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## The Geography of Ambiguity

“YOU MUST HAVE FELT DEVASTATED.” I’m on the phone with the school psychologist. She’s talking to me about my child’s diagnosis and I’m trying to understand her question. At least I take it as a question, I know it is some kind of probe. But I’m slowed down by the length of time between the diagnosis and the question finally coming through. It’s been two years.

How did I feel? I wasn’t surprised. A year before the diagnosis, I got out of bed at two a.m. to look up Asperger’s on the Internet. My book club had read *The Curious Incident of the Dog in the Night-time* and I remembered one of the book club members describing a visit to her friends’ where their son sat at the computer the whole length of the visit, filling out university application forms. Somehow, *curiously*, in the middle of the night I woke up connecting my son failing kindergarten with an unknown teenager struggling with university applications. Certainly, Colton does not resemble Christopher, the character Mark Haddon wrote about. But when the Web pages of information about Asperger’s come up, they are written about Colt.

It was spring when we received the diagnosis, a full year after my night-time research at the computer. After Dr. Fieldman told us Colt had Asperger’s Disorder, he gave us each a handshake, although we weren’t sure if we were being congratulated or consoled. “What do we do now?” I asked him. “There is no treatment, if that is what you mean,” the psychiatrist said. My husband and I must have looked stricken because Dr. Fieldman scurried around his desk, shuffling and sifting piles of paper. He came up with a coffee-ringed pamphlet for an autism conference that ran last month. “Contact the group that organized the conference,” he offers. “Read lots.” Our hour with him was over and we were shooed out the door, clutching the pamphlet like a diploma.

Later, I read that Dr. Simon Baron-Cohen, a leading expert on autism, said that the diagnosis of Asperger’s does not have to be a tragedy to families. It can be understood to be a cognitive difference, not a disability. It

only needs to be referred to as a disability in order to receive services. This makes sense to me but then I wonder, if Asperger's is not a disability, why does a child need services?

Dr. Simon Baron-Cohen, by the way, is the cousin of Sacha Baron-Cohen (Borat, Ali G). Irrelevant? Maybe, or maybe not: when you think about the family genes that produced a top scientist and a genius comedian, well, you start thinking about genes. And that is Dr. Baron-Cohen's intention. He uses the theory of assortive mating—choosing a mate on the basis of a similar or common trait—to explain how men and women with a propensity for systemizing skills are attracted to each other and then produce children with hyper-systemizing, or autistic, characteristics. The recent increase of women in fields of science and information technology improved the chances of male/female systemizer mating and reproducing. This is not a bad thing, according to Baron-Cohen; after all, he thinks, the trait of systemizing “has helped humans to dominate the planet.” In that way, you might say the rise of autism is an evolutionary progression.

The link between engineers and autism has been shown in a study in Britain that looked at the occupations of parents of children with and without autism: twice as many children with autism had parents who were engineers. For the record, I am not an engineer, but my husband is. But before it all gets blamed on him, there is another study that says four times as many parents of autistic children are poets, artists and historians. The latter category is mine (although I can't say I make much of a living at it). Mason and I met at the engineering company where he worked when I was hired as the technical writer. The stretch between studying narrative in historiography and writing software instruction manuals seems unusually tenuous but I heard of one software company in the US that hires only history graduates as their technical writers. It has to do with our ability to find patterns or, I guess, to systemize.

My urge to categorize is thwarted though, here in the land of the Asperger's Disorder diagnosed. The countryside is crowded with conflicting signposts. Is Colton disabled? Disordered? Just different? How different? He sees and hears more than the vast majority of people, but how does he interpret it? If I don't know the referent, will I understand his sign for it? Colton is physically present in my world, he lived in my womb, but there is a side to him that is somewhere else. When I try to make sense of where we are, place ourselves, two categories appear: Inside and Outside, or Autistic and Normal (or Neurotypical, as I learn to say), Real and Invalid, but the categories always flip or invert, or spin like a revolving door. The border between the countries of neurotypical and autistic is not crossed by climbing a wall, or passing through armed sentry posts, but through this revolving door that flips my son in and out unexpectedly. His father and I trail behind like wheeled baggage, or chase around like inept tourists, always dressed wrong, often missing the bus. Our collection of university degrees is useless here.

So, how did I feel when I heard my son's diagnosis? I felt my jaw go slack, I felt my hand being shaken by the psychiatrist, then I felt the paper pamphlet crumple in my hand. The psychiatrist looked at his watch and said our hour was over and shooed us out the door. I felt hit by a truck. I remember leaving the doctor's office and seeing a long white glowing tunnel stretching before us. We begin to walk, my assortive mating partner and I, our genetic (but adaptive) sport of a son between us, holding one of each of our hands. But we don't know where we are going.

