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Torture in the Name of Treatment: The Mission to Stop the Shocks in the Age of Deinstitutionalization

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For Silverio Gonzalez, Abigail Gibson, Linda Cornelison, Vincent Milletich, Danny Aswad, Robert Cooper, and unknown others broken down and killed at the Judge Rotenberg Center and inside institutions everywhere—you are not forgotten and your lives were worth living.

Inhumane Beyond All Reason

Half an hour's drive south of Boston sits a facility that the United Nations has specifically condemned for its use of torture, and that Massachusetts' own state agency for people with developmental disabilities described as

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“inhumane beyond all reason” [1, 2]. It isn’t a historical site, kept intact only as a memorial for its victims and a warning for the future. Nor is it an illegal operation that’s survived through secrecy and corruption. Instead, the Judge Rotenberg Center, a self-described residential school and treatment center, continues to use an inhumane, behaviorist approach in working with youth and adults with disabilities, as it has for over forty-five years, with the open complicity of and funding from Massachusetts, New York, California, and several other states across the country [3].

The Judge Rotenberg Center’s most infamous form of abuse is electric shock—a human dog shock collar in the form of a backpack that about one-fifth of its residents are forced to carry around with them throughout the day. Despite the singular attention given to this particular aspect of its program, though, the facility had been open for almost two decades before it started electrocuting the people in its care. Both its origins and its practices during that initial period make it clear that the device itself wasn’t what had made the program particularly bad. Rather, if any facility were to become the only one in the country, maybe even the world, to punish autistic and other disabled people with electric shock, it would hardly be surprising for it to be one started by Matthew Israel, a protégé of infamous behaviorist B.F. Skinner who wanted to bring his mentor’s fictional behaviorist utopia *Walden II* to life but needed a captive audience to do it, and one which had already killed multiple residents through abuse and neglect before [4].

The general public only became aware of and (briefly) galvanized in opposing JRC upon seeing footage—finally made public in April 2012—of a young man named Andre McCollins being repeatedly shocked while restrained face down, and this after numerous other media exposés of the practice in the decades since JRC’s founding. Autistic self-advocates, and disability rights advocates more generally, have been both aware of and actively trying to shut the program down for much longer. Our opposition goes beyond the program’s egregious practices in and of themselves. State agencies, state legislatures, courts, the federal government, and organizations such as Autism Speaks that claim to support us have all either refused to take a meaningful stand against JRC, its philosophy, and its practices, or have actively protected or promoted them. This speaks not only to how difficult a task it has been and will be to shut down this one

alleged outlier, but to how little members of our community are valued, and therefore how significant the barriers and dangers are, or are likely to be, in other areas of advocacy.

Tearing Down the Walls They Built

Places of confinement—like residential schools, group homes, mental hospitals, and prisons—have always sought people considered weird, scary, and subversive to keep inside their walls since their advent. Our history in autistic self-advocacy and disability more generally is riddled with institutions, which we know as places of constant violence, forced treatment, involuntary medical experimentation, isolation, and layers upon layers of abuse—even and especially the ones that seem nice on the outside. There were the Fernald radiation experiments where researchers recruited institutionalized disabled children for a “science club” so they could investigate the effects of radiation by feeding them irradiated cereal without their knowledge. There were the Tuskegee experiments where researchers deliberately withheld treatment from low-income Black workers with syphilis so they could study the course of the disease. There were the developmentally disabled men confined in a bunkhouse in Iowa and forced to work for decades in a turkey slaughter factory for a subminimum wage. And there were the Willowbrooks and Pennhursts—large-scale, state-run institutions where thousands of people with disabilities were incarcerated in squalor and subject to all manner of abuses.

The history of prisons as places of confinement is old and dark, the distinction between disability institutions (places that are supposed to provide care) and penal institutions (places that are supposed to detain and punish) constantly blurring until it’s hard to tell much of a difference.

Ableism is the idea that only some people’s brains or bodies are healthy, whole, functional, and valuable in society, and that the rest of us are broken, defective, inferior, and unworthy. Put into practice, ableism values us based on whether we seem “normal” based on constantly-shifting goalposts, whether we work and produce according to conventional measures, and whether we can maintain the social order in a profoundly racist and classist society.

