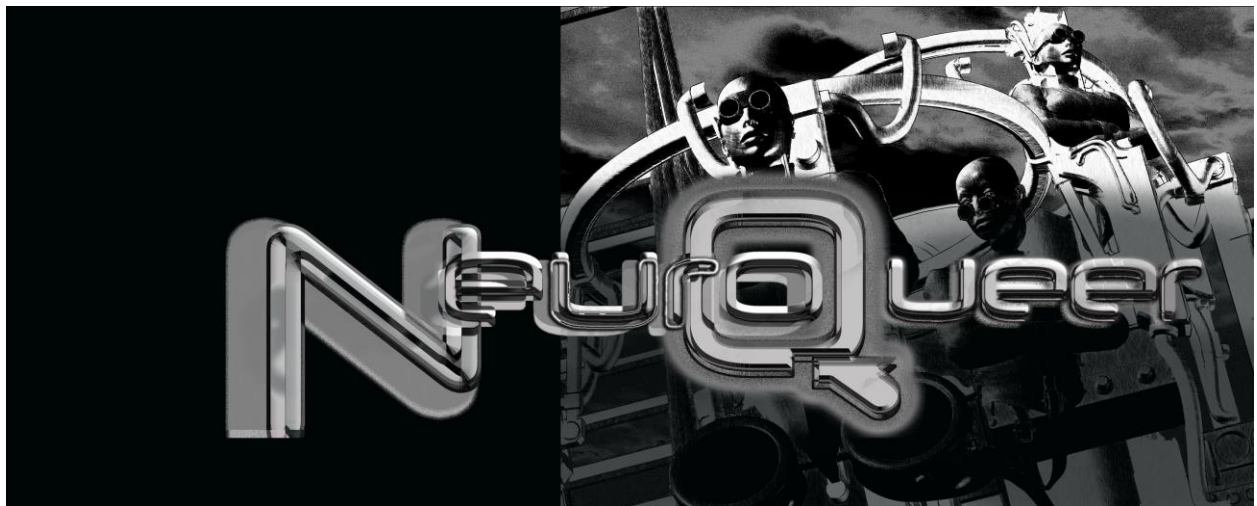
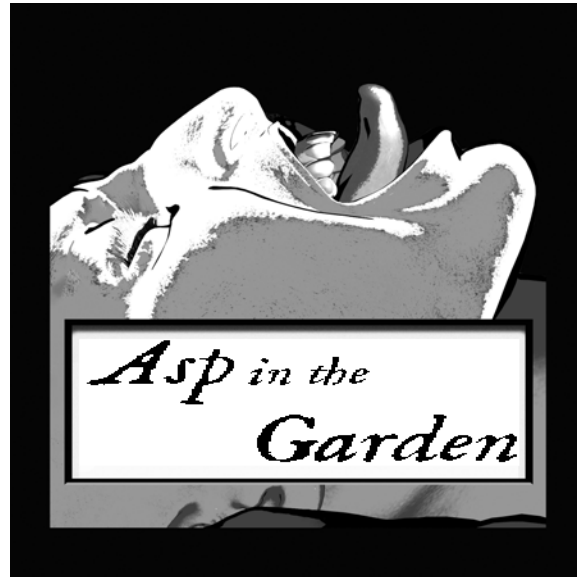


# NeuroQueer

## Editions

*Subverting the Dominant Paradigm  
of  
Neurodiversity  
One Semiotic Construct  
At a Time*





