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Dauphinee, "Repetition"
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Repetition

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Abstract

Utilizing a first-person narrative, this essay chronicles a mother's examination of the hidden politics of behavioural psychology as clinically applied to her three-year-old autistic child.

Keywords

narrative, autism, behaviourism, parenting, politics

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Dear Kara,

We are very grateful for your response to our request for a break in therapy. We are grateful for your concern, and for all that you've done for us. I respect you immensely. I hope that you have felt this in our relationship as much as I have tried to convey it. From the moment we met, I felt a surge of hope and confidence in you, and that has not waned.

Our desire to take a break from the therapy is not generated from the sense that we have the expertise to isolate and identify the variables that are at play in Henry and Gordon's development. We do not possess that expertise. I do not suffer the illusion that, because I am raising autistic children, I am now an expert. The knowledge that you and I have (you as clinician and psychologist, me as parent and social theorist) are not convertible currencies. What

I have to say is very difficult to articulate. Because of my respect for you and my gratitude, I want to try and trace some of the contours of our decision to take a break from the therapy.

A few weeks ago, I served on the Faculty of Graduate Studies' mid-list adjudication committee for SSHRC doctoral fellowships. I assessed files from several departments that were represented in my pool of 40 applications. One of them was from Psychology, and it was from a doctoral student who intends to conduct a study on the impact of autism treatment on the parents of autistic children. She indicated that there is anecdotal evidence that parents of autistic children experience significant psychological distress. Her goal is to develop a set of the best practices for practitioners to provide the support that parents need to survive their children's diagnosis and treatment. (She didn't use the word 'survive', but this is the word that came to my mind).

John and I have noticed over the last many months that we are not ok. This has crept up on each of us differently. But when we finally sat down in a series of discussions about what was happening, we reached the same conclusion: the joy has gone from our lives. Every interaction with our sons is refracted through the lens of autism therapy. Every move they make triggers an automatic assessment of their actions, speech, and behavior: 'Is this a function of autism? Is it normal for their respective ages? Should we mention it to the psychologist? Can they program for this?' Slowly, without any specific moment of awareness, we became observers of our children and, in turn, they became expressions of their diagnosis. The everyday joys of our lives have been sapped by this, and yet we have no tools (nor do I think these tools exist) that would allow us to differentiate between our sons as 'our children' and as 'expressions of their diagnosis'. Every therapy session ended with our question, 'how did he do?' - as though that mattered. As though it *mattered more than other things, like ‘does he feel loved?' and 'what are his needs and desires?’ Gradually, our perceptions of our own children have shrunk to a set of metrics that has bled the fullness from our lives. My joy as the mother of my children evaporated as they slowly transformed into sets of deficits that had to be addressed.*

My academic area of specialization is ethics. I am an 'expert' in Levinasian philosophies of ethics that posit responsibility as emanating from the alterity of otherness. I have written books critiquing the imperative to assimilate others as copies of the self. I have spent my career challenging the claim that the ethical imperative originates from the self, arguing instead that this imperative originates from responsibility to the other as 'other' – as exteriority. And yet I have undertaken a program of treatment that aims to shape my children into normative selves. How could this be? How could it be that I was unable to live my own ethics? I ask myself this. And the answer for me is that I have been motivated by fear. In ‘behaviorist’ terms, my motivation was not the desire for my children to be well (which I originally thought was my motivation). Instead, it was my fear that I will have denied them a chance to fit into ‘the world’ if they do not undertake this treatment. When I began to recognize this, I saw that my fear was destroying all the other things that my sons need to thrive and flourish - the right to be themselves, the right to live as they are - the right to live outside the shadow of the metrics that take away their freedom to be and to become in an organic sense.

If my motivation is for my children to thrive, then I have to consider other things – things that are not calculated in the annals of behaviorism. I have to consider what emotional resources John and I have to give them - to ensure that our home is a place of safety, peace, and acceptance, that they are loved unconditionally and that they feel this, and that who they are is not coded to them *as deficient or unacceptable. We are at a point where these crucial needs are declining in direct proportion to the increasingly pervasive sense that Henry and Gordon are problems to be treated rather than people to be loved. I don't think we can have this both ways. I don't think they can have the freedom to be who they are while they are being constantly assessed for deficits in the way they perceive the world. These are opposite imperatives. My increasingly clinical gaze is the antithesis of love.*

I have to ask myself this question about Henry, who is old enough now at the age five to 'get it': Will his perception of himself be shadowed by his autism because the world cannot tolerate him? Or is his perception of himself already shadowed by a therapy that has shown him the abnormality of who he is? And this therapy functions in anticipation of a world he has not yet encountered. A world that has not yet unfolded. Must we fear this world? A few days ago, a Critical Disabilities Studies doctoral student won her case at the Ontario Human Rights Tribunal. The Tribunal ruled that York University must provide academic accommodation to students without the disclosure of a diagnosis. Perhaps this will be Henry's and Gordon's future, and not the one I fear. Henry already knows that his difference is coded as a deficiency. A few months ago, while he was playing in the tub, I casually asked him, 'Henry, do you think you have autism?' He looked down sadly at his hands in the water and said, 'yeah'. The dejection in his voice was unmistakable. I could see that his perception of himself has already been damaged, before the world I fear has even gotten close to him. And who brought him this vision of himself? Surely, it was I.