JRC and institutions like it operate knowing that most people will readily accept myths about disabled people's incompetence, inferiority, and brokenness. It's easier to dismiss us as uncontrollable, violent, and aggressive for no reason than to recognize that many of us have survived years of trauma caused by compliance training, rejection, isolation, and serial predators. It's easier to believe that nondisabled family members and "experts" know what is best for disabled people than to believe us speaking for ourselves. It's easier to lock us away instead of doing the work necessary to make sure we can all belong and exercise autonomy. At JRC, fear, revulsion, pity, and hatred pervade the place so strongly that torture can be resold as "extremely beneficial and lifesaving [treatment]" [5] that "allows [JRC residents] to integrate into the community, which is an [Americans with Disabilities Act] requirement" [6].

JRC's abuses represent some of the most extreme forms of behaviorist violence. Yet as community pioneer Mel Baggs has observed repeatedly over the past two decades, JRC is not the worst institution to have ever existed, but rather, represents thousands of institutions where staff can abuse, torture, and murder disabled people with impunity and in silence [7]. An institution may be as small as a single person, Baggs has written, so long as that person lives under the control of others [8]. Survivors of institutionalization outside JRC, including both Baggs [8] and activist and commentator Cal Montgomery [9], often describe aesthetically pleasing and seemingly progressive institutions as the most dangerous [10, 11]. In this, JRC's threat becomes clearer—disguised by flashy and bright Big Reward Store and Yellow Brick Road rooms; clean and pressed shirts and ties for residents; and newly painted group homes in the neighborhoods surrounding the main building.

Worse, JRC's marketing model holding out its ostentatiously decorated rooms as proof of its benevolence, ironically ignores that a large portion of the people confined there are much more likely to be overwhelmed and overstimulated, sometimes even to the point of physical pain, by the design of those rooms. Non-autistic people, and especially neurotypical people, also seem woefully unaware of these particular issues, despite the increase in autism "awareness" campaigns of the past several years.

JRC has also always been an atypical private institution, in its largely negatively racialized population and its constant, domineering surveillance

over both residents and staff. Over the past five decades, JRC's population has shifted. Its residents were once almost entirely people with developmental disabilities with intense support needs. Now, its residents include large numbers of people whose primary neurodivergence is psychiatric disability or mental illness, many of whom arrive through referrals from the juvenile criminal legal system. According to the National Center for Education Statistics [12], in the 2015–2016 school year, JRC's school-age population was 81.5% Black or Latinx people, with all categories of people of color or racial minorities combined comprising 87.4% of its population.

This particular blend of ableist and racist targeting challenges the historically white autistic community and neurodiversity movement, by calling into question how and why so many activists working publicly against JRC have little to no understanding of the racial implications of JRC's population and increasingly overt ties to the criminal punishment system, including transfers from Rikers Island [13]. Further, those committed to anti-racism work, particularly our white and nondisabled allies, must also contend with JRC's exploitation and scapegoating of low-paid line workers who are largely immigrants of color and often the only JRC staff ever prosecuted for physical abuse (but never the shocks) while the largely white administration avoids any meaningful consequences. JRC, like all institutions, is the inevitable product of a society of prisons, which exist as a tool of social control for eradicating undesirable people and enabling appalling abuses (as punishment, treatment, or both) on those powerless to stop them from happening.

In recent years, National ADAPT, a grassroots direct action disability rights group consisting primarily of anti-institutionalization physically disabled activists, has organized multiple actions targeting JRC both in Massachusetts and in Washington, DC. ADAPT's anti-JRC work has been led in large part by the wisdom of several autistic leaders, including Anita Cameron, a proudly queer Black activist who has been organizing with ADAPT for decades, and Cal Montgomery, longtime autistic writer and activist who is also a survivor of multiple institutions. And while we haven't been able to participate in most of ADAPT's actions, we have supported and amplified their efforts in every way possible.

Now the fight against JRC is firmly in the cross-disability community's arena, and no longer the sole dominion of the small but mighty autistic self-advocacy movement, where generations of neurodiversity advocates have supported one another in fighting it. More promisingly, younger activists and advocates are now joining forces to renew the struggle against JRC and similar sites of violence, following in decades of work to tear down institution walls.

