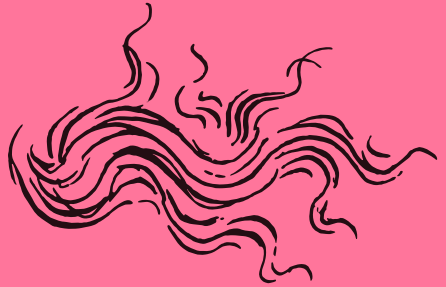


CULTURE AND POLITICS

Liberties



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*Accept the truth from
whoever utters it.*

MAIMONIDES

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JOHN SUMMERS

In the Counterlife of Autism

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“Tomorrow’s Child,” a story by Ray Bradbury, opens with Peter and Polly Horn traveling to a hospital for the birth of their first child. In their technological utopia, a helicopter conveys them across a sky spangled with rocket ships. An advanced birthing machine awaits, promising to eliminate Polly’s labor. At the moment of truth, however, the hospital’s machine malfunctions. She has delivered a healthy male infant. He weighs seven pounds, eight ounces, and sports a normal nervous system. There’s just one problem: the boy has been delivered into the fourth dimension. From outside the three-dimensional structure of human perception, he appears in the shape of a tiny blue

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pyramid, with three darting eyes and six wriggling limbs. The obstetrician says that the boy himself apprehends the phenomenal world around him cubically.

The Horns name their discarnate issue Py and take him home. But the existential limbo fills them with anguish and repulses their friends and neighbors. Desperate from isolation, Peter and Polly return to the hospital intending to abandon Py to medical science. The obstetrician surprises them once more. He hasn’t figured out how to retrieve Py, but reverse-engineering the birthing machine could place them in the fourth dimension with him. They could perceive him as he really is. The price, of course, would be their own geometrical transfiguration. Peter would take the shape of a hexagon. Polly would look oblong. With heavy hearts they assent to the bargain, trading expulsion from membership in the human community for the joy of sharing in their child’s perception of reality.

For parents and children wrestling with neurodevelopmental conditions today, Bradbury’s allegory has lost none of its poignancy. Autism, my son Misha’s primary diagnosis, constitutes “a whole mode of being” and “touches on the deepest questions of ontology,” as the neurologist Oliver Sacks wrote in 1995. If this is so, then the question is how people like Misha perceive the fundamental entities and properties of reality. “The ultimate understanding of autism may demand both technical advances and conceptual ones beyond anything we can now dream of,” Sacks wrote. He urged neurologists to limit the boundaries of “radical ontology” by shucking off their habits of detachment and accompanying their subjects in society. “If we hope to understand the autistic individual,” he contended, “nothing less than a total biography will do.”

Thirty years later, one in every thirty-six children receive the diagnosis. Neurologists still confine their percep-

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In the Counterlife of Autism

tion to the bell jars of the consulting room, while autism advocates promote “neurodiversity.” No advances, conceptual or technical, have struck up a symmetry between medical understanding and social belonging. “Tomorrow’s Child” today subsists in a permanent realm of uncertainty.



Misha is now eleven and lives with his sister and me in the very progressive city of Cambridge, Massachusetts. In photographs, his aspect betrays no abominations. He passes for any normal child his age (although, in my estimation, he’s handsomer than most). Tall and lithe, his hazel eyes are hooded by long lashes and framed by an oval visage. What his eyes perceive is anybody’s guess. His acuity rates 20/20. The signals that his brain gives to his ocular muscles, however, could be showing him a kaleidoscope everywhere he looks. He doesn’t say, as he has never uttered more than a handful of verbal approximations. Nor does he seem to reliably process speech directed to him.

“What’s your name?”

“Me.”

“Can you say, ‘Misha’?”

“Mi-ta.”

“Excellent. How old are you?”

—

“Misha, are you eleven?”

“T.”

“Where you do live?”

—

“Misha, who am I?”

“D.”

“Very good. What is your sister’s name?”

—

“Do you have a sister?”

—

“Misha, can you say the name of your sister, Niusha?”

“Yah-yah.”

His body is bandy, strung together by a physiology that mismeasures stimuli from his environment. A meek style of movement during his infancy suggested that he was never in possession of his body. Crawling in the yard, he trembled before a quarter-inch decline from the sidewalk to the grass. He hung his head over the side of his stroller in the neighborhood and fixed his gaze on the spinning spokes. Arriving at playgrounds, he refused to dismount. He didn’t stand up until his eighteenth month, and then he toddled on his toes. He clung to the inner edges of sidewalks and dragged his palm across the streetscape, refashioning walls, doors, and fences into an extended guardrail.

