Inhumane Beyond All Reason

The Torture of Autistics and Other People with Disabilities at the Judge Rotenberg Center Shain Neumeier, J.D.

They call what the Judge Rotenberg Center does to people with disabilities treatment. That's why it still happens.

For over forty years, JRC has used painful methods of controlling the behavior of Autistic people, people with intellectual disabilities, and people with mental illnesses. This includes long-term mechanical restraint to a four-point board, food and sensory deprivation, social isolation, and, most infamously, electric shock. Labeling these methods as aversive behavioral modification, and even aversive therapy, JRC has not only been allowed to use them on their students – both children and adults – but has in fact received the approval of parents, state agencies and courts in doing so.

JRC follows what its own administration has called a "radical Skinnerian" behavioral approach, relying on the principles of operant behavioral conditioning – namely, arranging an individual's environment to provide rewards for appropriate or desired behavior and punishment for unacceptable or unwanted behavior. JRC's founder, Matthew Israel, became fascinated with these principles after taking a class with B.F. Skinner, a pioneer in the field of operant conditioning, and reading his book, a novel called *Walden Two*, portraying a utopian society that was based on the ideas of behavioral psychology while he was a student at Harvard University. He in fact decided that it was his life's mission to create such a utopian community, and, to this end, worked under B.F. Skinner during the course of his studies.

Despite the fact that Skinner's actual research was performed on rats, pigeons and other animals, Israel, after graduating from Harvard, went on to try to apply these concepts to people following his graduation in 1960. Specifically, in the next decade, he started two communes in the Boston area that attempted to replicate the society that Skinner had written about in *Walden Two*, as well as an organization called the Association for Social Design, which had the aim of creating communes like this in cities across the world. In the following years, however, these efforts fell apart. While Israel attributed this to personal conflicts among the people living in the commune, others who lived in the communes and who were part of the organization reportedly became disillusioned with his vision, which required them to live their lives correcting one another's behaviors.

That being said, Israel's time in the communes gave him an experience that contributed significantly to his decision to start a behavioral modification program for children. Specifically, at the Arlington commune, he lived next to a housemate whose three year old daughter, Andrea, engaged in rude and sometimes violent behavior such as intruding into his room and whacking people over the head with a broom, as well as more typical childhood behavior such as screaming and crying. With his housemate's consent, he started to use operant conditioning in order to address these behaviors, rewarding her by giving her treats and going on walks with her when she behaved, but flicking her on the cheek when she acted out or cried at being punished. After a number of weeks of this, he only had to look at her and shake his head for her to stop doing something, and in this way became what he would later call a "charming individual."

Despite the fact that Skinner himself did not support, and in fact actively opposed, the use of punishment as a means of behavioral modification, Israel drew upon the methods he had used in correcting Andrea's behavior in forming and running the Behavioral Research Institute, which would later become JRC, in 1971. Originally a day school located in Providence, Rhode Island, BRI began with only two students, one of whom was Autistic and one of whom was diagnosed with schizophrenia. Over the next several years, it opened up residential homes for its students in other parts of Rhode Island, and, eventually, in Massachusetts. It also opened up a second facility under the same name in California in 1977.

As it has since, the program relied on rewards and punishments for specific target behaviors to the exclusion of psychotropic medication. BRI rewarded students for good behavior with verbal reinforcements, food and toys. On the other hand, at the time, its repertoire of punishments, or aversives, included things like spanking students with spatulas, giving them hard pinches or muscle squeezes, spraying them in the face with water and breaking ammonia pellets directly under their noses. The program also involved the use of physical and mechanical restraint on students, both in emergency situations and for punitive purposes. Even at the outset, these punishments were used not only for aggressive and self-injurious behaviors, but in response harmless ones such as crying and failing to follow directions, which it classified as "noncompliant," "disruptive," and sometimes bizarrely "health dangerous" behaviors. The idea behind this general use of punishment – which JRC uses even now to defend it – is that successful operant conditioning requires that a person's entire environment be altered in order to provide rewards and consequences for behavior, including minor or seemingly harmless ones. In particular, it emphasized, and continues to emphasize, the need to address so-called "antecedent" behaviors, or harmless behaviors that it said could lead to or were an alternate form of target behaviors.

