

Letter from Disability Advocates: A Call to Action to Eliminate the Use of Aversive Procedures and Other Inhumane Practices, September 2009

NOTE: This letter has been sent to: The Office of Disability, Department of Health and Human Services; the Secretary of the Department of Health and Human Services; the Secretary of the U.S. Department of Education; the Attorney General of the United States; the U.S. Department of Justice; the House Committee on Education & Labor; the Senate Committee on Health, Education, Labor, and Pensions; Amnesty International; Human Rights Watch; and Physicians for Human Rights.

September 30, 2009

We are writing to ask the Office of Disability, Department of Health and Human Services; the Secretary of the Department of Health and Human Services; the Secretary of the U.S. Department of Education; the Attorney General of the United States; the U.S. Department of Justice; the House Committee on Education & Labor; Amnesty International; Human Rights Watch; and Physicians for Human Rights take action to put an end to the use of electric shock, other painful and aversive procedures, seclusion, unnecessary restraint, and food deprivation – all inhumane and unnecessary methods of behavior modification used in some schools and residential facilities for children and adults with disabilities in the United States. This letter is signed by 29 disability organizations concerned with the humane treatment of people with disabilities.

The attached information focuses on the practices of the Judge Rotenberg Center in Canton, Massachusetts. While there are examples of the use of prolonged seclusion and unnecessary restraint in schools and residential facilities across the country, studies prepared by government agencies and investigative reports that have appeared in the media suggest that the Judge Rotenberg Center uses these procedures as well as painful electric shock and food deprivation. According to public sources, residents of the Judge Rotenberg Center receive painful electric shocks for behaviors as innocuous as stopping work for more than ten seconds, getting out of their seats, interrupting others, or whispering¹. In the view of the undersigned, the use of painful and dehumanizing behavioral techniques violates all principles of human rights. We are sending this letter to a number of government and human rights organizations. We ask that you show leadership in protecting the rights of all people in the United States by acting to put an end to these inhumane practices wherever they occur.

The type of practices against which we ask you to take action have been documented in numerous government reports and other public documents. One of the best documentations of these practices is the June, 2006 New York State Education Department report² that noted the following concerns about the Judge Rotenberg Center (JRC):

“Students wear the GED device [the device that delivers the electric shock] for the majority of their sleeping and waking hours, and some students are required to wear it during shower/bath time. The GED receivers range in size and are placed in either “fanny” packs or knapsacks. Staff carry the GED transmitters in a plastic box. Students may have multiple GED devices (electrodes) on their bodies. For example, one NYS student’s behavior program states, “C will wear two GED devices. C will wear 3 spread, GED electrodes at all times and take a GED shower for her full self care.” (p.7)

¹ *JRC Program Visitation Report – 6/9/2006*. New York State Education Department. Based on visits: 4/25, 4/26, 5/16, 5/17, and 5/18 2006.

² *Ibid.*

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"A combination of mechanical restraint and GED skin shock is also used to administer a consequence to students that attempt to remove the GED from their bodies. In instances where this combined aversive approach is used, the student, over a period of time specified on his or her behavior program, is mechanically restrained on a platform and GED shocks are applied at varying intervals. ... An example of this is found on one NYS student's behavior program; a consequence for pulling a fire alarm is to receive 5 GED [shocks], over a 10-minute period, while being restrained on a four-point board." (p. 9)

Another example of these inhumane practices was documented by NPR Health Reporter Joseph Shapiro, in his book No Pity. His observations of The Judge Rotenberg Center include the following:

" ... one young man got tired of picking out matching shapes on a computer screen. But his teacher demanded that he continue and pinched him on the palm for disobeying. The young man ... made a guttural noise of protest and tried to get up. In a second, two staffers had thrown him face down on the floor. This only made him more agitated. Then came a squirt in the face with ammonia water. The man spent a minute on the floor, trying to move and protest, but was restrained by one staffer's knee in his back and another's grip on his arm."³