A neurologist diagnosed Misha with autism at the age of four. Additional diagnoses piled up over the next years: mixed expressive-receptive speech disorder; sensory processing disorder; cerebral vision impairment. Of causes and treatments, his specialists have never developed so much as a working hypothesis. Molecular sequencing has revealed two genetic mutations, neither previously reported. “Your son,” his geneticist avowed, “is on the far edge of science.”

Misha is both profoundly disabled and benignly different. He doesn’t appear sick. He doesn’t appear well, either. The antinomies of his social being discharge their tension in a stigma that emerges during unrehearsed appearances in our community. He blisters the air with shrieks and squeals,

huffing and hissing, peeling with laughter out of nowhere. A sublinguistic rhapsody, unclassifiable as well as unignorable, sets the soundtrack: “We-we-we-we-we-we-we”; “me-me-me-me-me-me-me”; “uh uh uh uh uh uh uh.” The signals that draw his stigma are both embodied and undecodable.

I am resolved not to hide away Misha’s fugitive aspects. Only through contact with his given environment can he make a safe home for himself. Isolation within his sensorium would cause the anxiety that he bears on a good day to expand into a total loss of trust in his own being. “Loneliness,” as Hannah Arendt once observed, constitutes “the experience of not belonging to the world at all, which is among the most radical and desperate experiences of man.”

In a city of heavy objects constantly in motion, Misha exhibits no capacity for self-preservation. We were crossing Beacon Street in Inman Square one weekday afternoon. He flew to the passenger door of a car as it slowed before the yellow of the traffic light. He tugged on his door handle. The forward motion of the car jerked his arm. Another day, on a different corner, a man puffed a pipe. A breeze tossed the smoke. Misha chased the billows into the street. A car skidded to a stop a dozen feet in front of him.

At age seven, he made a half-hearted attempt to leave home unannounced, unlocking and unchaining the front door. I purchased an identification bracelet, a tracking device, and a harness. He sloughed off the device and chewed through the bracelet. I couldn’t bear to tether him to the harness. A police officer came to take his photograph and copy out his vital statistics, lest I should lose him.

When I want him to stay close, he wanders away. When I want him to depart, he stays put. He stopped once in the middle of a crosswalk in Harvard Square. My nudge in the small

of his back restarted his body. He screamed and yanked down his pants. Inside a grocery store on another occasion, he took our cart on a wide ride that ended with him knocking over a stack of soup cans and losing his grip on a carton of produce. A shopper tripped over the cans. She shot me a dirty look as she picked blueberries off the bottoms of her shoes.

On our strolls, he runs his fingers through hedgerows and drops shrubs in his wake. He flips open gas tank doors on rows of parked cars. He runs into the foyers of apartment buildings, presses all the buttons on the elevators, and scampers away with a chortle. In the bathrooms of neighborhood restaurants, he conducts boffo symphonies. He turns off the lights and triggers the automatic hand dryers while men fart and tinkle in their pits. In the local mall, he feels up mannequins and hooks his thumb to jewelry stands, toppling bracelets, rings, and necklaces. In the checkout line of department stores, he thrusts himself upon shoppers queued behind us and tries to untie their shoelaces. He fixates on such interaction rituals for months at a time. If you sneezed near him in the autumn of his eighth year, he instantly grabbed your hair.

Some encounters have been less than amusing. At the library once, he tugged on a thin and grayed ponytail that turned out to be attached to an elderly woman bound to a wheelchair. Her neck bent backward like a PEZ dispenser. I knew he didn’t intend to hurt her. That doesn’t mean she wasn’t hurt. I apologized for his particular offense. But I never apologize for the kind of person Misha is.



What kind of person is he? A more recognizable phenotype — Down Syndrome, for example — would provide an easement

for strangers in the path of his sensibility. A disability such as blindness would afford strangers a tacit medical context for tolerable inferences. The five senses reflect anatomically in our noses, ears, eyes, skins, and tongues, but it turns out that we have two more senses hidden from view. The vestibular sense, attaching to inner ear fibers, registers our internal balance during movement. The proprioceptive sense, registering external stimuli, provides us with assurance of our body's position in space. These secret senses flow unconsciously through receptors in our muscles, tendons, and joints, making adjustments to the rhyme and reason of the body's ego. "If there is defective or distorted sensation in our overlooked secret senses," Sacks pointed out, "what we then experience is profoundly strange, an almost incommunicable equivalent to being blind or being deaf."