## **The New Panopticon**

*Selene dePackh*

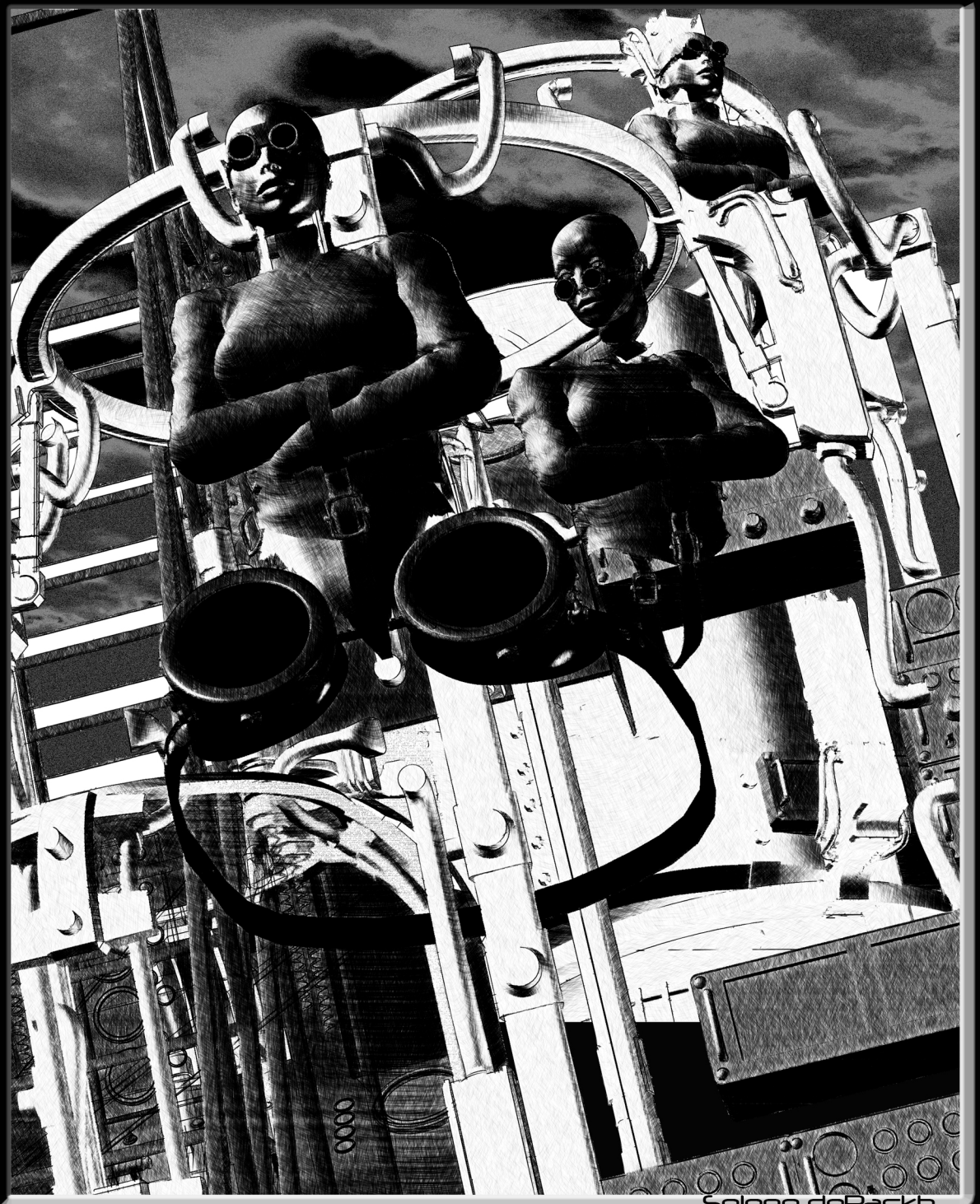
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**NeuroQueer Books**

# NeuroQueer

Because Enough is Enough



Selene dePackh

## The New Panopticon

The child is screaming “NO!” over and over as he is strapped, face down, onto the table. His tormentors step back; there’s a slight sound like a muffled bug zapper. The screams lose their words, dissolving into a shrill pitch of raw pain. We’re looking down voyeuristically from the ceiling. The video is grainy; the reproduced monochrome of the original shows a faint blue cast. The scenario will continue for another seven hours. Three days later the child will be admitted to the hospital with small patches of his skin burned away by electric shocks, in a state of posttraumatic catatonia.

This child has no constitutional protections where this takes place. The United Nations has voiced its opposition to the facility in the video, calling the device used on the boy an instrument of torture and a human rights violation. His citizenship, his human rights, are non-existent. The methodical, carefully documented torture he’s undergone is state-sanctioned, backed up by legislation and specifically approved by judicial ruling. He’s in the medical system of the Commonwealth of Massachusetts; he’s been diagnosed as autistic, and his crime was the refusal to remove his jacket when ordered to do so.