The JRC website describes these practices as "intensive treatment procedures"⁴ but almost every national disability organization agrees that the use of painful procedures to change a person's behavior is unnecessary, inhumane, and should be banned.⁵

With this letter, we ask The House Committee on Education and Labor to take legislative action to end the use of these practices. In our view the practices described in the New York State Education Department report on JRC meet the definition of torture in the United Nations' Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment that is, "any act by which severe pain or suffering, whether physical or mental; is intentionally inflicted on a person; for such purposes as:

- obtaining from him/her or a third person information or a confession;
- punishing him/her for an act s/he or a third person has committed or is suspected of having committed;
- intimidating or coercing him/her or a third person;
- or for any reason based on discrimination of any kind;

when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity."⁶

3 Shapiro, J.P. (1993). No Pity: People with disabilities forge a civil rights movement. Time Books: p 154

4 <http://www.judgerc.org/>

5 See for example: the National Down Syndrome Society's Position Paper on The Use of Restraints, Aversive Interventions and Seclusion (http://www.ndss.org/index.php?option=com_content&view=article&id=153%3Aposition-papers&catid=54%3Apublic-relations&Itemid=140&limitstart=7); the TASH Resolution Opposing the Use of Aversive and Restrictive Procedures (<http://www.tash.org/IRR/resolutions/res02aversive.htm>); The American Association on Intellectual and Developmental Disabilities' condemnation of such practices (http://www.aamr.org/content_169.cfm?navID=55)

⁶ Adopted and opened for signature, ratification and accession by General Assembly resolution 39/46 of 10 December 1984 entry into force 26 June 1987, in accordance with article 27 (1) (<http://www2.ohchr.org/english/law/cat.htm>)

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We the undersigned urge you to review the attached information which documents extensive instances of inhumane practices and take legislative and regulatory action to halt the continued abuse of children, adolescents and adults with disabilities. Through past pleas and campaigns, advocates have seen little action from federal, state or local regulatory agencies or the criminal justice system. These entities have been aware of the documented abuses for over thirty years. Even though there is broad professional agreement that a wide range of positive interventions are available which are at least as effective in managing dangerous behaviors, and which do not inflict pain on or dehumanize individuals with disabilities, no regulatory agency has been able or willing to act to eliminate these practices.

As a group of advocates concerned with the support of persons with disabilities, we call on these Government agencies and human rights organizations to work with us to expose and condemn these behavioral techniques, take the legislative and other necessary steps to protect the rights of people with disabilities, and bring an end to these practices.

For additional information, to discuss proposed action, or to contact the organizations below, please contact Nancy Weiss by phone: 410-323-6646 or e-mail: nweiss@udel.edu

Signed:

American Association on Intellectual and Developmental Disabilities
Washington, DC

Association of University Centers on Disabilities
Silver Spring, MD

The Arc of the U.S.
Silver Spring, MD

Autism National Committee (AutCom)
Forest Knolls, CA

The Autistic Self Advocacy Network
Washington, DC

Center on Human Policy, Law, and Disability Studies, Syracuse University
Syracuse, NY

The Coalition for the Legal Rights of People with Disabilities
Boston, MA

Cobb and Douglas Counties Community Service Boards
Smyrna, GA

Connecticut Council on Developmental Disabilities
Hartford, CT

Disability Rights Education and Defense Fund
Berkley, CA

Easter Seals
Chicago, IL

Exceptional Parent Magazine
Johnstown, PA

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Hope House Foundation
Norfolk, VA

The Learning Community for Person Centered Practices
Annapolis, MD

The Maine Independent Media Center
Waterville, ME

Maryland Coalition for Inclusive Education
Hanover, MD

National Association of County Behavioral Health and Developmental Disability Directors
Washington, DC

National Association of Councils on Developmental Disabilities
Washington, DC

National Association for the Dually Diagnosed (NADD)
Kingston, NY

National Disability Rights Network
Washington, DC

The National Leadership Consortium on Developmental Disabilities, University of Delaware
Newark, DE