What part of Misha's lack of poise is compensation for his scrambled secret senses? What part is clowning? As he doesn't speak, so he doesn't convey his perception of the reality of his body. Voluble rather than verbal, he vibrates sounds from the back of his teeth and throat without modulating his volume — probably because he cannot feel his phonatory organs without increasing vocal pressure. Maybe I have to remind him to swing his leg before striking a soccer ball because when his leg retracts, he cannot be sure that it remains attached to his trunk. Slips of time seem to lodge in his perceptual memory. We dropped by our neighborhood coffee shop. When we walked in the previous week, he sidled up to a jug of water on the countertop, drew a cup, and wet his whistle. On this occasion, the jug had been replaced on the countertop by a napkin dispenser. Yet Misha took an empty cup in hand and repeatedly pressed it against the dispenser, expecting water. He gazed upward at me quizzically.

In a surreal world, he moves as if inhabiting a waking dream. One November we visited a friend's home in seaside Hull for a birthday party. We ducked out a side door and stepped onto the cold sands. The ocean's waves roared in a stiff crosswind. This was no day for beachcombing. Back inside, slinking away from partygoers, Misha led me up a spiral staircase. The passageway was enclosed and carpeted. Even so, it disoriented him. Reaching the landing on all fours, he peeked at the ocean through the windows. He froze with fear, as if the house were a sandcastle bound to be sucked into a violent Massachusetts Bay at any moment.

At house parties and barbeques, Misha ensconces himself inside bathrooms for eternities. He rifles through bedroom closets, tampers with toys, strikes discordant piano chords, and swipes and swills beverages. I incant a mantra to guide me through. *Patience on top of patience*. But we are not ideal guests. During lunch at a prospective friend's home, Misha bellied-up to her kitchen table and stuffed his mouth with cheese, grapes, and crackers. Twice he fell off his stool and tumbled to the floor. Setting down his glass cup, he misjudged the edge of the countertop. The cup smashed to pieces on the floor. We were never invited to return.

Public spaces are freer of turbulence. I escort Misha to the Frog Pond at Boston Common in the summer and to Fenway Park in the spring. He loves a neighborhood block party as much as the next boy. Holidays I am determined to celebrate, even as he remakes their rituals. One Halloween, costumed as Mr. Incredible, he blew out the candles in every doorstep pumpkin he could reach. Invited to share a traditional Thanksgiving dinner in Somerville, we sat down with friends for turkey, stuffing, mashed potatoes, and gravy. Misha got up on his haunches and leaned toward the candles. Huffing a wet

breath, he extinguished them with gusto. Wax spattered across the turkey. Then he unplugged the chandelier and stopped me from relighting it. My feeble attempt at humor failed to bestir the table to solidarity. *What's a little wax in our bird?* Thanksgiving had been dipped in the shadows of the counterlife.

On vacation at the Jersey Shore, the roar of the crashing waves, the commotion of the boardwalk buskers, and the cawing of the seagulls replaced the city's frenzy of buses, leaf blowers, and fire trucks. Misha adored the carnival atmosphere of the beach. As the ocean waves petered out toward his ankles, he jumped half too low and a beat too soon. Strolling past the encampments of the sunbathers, he trampled their sandcastles. The haunted houses on the boardwalk wasted their spooks on him. A ride that lifted him to a modest height caused his palms to sweat. But he mounted the Merry-Go-Round's carousel of plaster steeds with the aplomb of a little Lord Byron. After, he romped through pinball, air hockey, and skee-ball, none the worse for defaulting at each station, and got his kicks by reaching behind the arcade games that others played and unplugging their machines.



"He's the king," his sister Niusha once quipped about the retinue of attention that Misha receives at home. With hilariously exaggerated deference, she bowed before "His Majesty" on the domestic pedestal. Our parlays in public bewildered her. "He's invisible," she said, "it's like he's not here." He is, and he is not. When Niusha was nine, and her brother was six, she sat with me for an interview about autism on a program broadcast by Cambridge Community Television. "Maybe when you go into a restaurant, people look at you funny or try to avoid

looking at you," the interviewer rightly observed. Niusha, chiming in, recalled an incident that had recently taken place in a luncheonette in Porter Square. Seconds after I had left our booth to fetch our drinks, Misha had climbed atop the table and swatted the pendant lights hanging from the ceiling. No harm, no foul. From a booth adjacent, however, a shriek of fear had rung out as if the end times were nigh. A manager quickened to the scene and waved a finger of reproach in Misha's direction.

"What do you want us to know about people like your brother?" the interviewer asked Niusha. "I want people to know not to be embarrassed by them," she replied, "not to keep them into hiding. I want them to be out in the open, actually, and trying to make the world a better difference, because people might not know that they have a lot more intelligence than people think, and they should be more appreciated because of that. They should be more noticed. And I bet they would like that, of course." I bet they would. The question is how people would perceive them.