We are taking this break in an attempt to recuperate the spontaneity of life that we enjoyed before these diagnoses. When I was tenured at York and became pregnant with Henry, we left Toronto so that we could build a good life on a single salary, so that our children could be raised by their parents and not an institution, so that we could decide one random morning to go somewhere on an adventure together, and so that we would have the slow time to know and love one another in ways that many other people never have the opportunity to do outside of the few hours between 5 and 8pm when they're not working. I need these things. I think we all need these things. The autism treatment life that we have slowly come to inhabit is crushing us. We do not know what the future will hold. But we cannot continue as we are going.

I know the academic in you will recognize that I do not write this as an indictment of your expertise. I know that your concerns are valid. But this knowledge does not change my mind because our decision comes from a place of deep need that is critical to our survival. We love our children. Their father and I love one another. We respect you enormously, and we are grateful for the direction and expertise you provided us so we could better understand what is at stake in our decision.

Yours faithfully,
Elizabeth Dauphinee

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Night after night, the anxiety grinds in my stomach.

What have I done?

***

‘Is eight a big number or a small number, Henry?’ The therapist’s voice floats up the stairwell, quiet but imperious. It feels sweet on the surface, but it has a cutting edge.

I know there’s only one right answer. If I didn’t know it from the way the question is posed, I would know it from the tone in the therapist’s voice. Henry does not know that. He knows about the number eight, though. He knows what color it is; he knows its shape and its sound. He knows how to spell it. Eight is one of Henry’s closest friends. Henry also knows seven and six. He knows seven thousand seven hundred and seventy six. He recognizes numbers into the millions. Henry is three years old.

‘Is eight a big number or a small number?’ the therapist repeats.

‘A small number,’ Henry replies in his piping sing-song voice. Born in Toronto, he has a New Jersey accent, like me. He says ‘small’ like ‘crawl’ – ‘smaw-al’.

‘I think it’s a big number,’ replies the therapist.

Henry is silent. I can picture him there, sitting on the table. Then, the therapists begin to explain to him that we don’t sit on the table.

‘Excuse me. Do Mommy and Daddy sit on the table?’

They don’t wait for him to answer. They don’t assume he might know the answer, but that the answer might be different from their expectation, because, guess what, lady? It’s not a table.

It's a nineteenth century Nepalese bed frame that I paid $3,000 for in an earlier lifetime and Henry must have heard us explain that to houseguests a dozen times or more.

'Henry, do your parents let you sit on the table?' They are calm in their inflexibility. It's their job to be calm. Their calm is one of the things I hate the most about them.

Yes, he sits on the table all the time.

Suddenly, Henry screams: 'NO NO NO NO NO NO! Want W!'

They have taken the plastic letter W away from him to make him sit in his chair. *They have taken W away from him to make him believe that the bed is a table – a thing that is not true.*

Henry sits on the 'table' to watch cartoons; his little brother, Gordon, who calls himself 'Goose' and who will be diagnosed just weeks from now, runs back and forth along it. He occasionally sails off and smashes into the floor or the couch. Then he gets up again and continues like nothing happened. Yes, Henry and Goose sit on the Nepalese bed platform we use as a table. Henry has even fallen asleep on it. I snapped a picture of him.

I rise from my desk – the desk where I keep trying to write academic articles – and I creep to the top of the stairs. I know where the old maple floor will creak, and I avoid those spots. But I can't hear anything except Henry's screaming. My heart is tight. They think he's screaming because he's autistic – because he's too rigid – he's too rigid for their rigidity – he can't abide chaos, loud noises, other kids, sitting down in chairs. Or maybe it's the *break in his routine* – one of their favorite doxologies.

They don't say: 'The chair is a site of control.'

He’s screaming because he sits on the table *all the time*, eating organic corn chips, drinking milk, watching counting videos, watching alphabet videos, and because he doesn’t know how to say that to them. The scream is his explanation. They’re not listening.

Do I intervene? They mean well, you know, these nice young women with careful makeup and pearl earrings who want to work with autistic children and help them lead *normal lives,* not sitting on tables but in children’s chairs, gripping their laced-together fingers in their laps, awaiting actionable instruction. Autistic children can’t answer, ‘yes, I sit on the table; it’s not a table anyway. It’s a fucking bed.’ Instead, the autistic child screams.

My autistic child screams.

And then the nice women with their psychology BAs take notes on the ‘episode’ – the ‘meltdown’ – the ‘behavior’ that occurred when they prompted him to sit in the chair. And he *has* to sit in the chair because in two weeks he is going to school and he can’t sit on the table there, he must sit in the chair like all the other children – all the *normal* children. I know. I know he has to survive the world outside and that there is nothing I can do about that. My body moves down the stairs, though, because Henry doesn’t scream when he’s with us – he has no ‘episodes’ or ‘meltdowns.’ He wants to tell you he sits on the table all the time, and that if he should sit in the chair it should be explained to him that the reason we have to sit in the chair is because we are going to school soon and in school we sit in chairs, not on tables, *and today we will practice that*.