Though We Be but Small, We Are Mighty

Though we grew up on opposite sides of the country, we shared many interests and experiences that both drew us to the issue of abuse at JRC, and that made us compatible, personally and professionally. While neither of us had been institutionalized in a program like JRC nor spent significant parts of our school years in a segregated special education setting, both of us had been targeted for disability-related harassment and discrimination by school officials as well as peers. As bold, outspoken, unconventional people from the start, we had frustrated and been frustrated by neurotypicals who'd valued compliance and conformity for their own sake and seemingly above all else, and whatever victories we might have won in these conflicts tended to be moral rather than actual.

Both of us also had tendencies to become interested in, and by neurotypical standards obsessed with, dark and violent subject matter, but from a perspective of wanting to solve the problems that we saw. Lydia, for instance, had had a longstanding interest in the terrorist attacks of September 11, 2001, and the U.S. government's subsequent repression of Arabs and Muslims as part of its so-called War on Terror. And while by this point Shain was no longer as fixated on the horrors of animal experimentation as they had been as a child, they'd continued exploring themes of abuse and oppression through fiction for lack of concrete ideas on how to confront them in reality.

We joined the decades-long fight to end aversives and close JRC in 2009, around the same time that we were both entering the autistic activist community in Boston. Lydia, who had grown up in the Boston metro area and known they were autistic since early adolescence, was a member of the

Autistic Self Advocacy Network (ASAN) Boston chapter. By then a high school student, they were already drafting, then introducing, a bill in the Massachusetts state legislature that would have mandated police training on autism. Lydia had connected with ASAN when they learned about the neurodiversity movement from autistic activists' criticisms of the charity Autism Speaks, and began reading blogs by activists like Bev Harp (Square 8, aspergersquare8.blogspot.com), Mel Baggs (Ballastexistenz, ballastexistenz.wordpress.com), and Kassiane Asasumasu (Radical Neurodivergence Speaking, timetolisten.blogspot.com). Lydia's early activism included organizing mass opposition to criminalization and restraints targeting autistic students in Arizona, Alabama, and Kentucky.

Shain, meanwhile, had spent much of their childhood undergoing, recovering from, or trying to avoid involuntary psychiatric and surgical treatment. However, they only learned they were autistic as an adult, at about the same time that they were applying to law school. Although they had initially joined online message boards like WrongPlanet and Aspies for Freedom to learn more about their autistic identity and find friends, they soon ran across information on the widespread, systemic abuse that autistic and other disabled people face in the name of treatment.

It was in this context, and in the aftermath of several recent and highly publicized exposés of abuse at JRC, that we separately became aware of the abuse going on in our own figurative backyard. As with other things in both of our lives that had horrified and fascinated us, we started painstakingly collecting information on the issue, then acting in whatever way became apparent—writing articles, speaking publicly, testifying at hearings—first on our own, and then, increasingly, collaboratively.

New Resistance and Organizing Against the School of Shock

While attending law school in Boston, Shain threw themselves into challenging JRC, confronting Massachusetts Governor Deval Patrick about JRC during a public appearance, authoring two papers on legal strategies

to stop JRC, leading a session at the annual Rebellious Lawyering Conference, and giving an invited presentation at the Symposium on Ethical, Legal, and Social Implications of Autism Research.

In April 2012, Shain attended nearly the entire medical malpractice trial against JRC for torturing Andre McCollins, sitting only feet behind Matthew Israel while taking painstaking notes for the public [14–20]. During that trial, video of JRC’s shocks first aired publicly.

Shain also began working with troubled teen industry survivors, including with the Community Alliance for the Ethical Treatment of Youth (CAFETY). While at CAFETY, Shain took a leading role in organizing what would be one of the largest anti-JRC protests in the next decade. In July 2012, outraged by the McCollins video, hundreds of activists, many forced treatment and institutionalization survivors, gathered in Boston for a State House rally, then reconvened outside JRC, marching through rain and barricades.

In Fall 2012, Shain moved to Washington, DC to work as CAFETY’s policy associate. Shain took the lead role in drafting and presenting a report on institutional abuse targeting youth for the United Nations Special Rapporteur on Torture’s expert consultation on torture in healthcare settings. There, Shain connected with Lydia, who authored a follow-up submission on JRC on ASAN’s behalf. Lydia’s report [21] later turned into an article, “Compliance is Unreasonable: The Human Rights Implications of Compliance-Based Behavioral Interventions under the Convention Against Torture and the Convention on the Rights of Persons with Disabilities,” published in a compilation edited by the U.N. Special Rapporteur on Torture [22]. ASAN meanwhile invited Shain to author a brief history of JRC for its groundbreaking anthology on the neurodiversity movement [1].