Even before BRI began to use electric shock, many opposed its use of aversives. Disability rights advocates argued that its use of aversives constituted abuse in any amount and that there were other, more humane and community-based alternatives available, even at the time. Additionally, in 1979, investigators from two New York agencies visited BRI as part of their oversight duties on behalf of New York students attending the program, and reported it to be the "singular most depressing experience that team members have had." In particular, it noted that students exhibited red skin and scrapes from BRI's use of corporal punishment, and that they were "controlled by the threat of punishment."

Despite these criticisms, professional organizations like the American Psychological Association openly supported BRI's use of aversives, saying that treatment providers should have the option of using them to address aggressive and self-injurious behaviors. B.F. Skinner himself, despite his well-known objection to punishment, came out in support of his protégé's work, claiming as late as 1987 that some people with severe developmental disabilities who exhibited dangerous behaviors could not be reached by any other method. According to Israel, Skinner's views on the subject were much stronger than that, in that apparently, when he had shown Skinner video footage of his working with BRI students and the type of behavior they engaged in, Skinner had responded by saying, "I didn't know. These aren't people; they are animals."

BRI's strongest support, however, came from parents of students attending the program. This is how it managed to defeat an attempt by the Massachusetts Office for Children to close it or otherwise stop its use of aversives. After the OFC, which had licensing authority over the program, banned further placements of students at the program in the aftermath of a student's death there, BRI and a number of parents whose students attended it brought a series of lawsuits, which eventually ended up before Chief Justice Ernest Rotenberg of the Bristol County Probate Court in Massachusetts. In response to BRI's bringing a self-injurious Autistic girl before him, Judge Rotenberg ruled in what is called a substituted judgment hearing that the child, who was legally considered unable to make decisions for herself as both a minor and a person with a severe disability, would choose to continue to undergo the aversive program at BRI if she was in the position to do so.

While the litigation continued even after this decision, the parties eventually settled in 1987. The outcome of this was a consent decree, under which the OFC bound itself, and any other state agency that would have licensing authority over BRI's treatment practices, to not interfere with BRI's operations as long as the program had a court-approved treatment plan for every child on which they wanted to use aversives. Court approval, according to the consent decree, would depend on parental consent, a treatment plan developed by BRI's clinicians, the opinion of two oversight committees, and the same substituted judgment hearing process that Judge Rotenberg had used in deciding to order the continued use of aversives on that first autistic child who came before him.

This attempt at oversight was, and continues to be, insufficient to protect children and adults from the misuse of aversives at the program. JRC's certification reports in recent years have revealed that the mandatory oversight committees haven't even been meeting regularly, let alone carrying out proper individualized reviews of treatment plans. Furthermore, both judges hearing the cases and attorneys appointed to represent the interests of JRC students independent from their parents or doctors regularly accept JRC's proposed treatment plans by default, even in instances where there has been testimony by experts showing that this treatment would be completely unnecessary and inappropriate. The result of this is courts approving treatment plans that include the use of aversives and that can be changed to include entirely different behaviors without further approval.

In spite and on top of all of this, the mere existence of the consent decree has given JRC and its use of aversives legitimacy, and worse, enforceability. Not only has JRC been able to market and defend its practices to the public as court-approved by individualized review, but it has also been able to use it to stop the state of Massachusetts from interfering with their use. In particular, in the nineties, it sued the state Department of Mental Retardation for making another attempt to ban it from using aversives and to ultimately close it down. The case went all the way to the highest court in Massachusetts, the Supreme Judicial Court, which also sided with JRC, forcing DMR to pay huge amounts of attorney fees and to temporarily lose authority to regulate the program in punishment for what it found to be contempt of court. Since then, state agencies have been wary to even enforce regulations that JRC has actively violated, let alone take any more aggressive stand to protect the rights of JRC students. For instance, when a former JRC staff member attempted to report abuse and neglect of students to a state agency specifically

charged with investigating such incidents, he was told that they could do nothing, since the use of aversives that he was reporting were legal.