Maybe they think he can’t understand that. They think he is screaming because of his *stickiness*. They learned this studying behaviorism – that cause and effect are two rational things and we can quantify their relationship, even though Henry’s not rational – you know that’s true, no three year old is rational – they melt down all the time. But this is not that – this is something *else*. Something *different.* Other children might not want to sit in the chair, they explain. But for Henry, this is not an act of willful defiance. It is a product of the inherent inflexibility of his neurology. He is simply unable to accept a new way of doing things, so they must ‘prompt’ him with a system of denials and rewards.

‘He does sit on the table. All the time,’ I say to them quietly from the bottom of the stairs.

The therapist whirls around and covers her mouth, suppressing a guilty smile. ‘Really?’ she exhales. And then, absurdly: ‘Should we find a different part of the house where we could work at a table he doesn’t sit on?’ I am amazed at her rigidity. She is more rigid than he, who is charged with being too rigid. That is the allegation against him – that he is too rigid. That is why these women are here, to reprogram him to sit in chairs and to sing in circles and to play in hermetically enclosed plastic playgrounds designed by psychology PhDs.

‘Is eight a big number or a small number, Henry?’ The other therapist soldiers on.

‘A small number,’ says a small voice.

The quiet admonition is inflected in her cadence. *Pedagogue.*

‘A small number? I think eight is a big number,’ she persists, and she is greeted again by Henry’s autistic silence. Does she think she will reprogram his knowledge that eight is, in fact, a small number?

What should a three-year-old know? The answer to this question is the baseline for all their knowledge, and they have a clear system of checklists to ascertain this.

The autistic’s silence is he, looking at eight in puzzlement and trying to see it as a big number when he knows that it’s not. Now he is sitting in the chair, defeated. I send him to the back of the house to watch cartoons with Goose. The therapists look at me expectantly, their soft hands folded in their laps.

'I understand that the kids in junior kindergarten might only know one through ten,' I say, 'and that eight might be a relatively big number for them.'

The therapists are attentive, polite.

'But for Henry, eight is a small number,' I continue. I can hear the blood pounding in my ears. I am not sure if they can see my rage. I'm trying to push it down.

They blink in unison and I want to laugh. But I feel this anger, and it's clouding my judgment. I am trying to think of what I want to say, what words I can say that won't ruin everything because what I want to say is *get the fuck out of my house*.

I hesitate.

The other defends herself: 'I didn't mean to say that eight *can't* be a small number; I was just offering an alternative.'

He's autistic, she doesn't say. He needs to learn alternatives – alternative ways of seeing the world; alternative ways of eating, of talking and walking and climbing stairs, *alternative ways of understanding the number eight*.

'You know he knows numbers into the millions. You guys know this. So of course eight is a small number for him,' I persist quietly.

Why can't I articulate anything? Who cares whether eight is big or small? Why does it have to be *either* big or small at all? Of course he should have alternatives. *Of course.* But that quiet, unopposable tone that silences even those whose preferred medium is silence – it enrages me.

They look confused again. And I suddenly see that they are looking beyond me; trying to hear me because they know they should – because I paid them $40,000 this year to help my child – but they don’t hear me. They don’t hear what I am saying. They are politely waiting for me to go away so they can get back to their data sheets, to note the ‘behavior’ and its ‘antecedent.’ I think they have to tell themselves and one another that I don’t ‘get it’. They have to do this so they can enact their protocol on the autistic, who is now an example of their diagnosis, and all this over the ridiculous question about whether eight is a small number, or whether we sit on tables. They can’t hear me saying, ‘Henry does not scream at home with us. He sits on the table, he sits in the chair, he eats eggs and counts and reads books about the alphabet and at night I sing him to sleep – ‘Slip Sliding Away,’ ‘Southern Cross,’ ‘Seven Bridges Road,’ ‘Katmandu,’ ‘Something So Right’.

Defeated in his chair, Henry cannot show what he knows and what he feels in a language they can understand. He cannot say, ‘Eight is not a big number, Kendra, I’m sorry, but I know a lot of big numbers and eight is not one of the really big ones. I can sign eight on one hand, that’s how small eight is.’ But he loves eight, too, and so even as these correctives ‘liberate’ him from the strictures of his autism, they destroy something else in him. If eight is small, perhaps it is not worthy of his love.

‘I think eight is Henry’s favorite number,’ Kendra offers in a conciliatory tone.

Henry doesn’t have favorite numbers! I want to scream. He treats each one with equal reverence and carelessness. He embraces and relinquishes them all in alternating rhythms like tides. She saw him for a moment one day, holding the number eight to his lips, whispering to it, and she assumed her millisecond of seeing had captured the only frame of his desire.