During the same period, Lydia worked alongside advocates from ASAN Boston to lobby Massachusetts lawmakers for measures to limit and stop JRC’s abuses. Lydia also began to curate information about JRC for a dedicated page on their blog Autistic Hoya, which would later become the JRC Living Archive and Document Repository (<https://autistichoya.net/judge-rotenberg-center>).

Throughout 2012 and 2013, former JRC employee Gregory Miller wrote a series of widely publicized anti-JRC essays [23, 24]. He described

vicarious trauma from witnessing abuse and being coerced to participate before realizing the full extent of the harm he was responsible for, his letters to JRC condemning it, and his resignation. Miller's Change.org petition [23] amassed over 200,000 signatures, and incited another rally at the Massachusetts State House. There, Miller spoke alongside Cheryl McCollins, who by now had been barraged with constant exposure to the video of her son's torture. The year saw three anti-JRC rallies before the July 2012 demonstration. Meanwhile, Lydia worked with Miller and others to present about JRC's abuses for various autism and disability advocacy organizations.

In January 2013, we planned a demonstration against the U.S. Food and Drug Administration's reticence to regulate the shock devices, set at its Maryland headquarters. The night before, we huddled in a college dorm building while creating colorful signs—Stop the Shocks, People Not Experiments, No Compromise on Torture, Disability Rights are Human Rights, Ban the GED (JRC's shock device). Three others joined us on the traffic island across from the entrance. It was a lonely day for us five, and nearly as many Homeland Security police cars arrived to watch us.

One month later, in February 2013, Lydia received an email containing a message from a survivor hoping to discuss JRC. Lydia replied to the letter writer, received permission to publish it anonymously, and began circulating it to increase consciousness of JRC's abuses [25]. Roughly simultaneously, Massachusetts quietly filed a motion to void the 1987 court order enshrining legality of the shocks.

Come 2014, and rumors that FDA officials would finally consider banning electric shock aversives, we were split with Shain in Oregon and Lydia in Jordan. The FDA announced a public hearing on the possibility of banning the shocks in April 2014. Shain mounted a campaign to raise funds to cover their and later Lydia's travel to present testimony. Before our flights, we worked for two nights across continents on our first anniversary preparing detailed, heavily-cited comments in attempts to pre-emptively bury JRC's supporters in research.

Amid hours of testimony from advocates who'd worked in a coalition bridging policy, research, and activism, and JRC's sometimes screaming supporters, survivors Jennifer Msumba and Ian Cook commanded

full attention from all present. Msumba's testimony, delivered by video, described intense pain, burns, and post-traumatic stress disorder caused by repeated shocks to punish and control her. Cook opened his testimony by announcing that since leaving JRC, he has come out as transgender, noting defiantly JRC's use of his deadname while confined there. His conclusion could compel no response from JRC's supporters—"I was in an abusive relationship two years ago, and part of why I fell prey to it is that JRC instilled a lesson in me that it is okay for people to hurt me so long as they are trying to correct me" [26].

Since that hearing, we have collaborated to support many other disabled people in organizing direct action and submitting testimony against the torture, drawing constantly on the leadership of survivors like Msumba, Cook, and Terri Du Bois, who have all spoken out against the horrors they survived and witnessed.

In October 2014, sensing declining interest in anti-JRC activism, Lydia hosted Shain and Msumba for a panel on institutional abuse targeting disabled people, which received modest press coverage amid announcements of Msumba filing a lawsuit. In August 2015, we organized community testimony against JRC for the perennial Massachusetts hearing, but once again, the legislature refused to act. In December 2015, we presented on JRC and other institutions' abuses to a packed room at a national conference.

In April 2016, two years after its hearing, the FDA finally announced a proposal to ban the shocks. Along with many others, we pushed for massive public pressure to finalize the regulation as law, but the FDA never made a decision. By 2017, the presidential administration changed amid conflicting indications about federal agencies' desires to either accelerate or severely delay their regulation-making powers. Apart from ADAPT's large-scale public actions in October 2016 (at JRC) and March 2018 (targeting the FDA in Washington, DC, and Maryland), public attention to and interest in JRC has largely faded.