*The diagnosis need not be a tragedy*, Baron-Cohen says. It's just a cognitive difference. Colton doesn't look different when he's born. He comes out slimy and cheesy like most babies do. The nurse places him on my chest and he looks up to my eyes. Mason comes over and says, "Hi baby." Colton turns to look at him. He recognizes his dad's voice from all the evenings we lay on the bed and Mason read *Alice in Wonderland* into my stomach. Our doula snaps a picture and then the nurse whisks him away to the nursery. I want to put the baby to my breast but she says, "No, he is too tired." Something is wrong with him. He is taken away from us and put in an oxygen tent. Round metal probes are attached to his chest and his heart rate is monitored. An IV is stuck in his tiny arm and he is pumped full of antibiotics. The IV needle is held in place by a splint and a long white strip of gauze is wrapped around his arm, wrist, and fist. The hospital photographer drops by but declines taking his picture. We are too stunned to disagree. This is our first hint that certain public traditions are reserved only for those who have the appearance of normal.

Soon enough Colton introduces us to the customs of his other country. He doesn't want to be cuddled but he wants to be held. He requires movement. At night, when he can't sleep, I jog around the dining table with him held out in my arms, my arms stretched in front of me, like I am carrying a bundle of firewood or a hot casserole. If I stop moving, he cries. If I hold him close, he cries. If I put him down, he cries. There is a certain degree of apartness/closeness he likes to maintain, and if I get it right, he rewards me by falling asleep. Outside, we do the daily round of shopping in our neighbourhood—the bagel shop, the fruit store, the local IGA. All the clerks greet Colt and smile, but it is not his tradition to smile back. He also refuses to laugh unless tickled. And no solid food, please. As he learns to sit, he begins to rock, bouncing his back repeatedly against whatever he leans against. Lining up one day at the drugstore, I hold on to the stroller to keep it from rolling away with each rocking bump. The customer behind me says, "I used to do that." I look at the man, he looks alright, an ordinary guy. At Easter, Colton is rocking on the sofa. My brother-in-law hisses, "Stop him. Don't you know what that means?" We're not sure that we do know what it means, the pediatrician doesn't think it means anything, we only know we couldn't stop him if we tried, so we don't. As he gets bigger, he rocks in the car as we drive from place to place. When he's eight years old, as we are stopped at an intersection, I

realize Colt is big enough to bounce the whole car in time to his rocking and I guiltily feel relieved when we trade in our little car for a tank-like mini-van. Someone from the parents' support group sends around a YouTube video of Bill Gates rocking in meetings and interviews. When Colton asks me if he will rock when he is older, I say, "You might."

Asperger's does not have to be a tragedy, but it can be a pain in the neck. Colton has difficulty with transitions: that includes getting dressed, getting undressed, leaving the house, entering the house, getting in the stroller, getting out of the stroller, getting in the car, getting out of the car. It starts to become clear that much of our lives is a sequence of transitions, starts and stops. Colt balks, refuses, dawdles, delays, refuses. His sensory perceptions seem skewed: he can't stand stripes, he can't see anything fuzzy when he eats, he can't cope with his car seat and its restraints and he bucks wildly against them after half an hour. Our road trips are limited to the grocery store. He finds it very difficult to sleep at night and is up every two or three hours. Mason and I take turns watching *Treehouse TV* in the dark while Colt rocks in his stuffed Scooby Doo chair. We are very tired.

Sometimes late at night we put on classical music concerts we tape off PBS. Colton loves classical music. His favourite conductor is Sir Andrew Davis, with Seiji Ozawa a close second. By the time he is three, Colt can identify every instrument in the orchestra by sight or by sound. All day long he has a chopstick in his hand, using it as a baton to conduct. His next love is animals: he amasses a large collection of plastic models and marches them in lines across the living room floor. He calls them by the last syllable of their names—phant, affe. We think it's cute the way he lines up all the animals for hours—we don't know that lining up objects is a classic sign of autism. We've been here three years and we still don't know the name of the country we live in.

When Colt is four we take him to the Montessori and Orff music school around the corner. He hates it and the teachers and other kids don't seem to appreciate him either. "He won't participate," we're told. "He just wants to rock on the futon. He doesn't make eye contact. He clings to his only friend." He doesn't fit in but we keep him there until he finishes kindergarten. That's when I make the Asperger's connection, lying in bed one night wondering how Colton looks to his teachers. That's when I realize that my son, whose every millimetre of skin, whose scent and sound, is so familiar to me and so beloved, is a foreign and incomprehensible exchange student to his teachers.