‘Henry doesn’t have a favorite number,’ I say calmly.

‘Oh,’ they look at me with feigned understanding, and then they try a different tack. ‘Has his routine been disrupted today at all?’

‘No,’ I answer. There’s no routine here. You are telling him things he knows to be untrue – that the bed is a table, that the number eight is a big number – and he has no way to challenge you. I don’t say this to them because I don’t think about it until later. All I have is the thundering of blood pulsing against my eardrums.

They are smiling at me politely, murmuring ‘mmmm-hmmmm’ – the vocal equivalent of a soothing hand pat. A cluck. Who can believe that a child does not have a favored thing? They have momentarily forgotten the autism they are trying to challenge, because they ‘do’ autism, but they don’t inhabit it or they would know that Henry is a theorist. ‘Autistic patterning’ for Henry means that he loves *systems* of things, like numbers and letters and shapes, and that each number, letter, and shape takes its place of prominence at different points in time and space. Why is this so hard to understand? There is no ‘favorite’ thing in the mathematically straight-line mounds and furrows of advanced industrial agriculture. Who can say which furrow is one’s favorite?

Why can’t they see that?

The therapists are looking at me like cows in a field, blinking. They don’t understand me. I can see that. They have a formula. It has to be applied. The autistic is inflexible. Let us teach flexibility through the strategic deployment of our own ideological power. It’s not that he’s too rigid. It’s that he’s not rigid in the ways we require him to be. Therapy is ideology.

We don’t sit on tables.

***

Henry was born at 37 weeks, via caesarean section. His mother reported experiencing gestational diabetes, treated with insulin. No other complications during pregnancy were reported. He was reported to reach developmental milestones, such as sitting up and walking, within normal limits. Henry was not reported to babble in a typical manner and his first word (purple) was reported to be said after his second birthday. He began to use two- to three-word sentences shortly after this time period. However, his parents reported that the majority of his language is scripted or echoed from others' statements…he is not yet demonstrating interest in peers or engaging in friendship-seeking behaviour.

During the cognitive assessment, Henry communicated using brief sentences, as well as nonverbal behaviour such as pointing, to show responses. He listened to instructions and waited before touching materials. He appeared to enjoy many of the activities, laughing at times and requesting to perform some of the tasks again. He remained seated and attentive at the table for approximately two hours, with brief breaks to change activities and to engage with preferred items, such as puzzles. He demonstrated good attending skills and no significantly interfering or disruptive behaviour was observed.

Henry's motor skills were another area of relative weakness, falling in the Moderately Low range of functioning. He was reported to run smoothly without falling, walk up and down stairs by *placing both feet on each step, and to throw and catch balls. He was not reported to ride a tricycle. In terms of his fine motor skills, Henry was reported to complete simple puzzles, turn pages in a book, and at times colour simple shapes. However, he was not yet reported to hold a pencil in proper position, to build structures with blocks, or to cut with scissors or paste with glue.*

In terms of his communication, the majority of Henry's speech was immediate or delayed echolalia, including repeating questions and statements made by the examiner, as well as repeating phrases that were believed to be rote phrases associated with specific activities. Henry's intonation was marked by abnormal pitch and quality. A variety of repetitive and stereotypical phrases were heard throughout the assessment, such as highly repetitive phrases coordinated with repetitive actions while playing with the pop-up toy (i.e., "Square here, circle here, star here, bop, bop, bop"; repeated approximately five times). In addition, Henry often referred to himself by name and was not observed to properly use the pronoun "I" during the assessment. Given the frequency of stereotypical and repetitive, echoed language, very little spontaneous communication was observed and reciprocal conversation was not sustained…'

Thus reads the Book of Henry – the archive built by the psychologist that plumbs and shapes the depths of his humanity.

Henry does not believe that he is impactful in the world. It was explained to us that this is why he freezes and screams on the ladder going up to the top of the slide when he notices another child climbing up behind him. The panic might never be eradicated, we are told. It must be *managed*. All of these *pathologies* must be managed. They are problems to be contained, the neurological spillover of synapses that comprise the other 90% of the brain – maybe the 90% that the rest of us don’t use.

‘He doesn’t see himself like other people,’ the psychologist explained. ‘He doesn’t see that his actions can impact the situation and change it.’

Is that what his autism is about? The abdication – the curious absence – of purposeful agency? I ask her this.

‘No,’ says the psychologist. ‘Some autistic children are very agentive. They know what they want and they will do whatever it takes to get it – even resort to violence.’

‘But the goal of the treatment in those cases is to manage their agency, or to contain it, right?’ I persist.

She looks at me strangely.

But is this not right? The goal of Intensive Behavioral Intervention, this autism treatment, is to direct the agency of the autistic into more *appropriate* behaviors. It’s a mirror of neoliberal capitalism. All of us facing in the same fucking direction at all times. I pause, groping for the thoughts that are scattering away from me. I can’t think well. I can’t say what I mean. How did that happen? When? I lost my ability to think with the flow of blood from my body giving birth to my sons.