Both legal and parental support for the program has continued even after a slew of preventable deaths at BRI throughout the 1980's, starting with that of twenty-five year old Robert Cooper in 1980, who died from a bowel obstruction after BRI failed to provide him with medical treatment before his condition became fatal. The state neither found nor held BRI responsible for his death. Five years after that, the situation repeated itself when Vincent Millitich, a student with a seizure disorder, asphyxiated after having a seizure while being restrained for "making inappropriate sounds," with his head in a helmet and forced between the knees of a staffer and plastic cuffs on his hands and feet keeping him in his chair. While his death led to OFC's attempt to close BRI and a later negligence lawsuit resulted in a judgment against BRI and some of its doctors, the program was officially cleared of responsibility for Millitich's death.

The relevant authorities made the same call when it came to the death of Linda Cornielson, a 19 year old nonspeaking woman with a developmental disability, in 1990. Cornielson, whose mother later said she had had no prior stomach problems, had been clutching her stomach in pain and refusing to eat while at BRI. The treatment staff thought that she was acting out, and proceeded to treat her symptoms as a behavior problem. Over the course of the two days leading up to her death from a perforated stomach ulcer, staff repeatedly used aversives – namely, muscle squeezes, spatula spankings, pinches and ammonia pellets - on her, including 57 such applications in just the four hours before she died. In an investigative report after the incident, the Department of Mental Retardation concluded that what they had done to Cornielson at BRI had been "inhumane beyond all reason" and had violated "universal standards of human decency." Even with this damning language, and with a verdict for Cornielson's family in a negligence lawsuit, the state did not, in the end, hold BRI responsible for her death. In all, six students have died at the program, and, in five of these cases, the most that it has had to face in terms of consequences has been civil lawsuits for money damages.

The one exception to this impunity came in the form of the state of California's response to the death of 14-year old Danny Aswad, a student with intellectual disabilities, while he was mechanically restrained to his bed facedown for over an hour at BRI's west coast facility. Even though the coroner had listed Aswad's death as somehow being the direct result of his intellectual disabilities and congenital malformations of the brain, the state Department of Social Services pursued an investigation into it, and into BRI's program as a whole. Among other things, the investigation revealed that BRI had used aversives excessively and unnecessarily, such as on a deaf child for failing to obey verbal commands; had deliberately concealed a student's bruises caused by the use of aversives from doctors and state agencies; had prompted students to act aggressively for the purpose of punishing them or demonstrating that they were aggressive as part of what it called behavioral rehearsal lessons; and had retaliated against students whose family members questioned the treatment program or threatened to make complaints. BRI of California, such as it was, did not survive the resulting lawsuit, and entered into a settlement agreement with the state in 1982 under which it agreed to stop using aversives and to ban Matthew Israel from involvement in its operations. However, the program continues to operate in California under the name of Tobinworld and is run by Israel's wife, Judy Weber.

Meanwhile, BRI's east coast facility continued to use the same methods it had used since it had opened, in fact the same ones that the California branch had been banned from using, despite the aforementioned two attempts by the state of Massachusetts to shut it down. Following its first victory, it not only changed its name to the Judge Rotenberg Center – both in commemoration of the Chief Justice of the Probate Court after his death and as a warning to anyone who would try to close or interfere with the program – and moved all of its facilities to Massachusetts, but it also introduced the use of electric shock as an aversive. For a couple of years, it used a relatively weak device, called the Self-Injurious Behavior Inhibition System, with a shock lasting a tenth of a second that reportedly felt like snapping a rubber band against one's skin. However, because of the extent to which the program used it on students – including one instance in which an autistic student named Brandon Sanchez was shocked 5,000 times in a single day – it began to lose its effect as students became inured to it over a period of months and years. When its representatives approached the developers of SIBIS to request that they make a stronger device, though, the developers refused.