~

A group of protesters stands in the spring rain outside the gates of the Massachusetts state capitol building. The speaker, a youngish man with deepset, dark-circled eyes, holds up a plastic-wrapped photograph of the child’s burned leg as he speaks to the small crowd. He’s the personification of exhaustion battled by force of will. He’s Gregory Miller, a former employee of the Judge Rotenberg Educational Center, where the incident took place. He’s appeared on several segments of Anderson Cooper’s program within the last few weeks, each time in an intensely adversarial sparring match with JRC’s legal muscle and supporters. He’s spent the last twenty-four hours traveling across the continent to lend his backing to what he knows is probably another futile attempt to shut the JRC down, or at least ban the use of electroshock “aversives” on the people in its care. It’s 2012, and the regular attempts have been more or less futile since the late 1980’s.

A woman with an intelligent, owl-like face stands beside him, holding a sign. She’s Shain Neumeier, a newly minted young lawyer with the singleminded patience of autism. She’s an activist for the rights of labeled children. She’s meticulously chronicled the malpractice suit Andre McCollins’ mother brought against the JRC, attending every day of the proceedings. Her blog gives a record starting with the description of the footage the JRC fought to keep private, but which was shown on the first day of the trial that began in mid-April of 2012:

*...The jury witnessed approximately ten of the 31 shocks that Andre received that day, which were accompanied by him screaming in pain, yelling “no” repeatedly, and, at one point, saying the word “sorry” over and over again, all to no avail. All but one of these shocks, it was revealed, was for tensing up or screaming, in anticipation of or response to shocks or restraints, while the other shock he received was for failure to remove his coat...*

The coverage continues for dozens of pages, to the foregone conclusion of an undisclosed financial settlement before the final verdict. Her closing paragraph sums up the level of change achieved by the court action:

*...Even since their clients signed onto this agreement, the defense attorneys have insisted that JRC and the three individual defendants were not liable, and have defended Andre’s treatment as reasonable. They went so far as to say they were glad that the tape was shown in court, allowing the jury to see that Andre was receiving proper treatment...*

## The New Panopticon

Gregory and Shain are social media friends within my online circle of fellow autistic advocates; part of me wants to ask more closely about what they've seen. Part of me sees enough in the shadows under their eyes in the pictures they post of themselves, smiling with their real friends.

Prime among the diagnostic criteria for autism is having a small number of intense, well-defined interests; one of mine is cultural criticism. I'm compelled to make sense of my matrix. The field is now mostly limited to the confines of American academia. That, to my mind, is unfortunate; it offers one of the few avenues to understanding why the JRC remains in operation.

The light went on in my head as I was trolling the surreal virtual corridors of the JRC on its carefully crafted website. Among the well-lit hallways were side-channels where one could find documents like a legally nuanced attack on Gregory Miller and a self-serving description of the forced retirement of founder Dr. Matthew Israel after he was held responsible for the destruction of surveillance tapes which had been requested by a Grand Jury. It wasn't in the archives that I had my ah-ha moment, though; it in was the slick, flashy front office sales brochure.

The first part of my stroll brought me to the front entrance of the building. Somewhat larger than human-sized statues of Daffy Duck and Bugs Bunny loomed from either side of the inner portal. Room after room followed, each gaudier and more heavily colored than the last. Masks of cartoon characters, sun faces and huge animals leered from the walls. An animatronic "Yellow Brick Road" beckoned with rewards for good behavior offered in an over-lit in-house shopping mall stuffed with chintzy goods redeemable for tokens of obedience.

It all seemed intended to appeal to the parents of a nightmare child, a paradise more appropriate to an adult consumer contemplating a theme park vacation than to a disturbed kid. It would be a distressing sensory overload to any autistic person I know. The easy part of the answer might lie in the fact that the JRC gets roughly a quarter of a million dollars per "student" per year, mostly from state education funds, with a total annual budget of between fifty and sixty million. Many students come from disadvantaged backgrounds; the largest contingent has traditionally been from the state of New York. Those expensively sparkling surfaces shine like an anglerfish's lure in the abyss.