As Colton grows older, the autistic traits wane and rise, escalate and fall. But the social and academic expectations of him continually grow. The bad days, when Colton can't cope, get more frequent. There are lots of tantrums, crying, shouting. He doesn't want to go to school. His new school denies his diagnosis and blames his behaviour on my poor parenting (somehow Mason gets off scot-free). Later, as Colton begins to melt down at school, or pace and cry most of the day, they no longer deny the

diagnosis but still seem unwilling or unable to install useful strategies. It is hard to access any autism services outside of school, as Colton is considered to be too “high-functioning.” I spend hours each day on the phone, calling psychologists but no one knows how to deal with a family living with Asperger’s. I write letters and emails to the school, suggesting strategies I find in books, urging action, trying to get some help. My mind goes in circles, angry arguments I invent in my head with a rotating cast of characters: the principal, the teacher, the resource teacher, the doctor, the psychologist, the psychiatrist. My teeth are clenched and I feel myself start to shake. Colton is dawdling and complaining and whining as we try to leave the house on time. “Just shut up!” I yell at him. He flinches and stares. “I thought you were safe,” he cries. “I thought you were safe.” My resentment grows and I am ashamed.

This year at school the children are taken to Camp Assiniboia. The schedule is sent home in his backpack: for a kid with Asperger’s it looks like a nightmare. Eight hours of activities: archery, survival skills, candle-making, fire building, rope-climbing. I want to send Mason as backup but he’s booked on a business trip in Ottawa. I drive down the road alongside the river to the camp and arrive before the school bus. I see Colt get off with the other children. He got this far, I think, *this need not be a disaster*. And it isn’t, for the first two hours. But from one o’clock to five, Colt wanders and cries, wanders and howls, is angry and cries, is angry and howls. His educational assistant, a nice but little-trained lady, trails behind him like a plump pull toy. I want to pick up my kid and stuff him in the van and drive off, and this is what I should do, but I can’t. On school territory I lose my authority. I don’t want to make a scene. Colt is making a scene. I don’t want to be seen. When Colt sees me, he grows angrier. I try to calm him, but he is too far gone. He goes up and down the meltdown scale. At one point, he settles down briefly and goes to the rope-climbing station. I sneak through the bushes with my camera, hoping to catch him successfully climbing. I hear him before I see him: he’s wailing at the edge of the group of kids with his lady assistant close behind. When he sees me, he runs. I leave.

They (the usual *They*) say parents of an autistic child mourn the child we expected but did not receive. I have tried to mourn Colton but it seems absurd. He has long eyelashes that stick straight out like paintbrushes. A sense of humour both slapstick and subtle. A zest for learning and a love of singing. The ability to curl and fit exactly, if not anymore within my body, then within the shelter of my ribs and arms. The autistic traits are part and parcel of him: his fascination with animals, dinosaurs, bees; his ability to hum and scat Bobby McFerrin-style great chunks of classical music; his charm. (“My compliments to the chef,” he says to my sister at Thanksgiving, “on this excellent jellied salad. It is the best jellied salad I have ever had.” He pauses. “It is the only jellied salad I have ever had, but if I ever have another, this will still be the best.”) How could I mourn any of this? Instead, I mourn the mother I thought I would be, the mother I had expected. The mother who knew what to do, where she stood.

He is rocking faster on the couch. The skin of his face stretching down, fading pale. The dam bursts. "Mom," his voice quivering, "Mom, are you and Dad who you say you are? Or will you turn and kill me? Or eat me?" He is almost afraid to look at me. I think that if I even said *boo* to him now, it would send him out of his skin forever. I have that urge. I am horrified by my power. But he is so afraid and he is mine. I tell him Dad and I are his parents and parents never can hurt their children. We are made to protect our children just like tigers protect their cubs, and elephants their calves. I feel a flash of his fear and remember watching *Silence of the Lambs* in the dark theatre in paralyzed misery, my knees up to my chest. One of the worst parts is when Anthony Hopkins removes the mask of the security guard's skin from his face and transforms into someone else, his real evil self. I tell Colton he is having a normal fear, that people worry that the ones we trust may stop being trustworthy. Don't we all worry about betrayal? And what would be worse, if the psychopath was a stranger or if the psycho with the dripping knife ripped off the mask and was your mother?