As a result, the program designed and began to manufacture its own device, which it called the Graduated Electronic Decelerator (GED). The GED's shock was designed to be, and is, far more powerful than that of SIBIS – three times as powerful, in fact, with shocks lasting for a full two seconds. The device consists of a battery pack and five electrodes – two attached to students' arms, two attached to their legs, and one to their stomachs, and is activated by student specific remote controls carried by JRC staff. JRC has described the level of pain inflicted by the GED as being no worse than a bee sting. Students, former staff members and visitors to the program who tried the GED on themselves have disagreed strongly with this assessment. One JRC survivor compared the feeling to that of being attacked by a horde of wasps, and investigators and former staff members report that the GED regularly caused burns, which were bad enough that it became medically necessary to stop shocking students for a number of weeks.

Still, students became inured to the pain caused by the GED through repeated use in the same way they had to SIBIS' shocks. Thus, only a couple of years later, JRC designed and began to use a still more powerful device, the GED-4, which was three times as powerful as the original GED. Additionally, they eventually designed and began to use other shock devices, such as a "GED cushion" that would shock a student who got out – or fell out – of their chair without staff permission. By means of these devices, electric shock became the primary aversive used at JRC, replacing the use of techniques such as spatula spanks, pinches, muscle squeezes and ammonia pellets that Matthew Israel thought too risky for staff and, supposedly, students.

Even with the introduction and widespread use of the GED, JRC's opponents in the Massachusetts legislature and the disability advocacy community were and have been consistently unable to get any legislation passed that would ban it and other aversives. Like in the lawsuits between JRC and the state, parents and guardians of JRC students played a significant role in ensuring the defeat of such measures. Year after year, legislators such as Senator Brian Joyce from Canton would file anti-aversives bills, only to have parents show up at hearings on the issue to tell how electric shock and other aversives had saved their children's lives. In some cases, JRC students themselves would be brought to testify, wearing the GED while they told the legislature how it and other aversives had saved or improved their lives. JRC has also brought Brandon Sanchez – the same Autistic person who was shocked 5,000 times in a

single day, and whose uncle Jeffrey Sanchez is a state representative – to hearings to show people the kind of behaviors, and students, it attempts to treat. As a result of this, Representative Sanchez has been a strong, and in fact a formidable, opponent of efforts to pass laws banning the use of aversives.

It wasn't until 2006 that JRC and its use of aversives faced significant public outcry and governmental opposition again. This began with a lawsuit, filed by Evelyn Nicholson on behalf of her son Antwone, both against JRC and against his local school district in his home state of New York for placing him at the facility, over its misuse of the GED. In one instance in particular, JRC staff told Antwone that they were "going to hang [him] up like Jesus Christ" for refusing to get ready for bed when he was told to, and proceeded to shock him when he was in the shower. Evelyn decided to take action, removing Antwone from the program and eventually filing the lawsuit, after Antwone called her from JRC and told her that he no longer believed that she loved him for letting JRC hurt him so badly.

While the Nicholsons' lawsuit was eventually dismissed on the grounds that Evelyn had initially given consent for JRC to electrically shock Antwone, in the mean time, the New York State Education Department responded to the family's allegations by conducting an investigation. After making two site visits to JRC, one announced and one unannounced, the investigators released a report that mirrored the California Department of Social Services' 1982 complaint in the extent to which aversives were used and in fact abused. In addition to its often-quoted reference to students being shocked for "nagging, swearing, and failing to maintain a neat appearance," it discussed JRC's punitive use of long-term mechanical restraint and food deprivation, and reported that JRC was using the same so-called behavioral rehearsal lessons that it had more than 20 years before. On top of this, the report contained highly disturbing findings about how these methods were used and in fact how the program was run, such as how staff would purposefully set students up by administering unfair punishments and would then further punish those students who made use of the school's official complaint process in protest. The investigators expressed serious concern not only for students' mental health, in that some of the students showed signs of post-traumatic stress disorder and depression, but also for their physical safety, writing that JRC's food deprivation programs put students at risk of malnutrition and that none of its shock devices were approved by the Food and Drug Administration.