Many of the kids have been in multiple institutions; problems have been amplified to a steady-state frenzy. Whatever trust and affection might have been salvaged in the hardest cases has long dissolved into pain and rage. These are the sullen, unadoptable pets in the shelter, the ones that rub their faces raw against the bars, chew their own legs bloody and snarl dangerously when food is put in their cages. These are kids with schizophrenia, PTSD, cerebral palsy, ADHD, autism, bipolar disorder and who knows what other syndromes and developmental disorders the latest names are for the ancient differences of chronic misfits. The constant is that they're intractable to those responsible for them. Some inhabitants of the center have been quartered there long into adulthood.

Cheryl McCollins had said she chose the JRC because every part of it was under constant surveillance; she thought her son Andre would be safer with the unusually high level of supervision. He wasn't one of the hopeless ones, but he'd had problems in other facilities. He was gentle, but prone to outbursts and self-destructive behaviors from overstimulation. One of the JRC's big selling points is that no child is turned away; it touts itself as offering education and behavioral improvement to the hardest of cases—children with profoundly aggressive and self-destructive behaviors, often paired with limited verbal abilities. The JRC offers itself as a haven where those behaviors are prevented and changed for the better. Court-appointed advocates would review each case and give approval to treatment plans. Andre's mother knew aversives would be used to control his behavior, and she thought she knew what that meant.

Andre would wear the electroshock harness with its battery pack that could deliver about six times more voltage than is used to start a car, albeit at a much lower amperage. Electrodes would be strapped to his body, and staffers, operating under the rigid guidelines of center rules, would trigger painful two-second jolts by remote control as they were needed while he went through his daily routine. The use of the shock system, with its specified hierarchy of intensity levels, would be

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supervised at all times by a central management staff who could intervene and provide guidance at any point.

It was in the images of the surveillance nerve center that the JRC began to make sense to me. Observers sat in a curved line, watching rows of DVR screens feeding live from cameras tucked into every spot in the facility. These observers, paid employees called “Quality Control Monitors,” must have seen what was being done to Andre, there in their matching office chairs all the same pale green, there in the Eye of Power. The curve ensured that not even the watchers were hidden from one another, no line of sight obscured. This was the Panopticon— French historian/philosopher Michel Foucault had written about the late eighteenth century concept of the thing, but it was never built—this was the breathing beast itself, come to life in the silicon age.

Foucault’s analyses of knowledge and power are in some ways brilliantly simple, but getting to an understanding of them isn’t for the dilettante. Books have been written on the subject by far more qualified interpreters than I. I’ve read with an amateur’s diligence; I don’t have university training. I’ve never been able to complete college. The stress of conforming to the academic grid eventually grinds me under; my insights, for what they’re worth, are mine.

In his work on social systems of discipline, Foucault riffs off Jeremy Bentham’s 1791 design for an idealized prison with a central observation tower through which every prisoner could be observed within his own cell by unseen guards, who were themselves the subject of an overarching system of observation. The Panopticon (pan=all; optic=eye) serves as a model for disciplinary power itself—it isn’t a tool of that power, but rather a diagram of it, for Foucault. Power systems arise not from single forces or motivations, but by complex interactions of elements; where a successful symbiosis is reached, a power system develops. Elements in direct conflict with one another can still be complicit in maintaining the structures of effective systems. Without its intractable inmates, the perfect prison is meaningless; power must be exercised in order to exist, therefore if there are no inmates to discipline, they must be created.

The Judge Rotenberg Educational Center is a sinisterly elegant example of a self-sustaining power system. The man who created it has been banished from it, yet despite the Massachusetts legislature drafting a bill to close it or at least curtail its practices in every session for more than two decades, it continues to function. Sometimes the bill makes it out of committee; sometimes it’s voted on by both houses. Activists in New York have recently managed to constrict state funding for their young citizens. Sometimes a Massachusetts court chips off a piece of the JRC’s impunity; the most impressive has been a prohibition on the use of shock aversives on new students, while keeping them in place for the rest. As of my last reading, JRC literature seems not to acknowledge that limitation.