I go to the cupboard and get the bottle of homeopathic rescue remedy. "Come on, sweetheart. Have some rescue drops." He comes closer and stops. "Is that poison?" He is on the knife's edge. What's the right thing to do? "No, little duck. See, I will take some myself." I pull out the eye-dropper and squeeze some drops in my mouth. He comes closer and trusts me, although I wonder how. From habit? Lack of choice? What would be his alternative?

In the late 1960s, Bruno Bettelheim published an influential work that blamed the outcome of autism on cold and unconsciously hostile mothers. From this characterization came the term "refrigerator mothers," the mothers giving their children the basics of life, but without warmth. It was not until 1998 that the IACAPAP (The International Association for Child and Adolescent Psychiatry and Allied Professions) announced at a congress in Italy that "parents have absolutely no responsibility for their children's autism." This news is slow to reach the school system and the psychologist there passes me a paper listing the causes of non-verbal learning disability (a commonly co-existing condition to Asperger's) along with Colton's test results. One of the causes is being dropped on the head as an infant. She asks for Colt's medical records and I refuse to supply them. Later she tells me that it was only a few years ago that schools stopped blaming the mother. I walk the school halls, volunteer in the classroom, and attend school plays and concerts feeling constantly under scrutiny. I continue to ask and ask and ask again for accommodations for Colton. I'm called a "parent advocate" to my face and something else behind my back. One day a staff member comes up to me and tells me that I'm "ticking her off." Her fist is clenched. I second-guess and microscopically examine my own actions until I am sick with anxiety and depression. I am stranded at the airport, with all planes down.

Each morning is a battle before school. I don't trust the staff to translate or understand Colton's behaviour, but Mason and I feel he somehow must learn to fit in with the world of neurotypicals. My boss is unhappy with me. I email him (I'm too cowardly to phone) that I will be late, that I'll work from home, that I have to leave early, that I can't come in. Colton is shrieking, Colton is not sleeping, Colton is puking, Colton gushes out diarrhea like brown paint when we bring him his jacket to go to school. By nine a.m., I'm already exhausted. I lie on the kitchen floor and cry. I arrive late into work and tell them that Colton has Asperger's. "He's a genius!" my boss exclaims.

A genius! Maybe that is why the psychiatrist shook our hands. Genius does seem to be the expectation for Asperger's—the children are often referred to as "little professors." Later, they are expected to work in universities, become the classic "absent-minded professor." I think we should be so lucky: a study in the UK showed that only six percent of adults with Asperger's have full-time employment and over half still live as adults with their aging parents. Kamran Nazeer, author of *Send in the Idiots: Stories from the Other Side of Autism*, writes that when his teacher found out he was autistic, she "kept expecting me to do something extraordinary in class, like finding a new subatomic particle while we made macaroni pictures, or reciting entire chapters of books from memory when we studied English, and was disappointed when I didn't." Colton can name the six types of camelids and identify the okapi and quagga, but can't add 2+3 or tie his shoes.

Dr. Fieldman said there was no treatment for Asperger's Disorder, but there is treatment, all kinds of treatment, everywhere. There is RD, OT, PT, the GF/CF diet, TCM, biofeedback, homeopathy, the sugar- and food dye-free diet, a doctor in Alberta with a ranch and a cure for autism. There is stimulant medication for the ADHD symptoms, anti-psychotics for the crankiness, anti-anxiety pills for the side effects, anti-depressants for the moms. There are social skill groups where kids from the spectrum sit around a table and practise scripted conversations. There are speech language pathologists who teach pragmatic language and social idioms and how to recognize emotions from the particular juxtaposition of eyebrows and lips. There is yoga for kids, mini-trampolines, soft plastic bracelets and tubes for chewing, weighted blankets for calming, crash pads for slamming, earplugs for loud noises. There is always something that could be done, that should be done, to fix our kids, fix the neurotypical world so our kids can live there.

Paul Collins, a historian, writes of his autistic son Morgan's tantrums. Morgan is registered for a special ed class, but the teacher says Morgan isn't ready because he has tantrums. Collins writes: "I feel my anger rising. Morgan has tantrums for a reason. Morgan is happy. He is happy when he is left alone, doing what he wants. It's the outside world that is the problem—outside people. Do this, do that. And it doesn't make sense; he cries,

he flails." Colton's school wants him to sit in his seat, start his work, do his work, finish his work, cooperate. Most of it doesn't make sense to Colton. *He cries, he flails.* The school staff don't understand that Colton's reactions are about information processing, about the frustrating clogs that form in the huge influx of information he gets that most people don't, all the sights, the sounds, the smells that slip below the range of everyone else's awareness. The teachers think they can make him behave like everyone else, but they don't understand the concept of coherence—the fact that what is important to them, or even the other children, just doesn't make sense or have value to him. We keep him in the school, we force and plead and cajole him to go, because we want him to fit in. We think they can teach him what he needs to know, but they seem bewildered by our expectations and say we are asking too much. And we are. We are asking that the inside and outside worlds overlap and overlay, but the shape and terrain keep shifting and the brief moments of congruence don't last.