As a result of these findings, New York passed emergency regulations that banned its students from being sent to any program, in or out of state, that used aversives. However, once again, parents came to JRC's defense, suing the state education department, counter-intuitively, on the basis of disability and other civil rights statutes. Once again, they were victorious, with a trial court preventing the enforcement of the regulations. Although the lawsuit has continued through a series of appeals, through which most of the parents' claims have been dismissed, New York continues to send students to JRC and fund their placement there.

The following year, an incident at JRC further strengthened the opposition to its methods and continued existence. In one of JRC's group homes, staff woke two students up in the middle of the night by shocking them, and proceeded to shock them a combined total of more than one hundred times – with one of the boys receiving 77 shocks – on the order of a prank caller, himself a recently escaped JRC student, who was posing as a senior member of staff. While the

people who administered the shocks were confused as to why the caller was ordering the shocks in the absence of any target behaviors, they followed these orders unquestioningly, even as the students offered up no resistance and in fact tried to make it clear that they were not doing anything wrong. In spite of JRC staff initially dismissing the students' complaints of pain from having been repeatedly shocked, one of the students was eventually hospitalized for having first degree burns. In the aftermath of this incident, the Massachusetts Department of Early Education and Care made an official finding that the two students had been abused and neglected, and that the staff members responsible for this had received improper training in the use of the GED. They ordered JRC to keep the video footage of the incident on file for them to use as needed, but, in the months following the event, Matthew Israel had the footage destroyed, later claiming to have thought that the investigating agencies no longer needed it.

Over the next few years, the use of aversives at JRC attracted federal and international attention. In America, both the Food and Drug Administration and the Department of Justice opened investigations into JRC's practices. Meanwhile, the United Nations declared that its use of electric shock and long-term restraint on children and adults with disabilities violated international human rights protections against torture. Still, the Massachusetts legislature failed to pass any state laws banning or regulating the shocks, and JRC continued to enjoy the support of its students' families, with Brandon Sanchez's father saying that he would rather put a bullet in his son's brain than have him go off the GED, claiming that it would be more humane.

For its part, JRC responded to this growing condemnation by using the arguments it had relied on since it had first opened. Despite the fact that the field of behavioral psychology had made significant advances in the area of positive, non-aversive methods of treatment since then, its administration and lawyers continued to tell lawmakers and the public at large that the choice for students with severe behavioral problems, or rather their parents, was between the aversives used at JRC and copious amounts of harmful psychotropic medications. Furthermore, even as JRC began to run radio ads calling for parents to send their children with truancy and academic problems, and even as they recruited students from impoverished backgrounds with minor, if any, disabilities, they insisted that it was a "school of last resort" treating the most severely aggressive and self-injurious people with disabilities in the country only after all other programs had failed them. In response to the allegations that JRC used shock and other punishments for minor and even harmless behaviors, they not only confirmed that this was the case but defended it as being as necessary as shocks for more dangerous behaviors. For instance, in his replies to some of the investigation reports, Matthew Israel justified the use of aversives in response to the target behavior of closing one's eyes by saying that a person who closed their eyes too frequently ran the risk of falling down stairs or otherwise coming to harm, and defended shocking a student for nagging by writing that this behavior was "so compulsive and frequent that it once led to caregivers at a previous placement trying to strangle him and lock him in a room."

Nonetheless (or instead perhaps unsurprisingly), opposition to JRC and its practices continued to increase. In 2011, the Massachusetts Office of the Attorney General prosecuted Matthew Israel for his role in hampering the investigation into the unprovoked use of shock on two students four years earlier. Israel, despite insisting on his having done nothing wrong, pled guilty to charges of misleading a witness and destroying evidence. As a result of this, he was forced to resign from his position as Executive Director and in fact leave JRC. The same year, the state of

Massachusetts passed regulations banning the most painful and restrictive aversives, including those used at JRC. However, it attempted to avoid further controversy by carving out an exception for the use of aversives on students whose treatment plans already included them, effectively doing nothing to protect them against continuing abuse.