Power systems come in a variety of types; a basic self-sustaining type is the hazing ritual, in which a pattern of roles remains constant as individuals move “up” through the positions. An adherence to tradition, as an ideal concept if not necessarily an accurate one, brings participants together even against their personal well-being. A monarchy is somewhat self-sustaining; it’s dependent on members of a family for its highly-visible center. Constitutional monarchies, refined during the Enlightenment, address that vulnerability through carefully crafted legal structures. An authoritarian charismatic church is a system with an exceedingly powerful but dangerously unstable grip; its members may drink the Jonestown Kool-aid or go up in flames in Waco, but the structure dies with its central figure.

Cultural criticism teaches one to look for the roots of systems—their origins and evolution as they morph to meet the requirements of their environment. The Panopticon model is based in the discipline of the individual, and arose just after the American Revolution, when paradigms of power were being restructured by the ideals of the Enlightenment. Gridding off and mapping the wilderness, whether of land or human nature, so it can be brought to accept the harness of Civilization is the concept behind it. The person in his or her cubicle, whether a dormitory room, a prison cell, school desk or hospital bay, is placed within the grid; any deviance becomes immediately obvious. The individual is now easily studied within his or her clearly marked confines.

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The roots of the JRC offer insight into the entity it is. It's been formed as much by the failures of its creator as his successes; while it's left him wealthy, it's outgrown him. Matthew Israel began as a disciple of the notably gentle behaviorist B.F. Skinner. Dark things have come from Skinner's concepts, but he himself was hopeful his ideas would lead to more humane and enlightened teaching practices. Skinner advocated for positive reinforcement of desired behaviors, challenging the educational patterns of rote learning and punitive discipline dominant in his day. Dr. Israel adopted Skinner's concept of radical behaviorism, discussed here by Wikipedia:

*Radical behaviorism differs from other forms of behaviorism in that it treats everything we do as behavior, including private events such as thinking and feeling... [which] are seen as subject to the same principles of learning and modification as have been discovered to exist for overt behavior. Although private events are not publicly observable behaviors, radical behaviorism accepts that we are each observers of our own private behavior...*

*...The limitations of Skinner's views can be seen from his argument that it is: 'a step forward' to 'abolish' the 'autonomous inner man.' (Beyond Freedom and Dignity (1971) p. 215)*

There is no privacy in the cubicle—no place to hide from the observing eye, which extends itself to modify the very nature of the subject's feelings. The subject has no existence beyond the “black box” of his or her observable behavior—no inner life independent of potential control. The subject becomes his or her own jailer in response to skillful conditioning. In the hands of a man who rapidly moved beyond Skinner's gentle systems of rewards, Radical Behaviorism provided the perfect tool.

In the 1960's, Matthew Israel began in the pattern of a David Koresh or Jim Jones, trying to establish behaviorist communes based on Skinner's novel *Walden Two*. Apparently he lacked the charisma to carry it off; they eventually disbanded. The seeds of the New Panopticon were planted, however, when a three year old girl who'd been allowed to become something of a spoiled brat by her communitarian parents annoyed Israel. He applied “mild punishments” of a corporal nature, and found her behavior to be much improved by the “transformative potential” of physical pain.

In 1971, Israel began a day school in Rhode Island with two students—one autistic, one schizophrenic. He called it the Behavior Research Institute; multiple BRI facilities followed in several states. Teachers used spanking with spatulas, pinching (called “muscle squeezing”), ammonia pellets under the nose, withholding food, and restraint while enclosed in “white-noise helmets” on their problematic charges. This was the humane alternative to psychotropic drugs that BRI offered.

By 1979, New York state agencies were becoming concerned. By 1985, two students had died, one restrained face down who died of “natural causes” in that position, and another who suffocated as he was tied by plastic cuffs on his hands and feet, his face masked, as he was subjected to a white noise-generating helmet. Dr. Israel began to get his presentation in order, refining it to the point where his creation could continue operation despite opposition—even to the point that it could function without him.