‘Henry’s missing a huge chunk of the world without the social piece,’ advises the psychologist. ‘He needs to master the fluid exchange of language.’

But language is not a ‘thing’ that one masters. It is the underlayment of human expression – a symbolic system that cannot capture what overflows around it. Henry lives in the overflow. We all do.

I wonder what huge chunk of the world I’m missing – chunks like astrophysics or quantum theory – chunks of the world where people speak other languages, where they worship other gods – worlds of monument builders and cosmologists. What world does Henry inhabit that they are trying to draw him away from? What little fold in time and space does he occupy? What world does he inhabit that he is so apparently disinterested in entering ‘ours’? I wish I could see it. I wish I could see what he sees.

‘…narrow, restrictive interests,’ finishes the psychologist. Fantasizing about the margins of Henry’s mind, I missed the entire first part of what she had said.

‘It’s not that he has no other interests, it’s just that he has a thing with numbers and letters,’ I explain. He does also like puzzles, as she said in the report. But was it a numbers puzzle? I think it was.

She’s looking at me with carefully cultivated sympathy. She thinks I’m resisting the diagnosis. But it’s not the autism that bothers me. It’s the treatment. I want to know how we can know that his interests are ‘narrow and restrictive’. How can we determine that? What if the world of his mind is immeasurably more expansive than mine? What if the way he sees the number three involves a complexity of detail that is greater than all the different facets of my life put together? What if it has a texture? A voice? What if it has agency? What if it operates in contexts that I can’t even see? What if that little stuttering snapshot of echolalic mimicry is not the inability to exercise agency, but rather the inadequacy of our language to express what he knows?

‘He’s not interested in the social world,’ I tell her.

‘That’s exactly the problem,’ she points out.

‘But that doesn’t mean his world is smaller than ours.’

She is silent. She tries a different angle. ‘The goal is to get him behaving in ways that are conducive to fluid, give-and-take social interaction.’

Like what we’re having now?

‘I know that. I know this is what he needs,’ I confirm carefully. ‘What I don’t know is whether his intellectual and emotional world are really restricted, or whether it’s that we are unable to see the breadth of what he sees.’

She nods while I am speaking. She nods before I finish my sentence. She is trained to nod. She is trained to validate what she destroys. ‘Does it matter, though?’ she replies in an affirming, non-confrontational tone. ‘Even if we could answer that, it doesn’t change the treatment goals, right?’

Why not?

I once knew why: because if he can’t express himself to anyone else, it doesn’t matter what he knows. There is no private language. I believed this, at least, this maxim from Wittgenstein. I believed this to be true. There is no private language. But then I loved Henry. And now I’m not sure.

***

‘Can you hear the trees, Henry?’ He is lying in my arms in the sand at the bottom of the playground slide. The leaves in the big sugar maple are rustling quietly above us. Henry is watching them intently.

‘Yeah,’ he says solemnly.

‘Can you hear them singing?’

‘Yeah.’ He is mesmerized.

‘The trees sing in the winter, too. But we can’t hear it well, because there are no leaves in the winter.’

‘There are no leaves, Mom.’

‘I know, baby.’

‘There are leaves in summer, Mom.’

‘That’s right.’ I hug him tighter. The sunlight filters through the big tree and he is illuminated in-between the dappled shadows.

‘If you were going to write a story, what would it be about?’ I ask him.

‘I don’t know, Mom.’ Solemn answer.

‘Would you write about how the trees sing?’

‘Yes.’

‘How would you start?’

‘I don’t know, Mom.’

‘Once, a long time ago, there was a tree…’ I begin.

Henry is silent.

'What do you think?'

He nods. 'Yes.'

'What did the tree do, do you think?'

'I don't know, Mom.'

'Did it have a name?'

'Yes.'

'Do you want to give the tree a name?'

'Yes.'

'What do you want to name the tree?'

'I don't know, Mom.'

'Try and think of a name,' I say.

'I want you to do it, Mom.'

'OK. How about Colin?'

He nods. 'Yes.'

'Do you think he has friends?'

'Yes.'

'Do you think he's friends with all the other trees in the park?'

'Yes, all the other trees in the park.'

***

Henry and I sit for the second year in a row at the point at Napili Bay, on Maui, watching the sun set across the ocean over the island of Lanai. We don't speak.

I wonder if I'm supposed to ask: 'Do you like the sunset, Henry?' or 'What colors do you see?'; or 'Do you see the waves?'; or 'What animals can you name that live in the ocean?'

But I don't have it in me to manage that clutter of 'prompting questions'. I was not a good mother for talking to babies. The exaggerated singsong and constant chatter felt absurd to me. It is much more pleasurable for me to sit with him in silence, listening to the ocean crash against the point, feeling the warmth of the volcanic earth releasing the heat of the day as the evening cools our beach-warmed skins. It is much more pleasurable for me to feel the weight of his warm, sharply angular body in my lap, resting my chin on the top of his head – feeling the coarse curls of his hair – my mother's hair – against my lips as I breathe in the scent of his scalp. I wrap my arms around him, and this is my pleasure, this autistic silence, this lack that we share near the power of the ocean's edge; this mutual lack of agentive power over the permanence of its own repetition. Over and over again, the waves crash against the rocks, replenishing the tide pools at our feet. Repetition. But that sameness comes back differently every time. You have to look closely.