In June 2018, when a Massachusetts probate court judge ruled in JRC's favor in the lawsuit stemming from 1987, one major door closed.

Freeing (All) Our People

Even after what seemed like an increase in the awareness of and activity to end abuse at JRC, it remains open. Worse, restraint, seclusion, food deprivation, physical assaults, abusive behavior modification therapies, and institutionalization of disabled people remain legal and widespread outside of JRC.

There is some reason for hope of progress at this point, at least as it concerns JRC in particular. As of the time this piece was written in early 2019, the U.S. Food and Drug Administration recently announced that it plans to finalize the proposed ban on the use of shock devices. Furthermore, although JRC won the most recent legal battle against the state of Massachusetts over the government's attempts to ban or even just limit the use of aversives, the state is in the process of appealing this decision. JRC has also lost its staunchest ally in the state legislature after former representative Jeffrey Sanchez, whose nephew Brandon has been at the facility for decades, was defeated in the 2018 primary elections. Meanwhile, there are both ongoing and forthcoming lawsuits by survivors and their families seeking justice, as well as by disability advocates hoping to bring about systemic change.

At the same time, though, there have been several recent instances of JRC staff being caught hitting or beating the people in their care that have resulted in criminal investigations and convictions. These incidents demonstrate that JRC's culture of abuse goes much deeper than its use of electric shock, and that even assuming the shock ban comes into effect, advocates will need to continue to press for JRC, along with other, similar breeding grounds for abuse, be investigated, defunded, and ultimately shut down.

While policy advocacy and lawsuits are two avenues through which to work toward these goals, the effectiveness of laws still hinges on the framework in which they're written, the ways in which they'll be interpreted, and the stringency with which they'll be enforced by judges, licensing agencies, and other decision-makers. Were it possible to get a law or policy banning the use of not only electric shock devices but all the forms of aversives JRC

has used as part of its behavior modification program, this would still not fully address the core problems that JRC represents. Namely, even many opponents of the egregious types of aversives used there still see behavior modification aimed at making autistic people be more compliant as worthwhile. Nor is there nearly as widespread a rejection of institutionalization as a whole except within small and still relatively powerless communities of dedicated advocates. To create a society in which not only is there no JRC, but also nothing remotely comparable, these more accepted goals and practices have to be challenged just as unequivocally as shock devices.

The good news is that this isn't just a job for lawyers, lawmakers, and protesters, or even for others with skills like writing letters or making phone calls that are often associated with political advocacy. While people in these roles can and should continue to lend our skills whenever possible, it also falls to educators and service providers to challenge the beliefs and systems surrounding autistic youth that allow abuse up to and including the type that occurs at JRC to continue. These same professionals can also change their own practices to honor the autonomy, dignity, and humanity of the people they work with, and train their colleagues to do the same. Likewise, parents of autistic people have the opportunity and responsibility to use their voices as culturally recognized authorities on autism to defend their children against coercive, abusive attempts to make them comply with neurotypical norms for their own sake. Researchers can also shape the types of interventions that are further explored, funded, or abandoned by studying not only what interventions are most "effective" but what they're most effective at, and conversely, what outcomes are worth effecting for the well-being of the people most directly involved. Meanwhile, journalists and artists can shape cultural narratives around disability, shifting them away from their current direction of encouraging a return to confinement and forced treatment in institutions and instead toward one that will make even more common forms of abuse seem unimaginably horrific within a generation.

The results of these efforts would go beyond the absence of coercion and abuse, though. In concrete terms, these positive changes could, should, and must include a service delivery system that's truly directed by neurodivergent people in every sense. For instance, to the extent that any sort

of congregate care or living facilities would still exist, they would be peer-run, non-hierarchical, and truly voluntary. Service recipients would have a meaningful ability to leave, choose different supports, or refuse placement in one at any point, without caretakers being able to override this decision or agencies being able to deny them services in their homes and communities. This would require directing resources away from institutional facilities and coercive practices, and creating a new system that prioritizes and in fact guarantees community integration and self-determination.

While most of these approaches and solutions can't shut down JRC on their own, they will be crucial in creating a society in which it's impossible for any place like it to exist, and more generally, where autistic people can live safely and on our own terms.

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