In 1986, confronted by yet another challenge to his techniques, Dr. Israel went before Judge Ernest Rotenberg with one of his most desperately self-destructive charges, pleading that to shut his facility down would either ensure that she'd mutilate herself to death or force her to be drugged into an eternal stupor. The good judge saved the BRI, which would eventually be re-named in his honor. Dr. Israel's systematic parading of frantically self-injurious sufferers when his operations were threatened became more effective with the addition of pleading families testifying to the miraculous changes wrought on their monstrous kin. He refined his system of torture so that fewer deaths resulted, but activists continued to attack whenever an opportunity appeared.

The drill would be repeated for the next two decades—there would be some suit-worthy disaster or official investigation into the center, sometimes done more harm than good by overzealous bureaucrats, and the passion play would be re-enacted. The performance has always had the same conclusion; the wise judges and legislators shake their heads and solemnly declare that there

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is no other course of action... the center must continue in its grim task of saving those beyond salvation.

~

I'd like to open one behavioral black box for you and show you inside. The black box I have the key to has the label "autistic" written on it. I can only show you one, because I can just see into my own box. Although the developer of the standard diagnostic tools for defining autism, Simon Baron-Cohen, will tell you this is because I lack a Theory of Mind, I'll tell you it's because I'm honest. Matthew Israel has been honest in his way, too. He's never had any interest in the contents of the black boxes in his care, only what behaviors they emit.

His meticulously consistent theories have never wavered. Non-verbal black boxes are not allowed to emit groans; groans are unseemly, even if they are the only sounds a given black box is able to emit. One black box died of peritonitis after hours of BRI-specified corporal punishment imposed on her for emitting groaning behavior; another black box was repeatedly shocked under JRC court-approved treatment guidelines for emitting groans until someone broke ranks enough to notice she had a broken tooth.

Here inside my black box, I can tell you that I spend a lot of my time stressed to the point of nausea by everyday noises, conflicting conversations, loud colors and smells that combine in my synesthetic brain into an inescapable mass of negative stimulus. Most other autistic people I've discussed this with say they experience something pretty similar. I deal with this by attempting to generate an internal stimulus to counter the stress. The more oppressive the stressor, the more intense the counter-stimulus has to be to keep me from losing my mind. Unless I've had nothing to breathe but smooth days of blessed silence, I usually do something that draws blood at least a couple of times a week, even after decades of highly motivated attempts at learning self-control. This is described as common by my autistic associates.

Peering out through the eyes of my box, I looked at the virtual entrance to the JRC and felt my stomach knot. I said to myself, in my feral brain; "this is a setup." If there could be décor designed to trigger negative synesthesia, this would be it. I would clutch my jacket around myself and try to lose myself in its comforting pillow. Looming figures and eyes from every surface, colors arguing with each other at the top of their shrill or lugubrious notes, mechanical motions and serrated grins—I would struggle not to drool in terror like a trapped alley cat if I were forced down that gantlet of a hall, knowing there would be no mercy for me at the end of it but that of the heart of the New Panopticon.

I was not a good child once I hit adolescence. I was rebellious and promiscuous and usually under the influence of something illegal. I sheltered with hustlers of several genders and got paid to take my clothes off in a variety of situations. Sometimes I discussed the Brandenburg Concerti with my clients; sometimes I kept my mouth shut. I survived because when anyone tried to push me around, I pushed back. I was a pretty girl, and sometimes my pushback had an unexpected kick. I got through it because my parents were too busy with their own dramas to try to control me, and in those years the whole world was working on its rebellions. It wasn't obsessed with sniffing out autism in children. If I had happened today, I might well be walking that hellway.

I would be hearing those furiously-lit chartreuse and coral/magenta walls calling for my blood, and I would reach for that moment of calm in the concentrated blossom of self-inflicted pain. I would be looking for some surface against which to impact the distress expanding the bones of my skull, and then I would receive the Transformative Potential as my reward.

