. According to the description, he seemed to be rocking rhythmically in his chair, or rocking when lying on the rug during story time, and the rocking was bumping his groin area.

It happens that my wife and I are both psychologists, and this description of our son's behaviour worried us a great deal. First, six-year-olds just don't engage in behaviour with a sexual intent. Secondly, repetitive rocking is a classic hallmark of anxiety in children: the physical motion is self-soothing. It ought to go without saying that any child who engages in strange or extreme repetitive behaviour should get help right away. But the school did not offer help. We were told that it was our responsibility to make our son stop misbehaving.

Very worried, my wife and I got to work. Immediately after that January meeting, we found private therapy for our son. We brought him to weekly occupational therapy for his movement problems and weekly psychotherapy to help him adjust to the stresses of the classroom. The movement therapist found that he had significant muscle weakness and co-ordination difficulties. The psychotherapist diagnosed him with school-specific anxiety. He saw himself as the dummy of the class because he couldn't even write his own name. When we brought him to school, he would cringe away from the staff and refuse to say hello. The repetitive rocking in the classroom was almost certainly a classic self-soothing strategy triggered by his anxiety about writing. The rocking movements in turn might have been affected by his co–ordination problems.

While we were busily making arrangements to help our boy, his school embarked on a campaign of its own. Our son used to attend an after-school programme run by the YMCA, where his teachers always spoke highly of him. Without our consent, someone from the school contacted the staff of the YMCA programme to tell them about his classroom difficulties. This person apparently labelled his problem as sexualised behaviour and speculated that his parents might be abusing him. The first we heard about this was when the after-school staff told us about it.

At around the same time, somebody at the school took our son out of class and interrogated him about his family. This person apparently told him that he couldn't let anyone know about the conversation, and indeed we found out about this second secret rendezvous only when he began to act it out in play. Unsurprisingly, the emotional conflict of being asked questions concerning something that he was, in his words, 'not supposed to talk about' caused him a considerable amount of distress.

The fact that the school was pursuing its suspicions in strange and secretive ways raised questions of its own. But we couldn't help a grain of doubt. Was the school right? Was his problem simply a pattern of willful and highly inappropriate behaviour? It seems significant that nobody outside the school ever reported any of our son's strange 'sexual' misbehaviour. He didn't do it at home. He was well–behaved at the after-school programme, at which he was said to be a delight. He had a group piano class every week and never behaved the way the school described. He had play dates with other children and was always his usual sociable, friendly self. His movement therapist and his psychotherapist never saw the misbehaviour. Nobody but the adults at the school ever saw sexually motivated behaviour in our six-year-old boy. We believe the school was looking at a childhood disability and interpreting it in a thoughtless and stigmatising way.

As I said, this is a story of escalating shocks. The next one came on 28 February 2013. The teacher emailed my wife to schedule a one-on-one meeting. At the last moment, I decided to come too, and it was lucky that I did. The meeting turned out to be an ambush.

The school principal came down to the lobby and led us to a room where we found an entire panel facing us: the learning consultant, the teacher, the nurse, the school counsellor. The principal sat us down and told us that our six-year-old son was masturbating in class. This masturbation took the form of abnormal movements as he sat by himself in his chair or on the carpet during story time. Everyone found it disturbing to look at. It was our responsibility to stop him. The principal also informed us that she had called the State of New Jersey Child Protection and Permanency services to report our family for investigation, since she suspected that our son might be the victim of sexual abuse himself.

We sat stunned. We had spent a year asking the school for help for our child and the principal's very first response was to report us to a state agency for possible child abuse. She hadn't talked to us first. She hadn't attempted to gather even the most basic facts about the case – for example, that our son had a movement problem. She didn't know that he was in private psychotherapy to help him with the stress he felt about going to school. She didn't know that his repetitive movements in the classroom had been diagnosed as symptoms of acute classroom anxiety, and that it was probably brought on by a writing difficulty that the school was failing to address. She didn't know any of this.

His teacher, on the other hand, was quite certain that our son didn't have school anxiety. After all, she explained, she never saw him cry. How could he be anxious?

Last summer, the head of pediatric neurology at the Children's Hospital of Philadelphia diagnosed my son with apraxia, sometimes termed dyspraxia or developmental co-ordination disorder. This condition has been called 'the hidden disability', because it is so easily overlooked. People look at apraxia sufferers and see a clumsy child who won't try hard enough, a child who must not be very bright because he can't keep up in math and reading, or a disobedient child who won't stop moving in weird ways and bumping into people. Anyone with a disability knows about stigma. The problem might be worse in apraxia because so few people can see the obstacle.