Henry is not looking at the sea. Maybe he doesn't need to see it. Maybe it's already inside him. Maybe it's already intimately known. Instead, he is looking at his hands as they move precisely through the motions of his own created sign language. Each finger, each bend of a knuckle, each angle of a hand in relation to its mate represents a specific number. The ocean booms on. The sun sinks behind Lanai and the ocean turns greyish. Henry's hands fly through the numbers, over and over until he comes to 99. And after 99, he needs me. He cannot sign '100' without another person to offer the shape of a zero with circled thumb and forefinger. He twists his head and looks up at me, but he doesn't say anything. I know what he needs, and he knows that I know. We sign Henry's sign for 100. He draws up his skinny legs and sighs a quiet, contented sigh.

What artifacts can he leave for me to find? Or I for him? How will we find each other? When the sun has set, we walk home hand in hand, like my mother and I used to do.

***

In advance of Henry's first day of junior kindergarten, we meet with the special needs teachers. They stare at me in bored disbelief when I tell them that he reads. He reads words like 'geometry' and 'hypotrochoid.' I had promised his father that I wouldn't do the talking, so I stop and chase the newly diagnosed Goose while Henry sits quietly, dwarfed in the adult chairs. His father is a deep well of quiet tolerance when there's something at stake. And he's proud of Henry. He says to the teachers, 'Henry knows shapes.' The dourest one smiles indulgently. 'He'll learn circle, square, triangle,' she drones. He knows parallelograms and trapezoids and quatrefoils.

'Is he a flight risk?' she asks.

'No.'

She ticks a box on her clipboard.

Henry swings his legs gently while they divine his dismal future. It is already decided. I take his hand and squeeze it in three short bursts – the number of syllables in the secret message 'I love you' coded to me by my mother on the fishing pier in Ocean Grove where we used to walk at night. I can feel myself closing down. The principal drones some shit about enabling each student to reach his maximum achievement. I bite the insides of my cheeks.

‘Does he hit?’ she asks, not taking her eyes from the checklist in front of her.

Henry swings his legs. Probably if we weren’t here with him, they’d say something to him about it. They’d ask the rhetorical question: ‘We don’t swing our legs, do we?’ I can hear their saccharin contempt, talking to him all stupid-like – the autistic kid with the swinging legs whose desperate mother has to tell herself he’s brilliant. But I’m not desperate. It’s just that I love him.

Henry is quiet. He will smile an uncertain smile the whole time they’re abusing him. He can’t distinguish love from abuse. I asked the therapists to work on that with him. They agreed it was ‘a really important piece’. *But none of us can distinguish love from abuse*, a quiet voice in the back of my mind whispers to me. That voice whispers its dissent about their ‘diagnosis’. It tells me in the night that nothing is ‘wrong’ with him – that what is wrong with Henry is the same thing ‘wrong’ with everything else around me – all of it, autistic repetition, the conformist social stutter of our economic system, the requirement for all of us to face the same direction at all times – in lecture halls, in traffic, *in formation*. Mechanized repetition is everywhere – the ‘antecedent’ and the ‘consequence’ of concentration camps, fascist aesthetics, mechanized death. Was it a coincidence that autism was identified in the 1940s, in the years when goose-stepping repetition emerged as the social phenomenon *par excellence*? This endless repetition, this enforced sequential patterning, this disconnect from the traumas of the world. What came out of the 1940s that we should want to save?

Mechanized genocide.

Psychology genocide.

You’re being ridiculous.

No. I’m not. It eradicates difference.

That’s going too far.

No, it’s not. Genocide only happens because its logical structure is already embedded in our belief system about who is an acceptable human being. Conform or face the consequences. Society must be defended, like Foucault warned us.

Neuropsychologists say that autistics lack a theory of mind mechanism. This means that they cannot put themselves empathetically in the positions of others. They don’t imagine that they could be anyone else, or that anyone else could experience an authentic fullness of thought. Other people are *objects* for the autistic.

But the things we call ‘objects’ are Henry’s friends. He lines them up, scrutinizes them, organizes and categorizes them by color, size, shape, and by other mechanisms that I have not been able to discern. He identifies us by number. For Henry, everyone has a number. His father is #1; Goose is #8; Fluffy was #5 and, when she died, her number was retired. A few new cats in the house for a while: their names were #16, #17, and #20. My sister in New Jersey is #6. Henry himself is #7. I am Zero. I laughed about that – all the mothers are zeroes. But then my friend, a crown attorney, reminded me that before the Arabs theorized zero, there was no trigonometry or algebra.