Autism is experienced cognitively and felt existentially, but it is diagnosed and treated behaviorally—from the outside in, as it were. In the luncheonette no less than in the neurologist's consulting room, how you behave is who you are supposed to be. But the prevailing concept of the self as an information processor, its integrity revealed in problem-solving or pattern-seeking, shuts out feeling and judgment. Science dismembers persons into discrete domains and reduces their parts to functional values. Society rigs up a phenomenology restricted to observable surfaces.

No such system of reasoning can understand the web of memories, conjectures, and perceptions that human agents bring to their appreciation of particular situations. "What

we call creativity is a characteristic that yields not merely something new or unlikely but something new that strikes us as meaningful and interesting,” Bernard Williams observes in *Making Sense of Humanity*, “and what makes it meaningful and interesting to us can lie in an indeterminately wide range of associations and connections built up in our existence, most of them unconscious. The associations are associations *for us*: the creative idea must strike a bell that we can hear.” Only the inner spaciousness furnished by art, literature, and history, Williams suggests, can overhear the chiming of certain bells.

Misha, so understood, is that rarest of creatures: a genuine individual. Improbable, inexplicable, and unimpeachable, he alights on the world like Peter Pan, betwixt and between, terrified and beguiled. When his eyebrows shoot up, I glimpse his curiosity radiating through his miasma of sensations. His blissed-out states sparkle with novelty. Once, amid a rainstorm outside the entrance to a grocery store, he stood spellbound before the opening and closing of the pneumatic electric doors. Their metronomic cadence was to him a pair of hands clapping for his private joke. He giggled uncontrollably. The shoppers had little patience for his attempts to choreograph their comings and goings. Amused and sodden, I obeyed Nabokov’s injunction: “I appeal to parents, never, never say ‘Hurry up,’ to a child.”

Sometimes, parents approach me with overtures of sympathy. They believe that they may have a cousin or a nephew of Misha’s dispensation. “But how did you know?” I returned one such parent’s inquiry. She had plopped down next to me on a playground bench to chat about the wrongness tainting my son. “Oh, I could tell right away,” she answered brightly. “I can’t imagine,” she continued through a benevolent sigh. “I don’t know how you do it.” Her remark

felt impertinent, as if his stigma had reassured her. *There but for the grace of the genetic lottery...* A rejoinder arched across my mind: Well, I don’t know how *you* do it, managing the banality of raising your carbon-copied child.



Cambridge, of course, is fully subscribed to the attitude of “neurodiversity.” Every April, the progressive potentates gather on the steps of city hall and celebrate “autism awareness.” Ceremonies of awareness have yielded a quotient of indulgence. No mishap or misdemeanor has damaged relations that I haven’t been able to repair with a nod, an apology, or a scowl. Strangers may startle or fluster. They swallow their grievance upon letting their eyes stray over his countenance. In this age of umbrage, I am grateful to avoid open conflict. But familiarity doesn’t reduce contempt. Our community steers clear precisely because it is aware of people like him.

This paradox accompanied the birth of neurodiversity discourse. A young Australian sociologist, Judy Singer, coined the term in 1998 to denote a new category of personal identity alongside “the familiar political categories of class/gender/race.” Singer invested her coinage with sweeping ideological ambition. “The rise of Neurodiversity takes postmodern fragmentation one step further,” she wrote. “Just as the postmodern era sees every once-too-solid belief melt into air, our most taken-for-granted assumptions—that we all, more or less, see, feel, touch, hear, smell, and sort information in more or less the same way—are being dissolved.” A freelance writer named Harvey Blume gave “neurodiversity” currency among journalists with an article in *The Atlantic* that same year. A couple of best-selling books, Andrew Solomon’s

Far from the Tree: Parents, Children, and the Search for Identity, in 2012, and Steve Silberman's *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*, in 2015, clinched the case. A cliché was born.

Neurodiversity discourse is now ubiquitous. It takes protean forms — a meme, a critique, an ideal type, a virtue signal, a paradigm for restructuring autism research. The discourse in all its permutations identifies symptoms that science and society have deemed pathological and re-describes them as coping tactics or benign differences unworthy of invidious distinction. In this respect, neurodiversity discourse might be understood as an effort to do away with stigma, a concept traditionally rooted in shame over the body's finitude. Yet the leveling impulse that motivates neurodiversity's loudest champions does not abolish stigma so much as remove it to the plane of language and throw it in the face of social institutions. Major institutions in the economy, government, and entertainment, on guard against accusations of insensitivity, have responded by editing marketing language and instrumentalizing neurodiverse forms of creativity in hiring practices. The Central Intelligence Agency, to cite one of the nation's newly enlightened employers, is hip to the competitive advantages offered by neurodiverse job candidates.