~

There've been quite a few stories written on the JRC and the question of what force keeps it open. A couple of them end with the scenario that plays out every time a bill to close the place gets to a vote in the Massachusetts House of Representatives. One of the more powerful state congressmen calls his brother, who drags out his non-verbal autistic adult son from the JRC in full electroshock regalia. There, in front of the chamber, he lets his son be free a moment. The son immediately begins to emit strange sounds and attack himself; his father then zaps him a good one and declares some form of "If I couldn't have this, I'd have to blow his brains out, because I love



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him.” The declaration of love and the term “blow his brains out” seem to be consistent across the various narratives.

No one describing this bit of twenty-first century bear-baiting has ever mentioned, to my knowledge, what might be inside the black box on display for all those flashing cameras and solemn legislators. No one mentions the high possibility that he is fully, even exceptionally sentient, as are most non-verbal autistics. He hasn’t had the benefit of the communication devices that have opened the door to that silent country. No one asks what might drive him to such a level of distress that it is easier for him to do deathly harm to himself than to endure such “love” uncountered by self-inflicted damage. No one wonders, or permits him or herself the terror of perhaps understanding, what the inside of such a black box must be like, that as soon as it scents any moment of freedom its first impulse is to seek the mercy of self-annihilation.

It’s a strong image to end on, but not the one I’d choose. I’m stuck with my relentlessly analytical thoughts; I have to ask not why the monster’s jaws stay open, but how it continues to be fed at ever-increasing rates. The New Panopticon grows constantly, but it needs its intractables, without which it can’t exercise its power. If intractability isn’t available, it has to be generated.

The raw material of intractability is becoming ever more plentiful. The success of the New York activists runs counter to the overarching societal trend. One bit of internet meme, found in late 2012 on the Facebook page of the father of an autistic child, shows the Autism Speaks puzzle piece with a black eye superimposed on the “head” and the phrase “What’s black and blue and showing up everywhere? 1 in 88—Are you scared yet?” The “one in eighty-eight” refers to one estimate of the rate of autism in the population, since raised even higher by another survey, to perhaps one in fifty. The “black and blue” meme is usually used for off-color jokes such as:

*What’s black and blue and yellow and lying in a ditch?*

*A blonde after the first date.*

This is the parent of a child who might have made it to adulthood unlabeled as anything but weird a generation or two ago, the same way I did. I could escape to my woods and watch minnows dart around in an inch of water for hours; I could go to my room and read for a weekend and not be diagnosed as anything more than introverted. I could be silent; I might be rude or arrogant or just shy. Now I’m a segment that doesn’t fit in the grid—something to be scared of, part of a faceless horde of malfunctioning puzzle pieces. I had behavior problems, not some sinister disease. I was tormented by bullies, but my parents didn’t wave a representation of assault due to my mental defects to the general public. I didn’t have to deal with that level of dehumanization. The ones who remain intractable in the face of it now have my respect. The shadows grow under the eyes of my friends who watch out for them.

One of the New Panopticon’s feeder conduits has been constricted by recent developments cutting off public payments to it by the State of New York for the “care” of children lucky enough to fall under its legal protection. The JRC’s response has been to send those sucker lines probing farther into the nation; it recently sent mailings to a number of Midwestern professionals under its fake-childish letterhead, featuring a digitally crayon-drawn sun and rainbow, with bruise purple and pea green dominant:

*Dear colleague:*

*The Judge Rotenberg Educational Center (JRC) is a residential special education school located in Canton Massachusetts, approved by the State of Illinois Board of Education.*

*Have you been searching for a residential education/treatment program that:*

- ***serves children and adolescents with developmental disabilities or severe behavior/psychiatric problems?***
- ***provides extremely effective, highly consistent behavior modification treatment that employs the widest range of available treatment procedures and has over 40 years of experience?***

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- ***minimizes or eliminates the use of psychotropic medication? has a near zero-rejection, near zero-expulsion policy?***

*If so, the enclosed newsletter may be of interest to you. The Judge Rotenberg Center provides residential services to students with emotional/behavioral problems or with developmental disabilities.*

*For more information, please call our admissions department at (781) 828- 2202, or visit our web site at [www.judgerc.org](http://www.judgerc.org).*

Heaven help the misfit children of Illinois.