At night, in bed, I lie awake and I think, *I don’t want their ‘treatment.’* I want to hoard Number 7 all for myself; his deep, changeable eyes, his sweet echo of everything around him. I love how he reads at night, always with the same inflection; how he made up his own sign language for counting higher numbers. I use his system myself now, an improvement over the way I’ve counted for 40 years. But the therapists deprogrammed that advancement, and now he counts like all the other kids, on the fingers of two hands. A while back, I caught his father trying to reteach Henry his own system – to resurrect that secret archive of knowledge they’re stealing from him. They are deprogramming his proclivity for stacking numbers, sorting numbers, lining them up, squatting down to assess the trueness of their alignment with his squinted, considering side-eye stare. His coarse hair is like buckwheat honey, curling around the nape of his neck and over his ears. What could I want to be changed about him? Why does he have to learn my language? Can’t I learn his?

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‘We will work on diversifying his approach to objects,’ says the therapist, ‘so he can develop a less rigid relationship with the things in his life. He shouldn’t understand people as numbers,’ she says.

I want to laugh. I want to ask her if she knows how many numbers I am: a Social Insurance Number in Canada, a Social Security Number in the United States, four bank account numbers, an employee number, a pension account number, a driver’s license number, an Ontario

Hospitalization Insurance Program number, two passport numbers…. And on and on it goes, this numerical list. Why shouldn't he understand people as numbers? *That's what we do.*

If something is wrong with my child, I think it must be because my body transmitted the hidden architectures of hypermodernity to the cluster of cells that became Henry.

I try to say it. 'Well, we're all numbers to the state,' I say. But it sounds hollow when I say it. I can't say what I mean. I don't speak their language.

The senior therapist – a 'board certified behavioral analyst' – looks at me quizzically. I'm trying really hard to like her, but her inauthenticity is so apparent and I can feel the contempt growing inside my chest cavity.

'We're all numbers, right?' I persist. 'Social Insurance Numbers? Other kinds of numbers? Bank accounts? You know?'

She hesitates. I can see that her hesitance is not because she's considering what I've said, but because she is not sure how to deal with me. 'Well, we *have* numbers for certain things, yes.'

No. The state does not merely give you a number. It makes *you a number. That is its organizing principle. Henry is only replicating this social formation – the social formation that we craft and then deny. You are hiding our own social illness by pathologizing his overt expression of everything that is wrong with us. But the pathology is ours, not his.*

Suddenly, I feel very sure of this. But I can't think of a way to say it that will make sense to them – that will show them what I see. And it validates the diagnosis, and I don't want to do that. I'm confused. So I change the subject.

I change direction. I want Henry to learn how to lie. I tell them this.

‘This is a tricky one,’ they say. ‘On the one hand, if he can lie, it shows that he is capable of making social judgments, and that’s good. On the other hand, we don’t want him to lie as a matter of principle.’

But the more grave the consequences, the more lies are needed.

I told him in the shopping mall, over a pot of French fries, that you have to know how to lie when it matters. The woman at the table beside us turned her head sharply, a watchful crow.

Knock, knock.

Who’s there?

SS.

Interahamwe.

Vojska Republika Srpska.

Homeland Security.

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‘Does Henry follow instructions?’ asks the principal. He is trying to gauge how much of a problem Henry will be in the classroom. He needs help putting his boots on and opening his lunch containers.

‘Yes,’ his father answers.

‘Does he follow two-step instructions? he asks.

Does he follow goose-step instructions? my mind sings in answer.

‘Yes.’

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‘Henry doesn’t have any of these “behaviors” at home,’ I tell the psychologist.

She is earnest, leaning toward me in the textbook gesture of the trusted confidante. She nods.

‘That’s a great observation, Liz. You and John have built a scaffolding around him to accommodate his specific needs – so he exhibits less discomfort.’

‘Oh.’ I try to think about that. We have built scaffolding to support him. The goal is to live without scaffolding.

I think of the anxiety that sits in my chest some nights. There are lots of anxieties. For example, I have to fly to Manchester for a conference in a month and I don’t like flying over the ocean at night. I have trouble getting on the plane. It happened once, a few years ago, that I couldn’t get on the plane. I stood in the boarding lounge at Toronto with my face pressed against the window, watching the pilots perform their pre-flight checks in the cockpit of Air Canada’s

777, and I couldn't do it. Deep in the heart of the night, I inch over to the father of my sons. He raises his arm in the dark and I tuck my head against his shoulder. For long moments, he scratches my back with his fingertips.

Scaffolding.

What is it about us that we still assume the rational autonomy of individuals? What is it about us that we cannot see the extent to which we need one another? What is it about Henry that the world cannot scaffold? What is it about the world that it can't scaffold him?

'He needs to be taught how to interface with the world,' the psychologist says – as though he were separate from it somehow. First we are ourselves, they say. Then we enter the world. But they can't really believe this. The ones with the doctorates must understand that this proposition is absurd. They know that there exist theories which say these two movements are actually one, and they can even acknowledge this. But this debate has no point of connection with their clinical protocols, because in their craft, there is no *politics* to that theoretical observation: We create the world, which in turn creates us. So, knowing theoretically that there is potentially no difference between the world and the self, *they set up their clinical protocols as if this distinction was real*. Servants to the clinical data, they don't have to acknowledge that their diagnosis created him, that their therapy also creates him, and that it creates him as a 'problem to be solved'. There is no politics in their clinical treatment. There's just 'the world' and 'the autistic' – value-free subjects whose interactions are precisely knowable.