Movement disorders are not entirely new to me. I'm a professor of neuroscience myself, and I've worked extensively on how the brain controls movement. My wife is also a neuroscientist and has a degree in psychiatry. You might think we would be excellently qualified to pick up our son's problems pretty early on, but in fact it took us a while to fully understand. Apraxia is a complicated disorder with many different shades and symptoms. Its signature is difficulty in co–ordinating movements and learning new sequences of motions. Actions that come automatically to the rest of us are difficult to master. It's easy to think that an apraxic child is simply being defiant or lazy for not tying his shoes, but a task like that can take years of hard practice to learn. It's an exhausting and never-ending process of practising basic movement skills.

What causes it? No one really knows. The scientific literature has paid close attention to a region of the brain called the Supplementary Motor Area (SMA), which is thought to play a role in co-ordinating complex movement sequences. Another brain area that might be related is the posterior parietal cortex, involved in spatial processing. It is not known how much of apraxia can be blamed on malfunctions of these brain areas. Another possibility is that the white matter, the cabling in the brain that connects different regions, develops incorrectly. Perhaps there are many causes and many types of apraxia.

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To add to the confusion, there are the so-called 'co-morbidities', or additional disorders. The condition is often accompanied by attention deficit and hyperactivity disorder (ADHD). The line between those two can be extremely difficult to spot. An apraxic child might wiggle and shift in his seat, and if you didn't know better he might look hyperactive or inattentive. He might also feel stressed if he can't perform in the classroom, which is likely to manifest as hyperactivity and inattention.

There are more puzzling associations, too. Children with apraxia also have an elevated risk of autism, dyslexia, and sensory processing disorders. Why these deficits tend to come together, nobody knows. Our son has some sensory processing issues, especially sensing his body in space. Thankfully for him, that seems to be the only extra problem on his plate.

There is, of course, no cure for apraxia, but if it is noticed early and handled responsibly, schools can help to manage it with occupational and physical therapy. Systematic daily exercises, overseen by experts, can help to develop strength, co-ordination, writing and many other skills. An apraxic child might never become Joshua Bell on the violin, but he can learn to manage quite well. The biggest challenge of childhood apraxia might be the stigma that so commonly comes with it, rather than the disorder itself.

Childhood apraxia is now a part of my family and my work. My interest in it is understandable. But why should you pay any attention? Simply put, because apraxia is *extremely* common. It is also probably under-diagnosed. One in 15 or 20 children are estimated to have it, which is about one in every classroom. If you work with children, some of them probably have it, whether or not anyone has noticed yet. And the way you respond to them will have an enormous influence on the trajectory of their lives.

After the surprise meeting with the school principal, we waited for a state investigator to inspect our home for signs of child abuse. A formal state investigation puts a family under incredible stress. Parents are left at the mercy of their worst fears. Children can get taken away. Schools are, of course, entirely within their rights to call an investigation at their own discretion, but it seems to me that this step should not be taken lightly. At that surprise meeting, we faced a roomful of people talking nonsense about the supposed sex acts of a six-year-old. Nobody in the system was telling them to slow down or to talk to the parents before triggering an investigation. No one seemed to know anything about child behaviour, certainly not enough to make the diagnoses they were making. A horrible idea had taken hold of them and they were running with it. We felt utterly powerless.

Our son's psychotherapist wrote a letter to the school to tell them about his classroom anxiety. Our son's pediatrician also wrote a letter to the school telling them that he saw no medical evidence of any abuse. These experts asked the school to intervene with a step-by-step behavioural plan to help our son's classroom difficulties. Under federal law, he was entitled to what's called a 504 plan, in reference to Section 504 of the Rehabilitation Act of 1973, which is meant to ensure that disabled children have full access to education, but the school refused.

In frustration, we went over the head of the school to ask the district administration for what is called a Child Study Team, or CST. A study team convenes, tests the child, and arrives at recommendations. That type of evaluation takes up to 90 days. We were very happy that the district was willing to set this process in motion. However, we also thought our son needed immediate help for his anxiety in the classroom.

On 21 March 2013, at 10 am, the New Jersey inspector visited the school to tell the principal that our family had been cleared. No abuse was taking place in our home. The school's response, to our astonishment, was to suspend our son.

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Perhaps we shouldn't have been surprised. When a child's home is under state investigation, he cannot legally be suspended from school because that would force him into a potentially abusive family life. Once the family is cleared, the school is free to exclude the child. For the month that we were officially under investigation, our son remained in school. Within two hours of the inspector informing the principal that our family was cleared, she abruptly changed tack. Instead of accusing us of abusing our son, she now accused our son of sexually assaulting other children. The principal called me at work shortly after lunch that day and told me to collect my son.

We received a formal suspension letter a short while later. It contained only a vague account of what our son had done. It neglected to mention that we had the right to protest the decision at a hearing, and it gave no end-date to the suspension. The nearest thing to a ray of hope it contained was the claim that re-admission would require clearance from a child psychiatrist. Here was something we could work with. As soon as we could, we took our son to a psychiatrist, a well-respected one who had practised in the Princeton area for 30 years and who worked extensively with the school district.