~

This is a different world for kids; the stimulus is unrelenting. If a child has any tendency to wither or rebel under the inescapable digital and chemical bombardment of the Middle American home, he or she will be headed for the examination room. A child like I was would be pathologized; my behavior patterns would become symptoms. A parent with the level of understanding shown by the “what’s black and blue” father would seem to have little difficulty offering the problematic black box in his care to the Panopticon.

Once there, the intractability would be ensured. If there were anything but a few anecdotal “cures” produced by the JRC, its methods would become widespread and standardized, and it would no longer stand as the isolated citadel of symbolism it is. To return to Foucault—its failure is the reason for its existence.

This is the outpost at the edge of reason, the point of attack that must be taken before the others can be breached. Any other treatment of these human rejects can be held defensible in comparison as long as it stands. The Transformative Potential, and the phalanx of “therapies” arrayed in its shadow, await those who fail to fit neatly into the puzzle. Once we’re branded with our defects we’re no longer protected citizens; we’re under the rule of medical science in the service of the social structure. We mustn’t appear strange on the crowded bus, rocking ourselves or humming a self-soothing note to remain focused enough to find our stop amid the rush-hour confusion. We must swallow our panic in the shuddering, cramped, overlit elevator with its inescapable coded noises. The consequences could be far worse than the chilly stares we’re habituated to.

We must under no circumstances fail to comply with instructions we may only partly grasp even when we’re calm. The officer with a taser will protect the public; we’ve been informed of what’s appropriate. Our lives are not as valuable as those of actual members of society; those of us who dare step outside are at real risk from authority. We die in significant numbers at the hands of law enforcement who perceive our frantic stress-response as aggression. Our caretakers are regularly treated with compassion when they kill the most “burdensome” of us. The New Panopticon stands guard over the grid of acceptable modes of being; the authorities and constitution don’t protect those labeled as pathologically noncompliant. The JRC is a model of the machinery of modern social conformity. The price of deviance has rarely been more costly since the so-called Enlightenment. The New Panopticon serves as a threat and a warning; any of us who defy its ideals can be brought down. We couldn’t survive it.

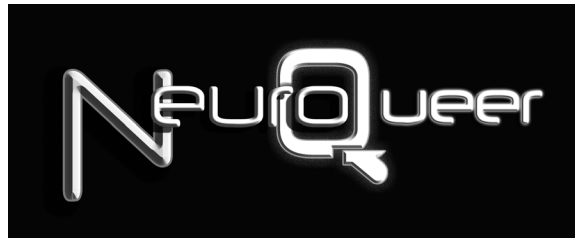
The New Panopticon gorges on discipline for its own sake. Its subjects have no existence other than as receptacles of punishment. Rigid grids of black boxes, having no rights or acknowledgement of sentience beyond those granted by the medical system of the center itself, are neatly aligned for torment. The court-approved “treatments” include “treating the antecedent,” which translates as any behavior which might lead to a disapproved behavior. Therefore, students are shocked for asking to go to the bathroom, and then shocked for wetting their clothes. If a teacher refuses to shock a child, he or she is given a write-up headed “Performance Improvement Opportunities.” Staffers, most with only a high-school education, are subject to the same relentless digital observation as the students. They report a level of depression and paranoia not too greatly exceeded by those on the other end of the remote control. The loop is complete.

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The highest level of art expressed by the JRC is the “Behavior Rehearsal Lesson.” I could not imagine a more elegant fulfillment of what Foucault calls a “Meticulous Ritual of Power.” It is used primarily on children who dare to usurp the center’s right to hurt them by hurting themselves. The child is restrained and then ordered to perform the self-harming action he or she is to be punished for—head banging, skin gouging, self-asphyxiation, etc. If the child refuses, he or she is shocked; if he or she complies, the shock is more powerful. The ritual continues until the child is frozen in complete immobility for the prescribed period.

Somehow, some inmates manage to stay sane enough to continue resisting. I try to conceive of myself having sufficient character to do that.

*Selene DePackh*  
2013



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