In the institution of the family, the gravamen of the indictment hits home. The claim that neurodiversity denotes a personal identity, one that is rooted in ontological sovereignty, invites its unelected representatives to intervene with parents on behalf of their children. When, as in my case, a neurodiverse child is born to a parent labeled "neuro-typical," the dialectic of love and authority is automatically held to be adulterated. I, too, am cast betwixt and between prescribed social parameters. "Inside us there is something that has no name," José Saramago

wrote in *Blindness*, "that something is what we are." That something is what this society cannot let be.

So far, neurodiversity (and its slightly more opinionated cousin, neurodivergence) has followed the path of vanguard movements organized around abstract and categorical postulates of identity. As an expression of cultural radicalism, neurodiversity perpetuates the assault on the conventional family. As an ideology, it reaffirms the assumption that freedom lies in incommensurable acts of appropriation and consumption. As social criticism, it hardens the community's distinction between them and us. And as a politics, it leaves the distributions of power undisturbed.

Every other autumn, candidates seeking election to Cambridge's school committee or city council knock on my front door and make their pitches. I explain why I am a single-issue municipal voter. I ask for their disability policy initiatives. My question invariably takes them by surprise. I haven't met one who has given such policy any forethought. But as they stammer over substance, they always carefully rephrase my description of my own son as "neurodiverse" or "differently abled." I wouldn't care, if the politicians of identity would actually do something.



The biggest social crisis of recent years let the hot air out of such lip-service. Covid-19 came. The mayor of Cambridge issued emergency communiques every day. She sought to reassure the "most vulnerable" members of the community by naming them in successive numbers — veterans, elderly, "unhoused people," "undocumented people," "people who are transgender and gender non-conforming," and "people

of color.” Two months into the city’s pandemic response, the mayor still ignored people like Misha. I wrote to insist on my son’s existence. She pledged to “do better.”

The lockdown did all the work we needed. For years I had worried about testing our community’s elasticity. Now our community itself quarantined. I had always winced as our neighbors kept a wary distance from us. Now they stayed six feet away from one another. I had fought off dread of the future. Now everyone felt encumbered by an emergency without end. As social friction thinned, we slipped out of the liminal state all together.

One memorable day — July 13, 2020, to be exact — we dipped into the city’s public swimming pool. A facility with a capacity for a hundred entertained a dozen swimmers this day. Misha tap-danced toward the deep end. He was bolder than I had ever seen him in the water. He drew a breath, semi-sealed his lips, and dunked himself for the first time. A fit of spontaneity propelled him from one side of the pool to the other. He was teaching himself how to swim, repossessing his corporeal identity in the water’s pressure. As he clawed toward me, grinning ear to ear, I thought of Wordsworth savoring

that serene and blessed mood
In which the burden of the mystery,
In which the heavy and the weary weight
Of all this unintelligible world,
Is lightened.

That October, however, an indiscretion put us back in our place. On a Saturday afternoon at Riverside Park in Cambridge, families of diverse ages, genders, and colors were tossing frisbees, listening to music, riding bicycles, and

sunbathing. Misha frolicked on a spray deck, flapping and squealing, as happy as his happy can be. I sat with Niusha on a bench nearby. We were admiring the pontoon boats and kayaks afloat on the Charles River when suddenly a woman staggered into our picture and began rubbernecking at Misha. By her ruddy appearance and her haphazard gait, she looked to be one of the “unhoused people.” Suddenly she let loose a bark about “your retaaarded son.”

“We’re not leaving,” I whispered to Niusha. “She’s drunk. She’s not driving us away.” Seconds later, the woman captured the attention of the park when she repeated the epithet at the top of her lungs. We turned the other cheek and headed home.

That evening, Niusha sobbed with shame. I couldn’t find words to console her. Sitting on the edge of her bed, I stroked her hair and wiped away her tears in silence. My imagination drifted to the predicament of Peter and Polly Horn. I remember thinking that I would make the same choice in a heartbeat.



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The insignia that appears throughout *Liberties* is derived from details in Botticelli's drawings for Dante's *Divine Comedy*, which were executed between 1480 and 1495.

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A civilization that fights tyrannical barbarism must know at what points its sins approach the barbarism of its foes. But it must also know at what points it is the custodian of values that transcend the sins of its "imperialism." Otherwise its uneasy conscience will betray it into the hands of those who have no moral scruples at all. It is a good thing to know what do with an uneasy conscience.

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