Colton's best friend has the flu. He's been away from school for three days. Without Kit, Colton is lost, no one else makes sense to him. I drag Mason away from his desk and we walk together in the last bit of November sun to school to pick up Colton. He comes out of his classroom grumpy. He says the other kids invited him into the snow fort at recess, but once inside, Colton says, "They excluded me." We probe with questions and slowly figure out that once in the snow fort, Colton didn't know what to do next and so felt excluded. Mason gives him a list of strategies to try next time. I watch the strategies fly over Colton's head like snow. I finally mouth to Mason behind Colton's back to let it pass for now. Colton just doesn't get it, he doesn't get it, and we don't get how to help him either.

I flit from book to book and Web page to Web page searching for the answers, for guidebooks. A link catches my attention—*Refrigerator Mothers, Warrior Mothers: One and the Same?* The refrigerator mothers cause autism. Warrior mothers cure autism (think Jenny McCarthy). The author of this Web article, Kristina Chew, is a self-described "autism mother." In her blog, she quotes the author of *Defeating Autism: A Damaging Delusion* who says that both kinds of mothers are similar—the link between them is "feelings of guilt, anger, and blame." *Guilt*, check. *Anger*, check. *Blame*, check. I have my passport to both groups. Chew writes that her husband, a theology professor in New York, connects these mirroring identity structures to conversion narratives which are "narrative[s] of a subject in search of a transformed or redeemed 'self'." He says that the only fit story in the eyes of these mothers is recovery or cure of their child. Is that what I am doing? Am I looking to cure my son? Am I seeking to redeem myself? I remember saying at a meeting, "Having a son with a disability has changed my life. I am a different person. I think I am even a better person." Is this essay my conversion narrative? I suddenly want to distance myself from the concept *better person*. I want to distance myself from myself. I want to stop wanting to change my son.

I stumble onto the website of the autistic and non-verbal woman Amanda Baggs. I watch awestruck the beautiful and moving video titled "In My Language" she posted on YouTube. She writes, "I find it very interesting by the way that failure to learn your language is seen as a deficit but failure to learn my language is seen as so natural that people like me are officially described as mysterious and puzzling rather than anyone admitting that it is themselves who are confused." I discover Amy Nelson, who writes, "In the same sense that this would be entirely unacceptable to cure someone's skin colour, we feel that our differences need to be respected and our minority group to be protected." For a few hours, I am buoyant: I don't have to fix Colton, he is not broken at all. I feel suddenly free of Colton, free of fighting the school system, free of trying to know what is the right thing to do. I feel the only thing that needs to happen is for everyone to *accept him just as he is*. For a few hours, I feel this is possible, it is even easy. But my mind begins to churn and I think that installing everyone in their own separate but equal worlds is not enough. We must learn how to communicate and how to facilitate relationships and movement between the worlds. We need to broaden our understanding of what defines human, what constitutes a valid or real life. The border separating who is different and who is the same needs to be permeable. But the road to this change does not appear clear.

How did I feel when my son was diagnosed? I think that question also means: how did I feel when I found out the characteristics of my son that are autistic are permanent. Really, when I think about it now, when the doctor said to me, "Colton has Asperger's Disorder" he was asking me: this is your son, do you accept him? This is why my tongue sits fat and heavy when the school psychologist says, "You must have felt devastated." When my child was born, like most mothers, I suddenly felt I understood the word *miracle*. I look around me now and find *miracle* still carved on the rocks and trees and sky and *miracle* still marked on the forehead of my child. When Dr. Fieldman asks me now, asks me now in my mind and in my heart: this is your son, do you accept him? I say: I do.

In the end, there is no recovery, no cure. There is no better person or transformation, for me or for him. There are moments of light and darkness. Acceptance and anger. The inside and outside world blur and clash, clash and blur. In the end, there is no recovery. But there is a change in geography. The border lines between our countries, our worlds, our places are no longer solid, but dashed. The spaces between allow for slippage through. In the end, I am responsible for his autism and I'm not. In the end, I follow him to new countries and I lead.

"Mom," he says this to me last night, curled up in his bed, "Let's start making my life better tomorrow." I lean over and kiss his sweet head. "Alright." I will go where I need to go. "Alright." □