Respect ABILITY Law Center
Royal Oak, Michigan

RHA Howell, Inc.
Raleigh, NC

Self Advocates Becoming Empowered
Kansas City, MO

TASH
Washington, DC

United Cerebral Palsy
Washington, DC

University of Medicine and Dentistry of New Jersey, School of Nursing
Newark, NJ

University of San Diego Autism Institute
San Diego, CA

The Voices and Choices of Autism
Lakewood, CO

cc: *The Office of Disability, Department of Health and Human Services; the Secretary of the Department of Health and Human Services; the Secretary of the U.S. Department of Education; the Attorney General of the United States; the U.S. Department of Justice; the House Committee on Education & Labor; the Senate Committee on Health, Education, Labor, and Pensions; Amnesty International; Human Rights Watch; and Physicians for Human Rights*

Addendum to the September 2009 Letter from Disability Advocates: A Call to Action to Eliminate the Use of Aversive Procedures and Other Inhumane Practices

The information in this addendum supplements the September, 2009 letter from disability advocates calling for the elimination of the use of aversive and other inhumane practices. This addendum contains supporting information from a 2006 New York State Education Department Report and information from news sources such as the New York Times, The Boston Globe, Mother Jones Magazine, Boston Magazine and others. The New York State Report can be found here: http://boston.com/news/daily/15/school_report.pdf and additional information and confirming reports are cited within and are available by conducting an internet search for the Judge Rotenberg Center (JRC) in Canton, Massachusetts, or the facility's former name, The Behavior Research Institute (BRI), at its prior location in Providence, Rhode Island.⁷

Jennifer Gonnerman wrote in the August, 2007 issue of Mother Jones Magazine, “***Eight states are sending autistic, mentally retarded, and emotionally troubled kids to a facility that punishes them with painful electric shocks. How many times do you have to zap a child before it's torture?***”⁸ In the article, Gonnerman writes,

“Of the 234 current residents, about half are wired to receive shocks, including some as young as nine or ten.” Later in the same article Gonnerman reports, “The Rotenberg Center is the only facility in the country that disciplines students by shocking them, a form of punishment not inflicted on serial killers or child molesters or any of the 2.2 million inmates now incarcerated in U.S. jails and prisons. Over its 36-year history, six children have died in its care, prompting numerous lawsuits and government investigations. Last year, New York state investigators filed a blistering report that made the place sound like a high school version of Abu Ghraib. Yet the program continues to thrive—in large part because no one except desperate parents, and a few state legislators, seems to care about what happens to the hundreds of kids who pass through its gates.”⁹

The device used to deliver shocks to students at the Judge Rotenberg Center is called the Graduated Electronic Decelerator (GED). It was developed by and is manufactured by The Judge Rotenberg Center.¹⁰ The New York State report says, “The GED is manufactured by the JRC. While JRC has information posted on their website and in written articles which represents the GED device as ‘approved’, it has not been approved by the Food and Drug Administration (FDA)”¹¹(p. 7). The report goes on to describe the device: “the GED is adjustable with an average intensity of 15.25 mill amperes RMS, a duration of .2 seconds to 2 seconds, an average peak of 30.5 milliamperes, and 24 students are receiving GED (referred to as a GED-4) skin shock which has a maximum current of 45.0 milliamperes RMS, an average peak of 91 milliamperes, and a maximum duration of 2 seconds.”¹²(p.8)

The shock delivered to children by either the GED or the GED-4 is much stronger than that delivered by a cattle prod at .4 milliamperes or a dog collar at 4.8-5 milliamperes and both of these devices deliver a shock for only a fraction of a second. The shock delivered by the GED can last for a maximum of two seconds, four times as long as the shock from a cattle prod. The New York State Education Department

⁷ Israel, M. History of JRC, Judge Rotenberg Center website: <http://www.judgerc.org/>

⁸ School of Shock, Mother Jones, August 20, 2007, <http://www.motherjones.com/politics/2007/08/school-shock>

⁹ School of Shock, Mother Jones, August 20, 2007, <http://www.motherjones.com/politics/2007/08/school-shock> (emphasis in the original).