The psychiatrist quickly discovered just what had been going on immediately before our son was pulled from the lunchroom. Apparently, he had been playing zombies. He was not alone: it was a common game among the first-graders. During the game, our son had embraced another child. That's the only clear description we ever received of our son's 'bad behaviour'. As the psychiatrist laconically wrote: 'I never regarded this conduct as sexually predatory as apparently school staff do.' He cleared our son and recommended that he be readmitted to school. But the principal refused.

My wife said to me: 'I feel like I'm in the wrong movie.' The school was manufacturing a sex scandal around our six-year-old son. He didn't know what was going on except that he was excluded from his friends in school. He thought he was being punished for breaking the rules, but of course he didn't know what the rules were, because there weren't any.

Throughout the suspension, we kept trying to meet the district and work with them toward a resolution. We were especially eager to move forward with the CST evaluation that we had requested. However, when the district sent us a formal letter outlining its plans for the study, it emerged that the team they had appointed included no physical therapist, no occupational therapist, and nobody who could assess or help our son with his movement disability. On the other hand, it did include the principal who had kicked him out of school in the first place.

This seemed like a bad sign.

The district insisted that they would not consider letting our son back to school until the CST had met. This condition, which was unambiguous and made in writing, also turned out to be illegal: parents have a legal right to refuse a CST without retribution from the school. Our son's constitutional right of education had been denied. As a last resort, we took the district to court.

In the court documentation, the district accused our son of being 'sexually assaultive' and us of being 'unco–operative with the process.' The principal's written testimony included a set of classroom notes about our child to show how he wilfully misbehaved. Strangely enough, the school had given us an alternative version of this document about a month earlier, which we still had. The notes are attributed to a young classroom aide and detail her observations of our son in class over a period of two days (19 and 20 February 2013). The version that was submitted to court as sworn testimony offers a noticeably different account, including several additional sentences that make our son's conduct sound wilful and sexual. It looks to me very much as though somebody in the district was willing to lie in court and falsify documents in order to damage a child.

According to the written testimony of the principal, the psychiatrist supported her claim that our son was sexually assaultive and a danger to others. Fortunately, we were able to show this testimony to the psychiatrist himself. When he read it, he was so disturbed that he wrote a letter rebutting it, specifically noting that he thought our child was *not* sexually assaultive, *not* a danger to others, and should never have been suspended from school.

It was two very tense days before the judge gave a written ruling. She ruled against the school in every respect. She noted that no expert on the part of the district had adequately evaluated our son. Several outside experts had made clear diagnoses and recommendations, but the school ignored them. The school provided no help or intervention for a child in distress, choosing instead to illegally suspend him. The school had not shown that our son was a danger to anybody. For his own psychological health, the judge ordered our son to be sent to a different school in the district. The district was to provide a formal 504 plan to help him with his classroom difficulties.

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Looking back, the most charitable interpretation I can put on the whole experience is that maybe when large bureaucracies start moving in one direction, they reach a point when they can no longer resist their own momentum. Someone at the school made a bad judgment about our son, the system clanked into motion and from then on there was no stopping it. It certainly felt like we were caught in a machine that had no guilt about telling lies, no inhibitions about destroying children and families. And as far as we could see, there was no reason for any of it other than carelessness and arrogance and, in the end, self-protection. It served no function except, perhaps, to save the district some money on movement therapy. When the judge asked what could possibly justify the open-ended suspension of a first-grader from school, the district declared that our son presented ‘a danger to others’ – including a danger to the adults at the school. By this stage, our son was six years and eight months old.

It is only fair to point out that we also encountered several true heroes who cared about children and tried hard to help our son. We were particularly impressed by the staff at his new school, who made it their business to give our son a warm and supportive experience. In May 2013, on the order of the court, our son was enrolled in Riverside elementary school in Princeton, New Jersey. From his first day at the new school, the teachers, the principal and the psychologist reported to us that he was a delight to have – funny, sociable, kind, gentle, and eager to do well. He loved turtles, platypuses, and Harry Potter. He made friends easily. His behaviour was not disruptive to the classroom. Nothing he did was a danger to himself or to anyone else. Nobody ever saw any ‘sexual’ misbehaviour. He was, however, observed to rock in anxiety in his chair when he was tasked with a writing assignment. The psychologist was able to help by talking to him and by instituting a reward system for good class work. Within a few days, the rocking stopped.

I wish I could say that the move to the new school magically solved everything. But that is not the case. A year later, he still has lingering trust issues with school and teachers, and significant anxiety in the classroom. It takes a long time to recover from stigma and rejection. That's why children's disabilities ought to be handled with great care and compassion. My wife and I have degrees in neuroscience, psychiatry, and psychology. We have the means and the leverage to go to experts and to the courts. But even with all that leverage, we still barely saved our son from a system that couldn't grasp the disability it was dealing with. How many families and children get ground up by that system? If our experience is any guide, parents should be vigilant, and if something doesn't seem right, always stand up for your child.

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