Finally, in 2012, the public saw what JRC does to people like disabilities, through proof that was irrefutable and impossible to ignore. This came to light in the form of a video, shown to a jury and news cameras as part of a lawsuit against JRC after being suppressed by the request of JRC's attorneys for eight years, of a young Autistic adult named Andre McCollins being restrained and shocked 31 times over the course of seven hours at the program. The footage begins with Andre sitting calmly in his chair while JRC staff asks him to take off his jacket. He doesn't move to take it off, and suddenly, he's screaming in pain from a shock, and he gets off the chair to hide under his desk. The staff members in the room drag him out, and five of them hold him down, meanwhile shocking him for tensing up and screaming in fear and pain. Later in the tape, he's shown strapped facedown to a four-point restraint board, yelling out, "No! No! No! No! Help me! Help, help, help, help! HELP!" before screaming in pain, and a buzzing sound in the background makes it clear that he's been shocked again.

The outcry, this time not just by disability rights advocates but by the public at large in Massachusetts and around the world, was enormous. Nearly a quarter of a million people petitioned the Massachusetts state legislature to ban the shocks after seeing what happened to Andre McCollins, and indeed JRC opponents in the Massachusetts Senate renewed their attempts to pass a total ban on all painful and restrictive aversives. On the same day that a hundred people gathered in protest in front of the Massachusetts State House and the JRC itself, the United Nations condemned JRC for its torture of people with disabilities a second time and demanded that the U.S. government investigate and take action to stop it.

Still, as of writing this, JRC is still open, and continues to shock, restrain, starve and otherwise abuse approximately one hundred of its students – many if not most of them Autistic or otherwise disabled – in the name of treatment and under the protection of the law. Despite all the information that exists to show why JRC should be closed and its methods banned, many people, including politicians, journalists and treatment professionals, refuse to take an outright stance against them even where that stance could very well make enough of an impact to accomplish either or both of these things. They insist that there must be two, and thus two equally valid, sides to every story, and continue to give JRC and its supporters a forum to make the same arguments, untrue as they always were, that they've made for forty years. They assume that doctors, parents and other caretakers who deal with people with disabilities know best, and thus what they do to, or agree to on behalf of, people with disabilities must be necessary. They take it for granted that people with disabilities' dangerous behaviors are incomprehensible and thus must be managed rather than understood, and are then willing to have that principle extended to everything else a supposedly dangerous person with a disability does.

Even now, they call what JRC does treatment. That's why it still happens.

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REFERENCES

Laurie Ahern & Eric Rosenthal, Mental Disability Rights International, Torture Not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center (2010).

Fredda Brown & Dina A. Traniello, The Path to Aversive Interventions: Four Mothers' Perspectives, 35 Research & Practice for Persons with Severe Disabilities 128 (2010).

Polyxane Cobb, A Short History of Aversives in Massachusetts (2005).

Department of Social Services, State of California, Complainant's First Amended Accusation/Statement of the Issues, In the Matter of the Accusations Against the Behavioral Research Institute of California, No. L230-1278 (29 January 1982).

Jennifer Gonnerman, Mother Jones Magazine, School of Shock (20 August 2007).

Matthew Israel, Ph.D., Behavioral Skin Shock Saves Individuals with Severe Behavior Disorders from a Life of Seclusion, Restraint and/or Warehousing As Well as the Ravages of Psychotropic Medication: Reply to the MDRI Appeal to the U.N. Special Rapporteur on Torture (2010).

Judge Rotenberg Center, JRC Responses to Allegations in NYSED June 9, 2006 Report (2006).

Paul Kix, Boston Magazine, The Shocking Truth (July 2008).

Massachusetts Department of Early Education and Care, Investigation Report, Incident # 49037 (1 November 2007).

Shain Neumeier, Autistic Self Advocacy Network, *The Judge Rotenberg Center on Trial* (April 2012).

New York State Department of Education, Observations and Findings of Out-of-State Program Visitation: Judge Rotenberg Educational Center (2006).

Settlement Agreement, *Behavioral Research Inst. v. Leonard*, No. 86E-0018-GI at *16 (Mass. Sup. Ct. Jan. 7, 1987)

Joseph Shapiro, No Pity: People with Disabilities Forging a New Civil Rights Movement (1993).