They group categories of 'community helpers' on flash cards for Henry to match. They put paramedics, firefighters, and police officers together in this group. I ask the therapist to remove the police officer from the pile of community helpers. 'Police are not community helpers,’ I explain in a carefully neutral tone. ‘They are law enforcers. Sometimes they help you, and sometimes they harm you. It depends on which side of the law you’re on, you know? They’re not the same as firefighters and paramedics.’ She looks perplexed, but she removes it.

‘The values of the families are important in helping kiddos understand what’s important,’ she acknowledges.

I hate that word: ‘kiddo.’ Such a trivial word for a human being. They group other categories: furniture; ‘things in a park’; ‘things in the kitchen’; ‘things in the bathroom’.

Henry comes home from school with a sheet of green construction paper. On it are ‘opposite’ words. ‘Small’ and ‘big’; ‘left’ and ‘right’; ‘happy’ and ‘sad’; ‘high’ and ‘low’. ‘You see this, Henry?’ I wave the sheet of opposites in front of him.

‘Yes,’ he acknowledges.

‘This is power.’

He smiles at me with his moss-colored eyes. They have his father’s variable color, but my father’s shape. He collects a sippy cup full of milk and ambles off to the living room. I throw the opposites sheet in the recycling. But it is an empty gesture – the movement of a person who is only capable of selective symbolic acts – the movement of a person who is *not impactful in the world*.

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The province of Ontario subcontracts its autism treatment eligibility assessment to a private third party. The contractor hires a woman with no medical qualifications whose job it is to gather information about the autistic and feed it back to a psychologist, who then makes the determination on whether your child is eligible for publicly-funded treatment, all without ever having seen him. Only the most severe cases are approved for the intensive behavioral therapies. But their own research shows that only the milder cases 'benefit' from this therapy. If the woman who does the intake decides to write the report in a suitable way, the best-case-scenario wait time for this treatment in east-central Ontario is three and a half years. In three and a half years, Henry will be seven. At seven, intensive behavioral interventions are considered to be relatively ineffective. He is number 96 on the list. 'Why bother?' I asked the nice woman on the phone who called to say that he was eligible. 'Well, the new provincial government might allocate more resources,' she offered hopefully. But that didn't happen. It's been two years of waiting for publicly funded treatment already, and when the two years were up, they decided that everyone over five years old would be removed from the list. We got $8,000 instead.

'It's Mommy!' he delights when I walk in the door from work.

'It's Henry!' I respond, and I can feel the tenderness in my heart, my fear for the future, the precariousness of all this built around us. In the snap of a finger, it's gone. On my way home from Toronto, the commuter train slips into Bradford station. Outside the window, the neat rows of onions defy the natural variability of the unbuilt environment. They are the perfectly arrayed architectures of an autistic's hand. Unending repetition. Unending replication. Duplication. The human mind, stuttering over the fabrications of social life – our identically spaced concrete sidewalk slabs, identical rows of pressure treated fencing, unidirectional highways, geometrically intersecting runways, the unbroken yellow line that runs down the center of the road, the march of the high-tension power lines across the clear-cut forests, our repetitive labor in a capitalist political economy.

The neurologist orders blood work, to eliminate the possibility of Fragile X syndrome, for which there is no known cure. *No known cure*. I used to enroll him in studies when he was an infant, before we knew him at all. I believed in research, not to find 'cures' but for research's own sake. I draw the paperwork from the 'Henry' file folder – a big leather binder full of notes and papers that once held the collected archive of his father's immigration application when he came to Canada – a refugee from our crumbling American Empire. Fragile X syndrome means that Henry will not 'improve with therapy', although the province does not ask whether he has been tested for this as part of their criteria for determining who is eligible for treatment.

'Get the blood drawn at Sick Kids,' the neurologist had advised. 'They know how to draw blood from a three-year-old with minimal trauma.'

I lean against the kitchen counter, staring at the requisition in my hand. Something inside me is changing. Something in my infrastructure is collapsing. I can feel it.

I call into the living room, where Henry is lining up pink construction paper numbers cut in real time by his patient father.

'Hey, Henry! Do you want to go to Toronto and get your blood drawn?'

Henry replies slowly, 'Noooooaaahhhh,' and puckers his lips around the long rising vowel that he adds at the end.

'Me, neither,' I answer. I step on the foot pedal of the garbage can, and out goes the requisition form. I have never before done such a thing. As I step into the living room, Henry turns to look out the window. He stares through the rain into the street.

‘What do you see out there?’ I ask him.

He nods solemnly. ‘Yes.’

Something changed in me.

I stopped caring about research.

Research is repetition.

I want to survive.