¹⁰ BRI News, Winter, 1991, Behavior Research Institute, Providence, RI. NOTE: *The Behavior Research Institute (BRI) changed its name to the Judge Rotenberg Center in 1994.*

¹¹ JRC Program Visitation Report – 6/9/2006. New York State Education Department. Based on visits: 4/25, 4/26, 5/16, 5/17, and 5/18 2006.

¹² Ibid

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Report states, “JRC’s GED was modified from other similar devices on the market by doubling the intensity (amperage and voltage) and increasing the duration by 10 times (from .2 to 2 seconds) of the shock administered and by expanding the positions on the body where the electrodes could be placed.”¹³ (p 7).

The Judge Rotenberg Center’s director, Matthew Israel, claims that the center uses these techniques only on students who engage in “self-mutilating [or] other life threatening behaviors”¹⁴ but public reports contradict that assertion. The New York State report found students as young as nine years old subjected to sudden, painful, repeated electric shocks for such harmless behaviors as ‘refusing to follow staff directions’, ‘failing to maintain a neat appearance’, “stopping work for more than ten seconds”, “getting out of seat”. “interrupting others”, “nagging”, ‘swearing’, ‘whispering’ and ‘slouching in chair’, and ‘moving conversation away from staff’¹⁵(p.3 & 14). The Judge Rotenberg Center’s own report states that students are shocked for getting out of their seat without permission.¹⁶ The New York State report says, “some students are made to sit on a GED cushion seat that will automatically administer a skin shock for the targeted behavior of ‘standing up’, while others wear waist holsters that will administer a skin shock if the student pulls his/her hands out of the holster”¹⁷ (p. 8). A former employee wrote, “Some students were shocked for stopping work for more than a specified number of seconds. One boy was shocked for closing his eyes for more than five seconds while sitting at his seat. Almost all students on electric shock devices had in their student plan the behavior, ‘refusing to follow staff directions,’ for which they were shocked.”¹⁸

The Judge Rotenberg Center describes the shock from the GED as a hard pinch or a two-second bee sting¹⁹ but others who experienced the shock describes it very differently. During a legislative hearing, Massachusetts State Representative James V. DiPaola attached the Graduated Electronic Device to his own forearm and delivered a shock to himself. Audience members observed him to leap out of his seat, cry out in pain, and claw at the arm on which the device was attached. The Boston Herald interviewed DiPaola after he experienced the shock of the milder GED. The Herald quoted DiPaola as saying, "It was torture. It was very painful."²⁰ People who attended that meeting still talk about the horrifying experience of observing the application of this one electric shock, received by an adult who expected it and had chosen to experience it.

The Boston Globe said this about the testimony of two former employees at the same hearing:

“The employees, Gail Lavoie and Colleen Seevo, said they also worked with a female student who received as many as 350 shocks in one day, another figure confirmed by the school. The women, who left the school at the end of 1992, said the shock is more painful than described by school officials. "I got hit accidentally on my thumb and I had a tingling up to my elbow, on the inner part of my arm, I would say for four hours," said Seevo, referring to a shock. "I was saying

¹³ Ibid

¹⁴ Israel, M. *Response to Jennifer Gonnerman’s article, “School of Shock”*, <http://www.judgerc.org/ResponsetoGonnermanArticle.pdf>

¹⁵ *JRC Program Visitation Report – 6/9/2006*. New York State Education Department. Based on visits: 4/25, 4/26, 5/16, 5/17, and 5/18 2006.

¹⁶ Rivera, P.M., Israel, M.L., McGarry, C. and Sutherland, H., *Using the Graduated Electronic Decelerator to Target Antecedent Behavior in MR/Autistic Students*, http://www.effectivetreatment.org/using_graduated.html

¹⁷ *JRC Program Visitation Report – 6/9/2006*. New York State Education Department. Based on visits: 4/25, 4/26, 5/16, 5/17, and 5/18 2006.

¹⁸ Miller, G. Response to Dr. Matthew Israel’s letter entitled “Outrage Over Jennifer Gonnerman’s Article, ‘School of Shock’” Mother Jones website: <https://www.motherjones.com/politics/2007/08/school-shock?page=5>

¹⁹: <http://www.judgerc.org/introtojrc.html> (accessed 9/2/09)

²⁰ The Boston Herald, February 24, 1995.

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I can't believe these kids can do this. My hand was shaking. I wanted to go home, that's how bad it was." Lavoie said the device also had side effects and she had observed students whose skin was burned and blistered by the shocks."²¹

A former Judge Rotenberg staff person wrote the following in response to the Mother Jones article (published on the Mother Jones website): "Students on the stronger "GED-4" devices often show red spots on their skin after a shock. The red spots are about the size of pencil erasers that overnight develop into scabs. Students on the strong devices mostly wear what are called 'spread electrodes' which is where the electrical current passes through the skin between two electrodes about two or more inches apart during the two-second shock. I was told by the staff responsible for making the electrodes that the objective for the spread electrodes was to create the maximum amount of pain with the least amount of physical damage. Two scabs may occur overnight after a single electrical shock with the strong device. Certain students with autism sometimes get up to 30 shocks in a single day, the cut-off point when shocks must stop unless the student's psychiatrist gives permission to go beyond 30 shocks Students with autism who are on the strong injurious shock devices sometimes have so many scabs on their bodies that the nurse orders that the shock devices be removed for five to six weeks until the skin heals up. Some students go back and forth between several weeks off electrodes while their skin is healing, to sometimes only three or four days back on devices re-injuring their skin, to going back off of devices again, in a cycle that has no end. There was nobody monitoring to see whether electric shocks were working as effective treatments for these students. The students I have seen taken off of the electric shock devices due to their skin injuries have looked pretty bad. They don't take students off of the electric shock devices unless they absolutely must."²²

A 2007 New York Times article notes, "a former teacher from the school ...said he had seen children scream and writhe on the floor from the shock." The Times article also speaks to how painful the shocks are, "Technically, the lowest shock given by Rotenberg is roughly twice what pain researchers have said is tolerable for most humans, said James Eason, a professor of biomedical engineering at Washington and Lee University".²³

A former employee, Greg Miller, wrote an article called, *I Wonder if Parents Really Know What Happens to their Children at the Judge Rotenberg Center*. In that article he asks whether "parents, judges and state authorities know that:

- a non-verbal student with autism gets shocked for closing his eyes for more than five seconds while sitting at his desk;
- some students get shocked for standing up from their seat, raising their hand, and politely asking, 'I would like to go to the bathroom, please';
- some students get shocked for going to the bathroom in their pants – even if they have been asking for the bathroom for nearly two hours;
- some students get shocked for yelling when they think they are about to get an electrical shock; and,
- some students get shocked for instinctively trying to remove the electrode while the electrode is shocking and burning through their skin for two seconds.

²¹ The Boston Globe, April 28, 1995

²² Miller, G. Response to Dr. Matthew Israel's letter entitled "Outrage Over Jennifer Gonnerman's Article, 'School of Shock'" Mother Jones website: <https://www.motherjones.com/politics/2007/08/school-shock?page=5> (accessed 8/14/09)

²³ *Parents Defend School's Use of Shock Therapy*, Leslie Kaufman, New York Times, December 25, 2007

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Miller says, “Most Americans don’t know this type of pain, which is severe and can leave burn marks and even bloody scabs all over a child’s body; it is not a ‘bee-sting’. Students are expected to forcefully suppress their own normal bodily reactions to fear, or else. Do parents and authorities know this before signing permission for their child to be shocked?”²⁴

The director of the Judge Rotenberg Center testified at a Massachusetts legislative hearing that one student received 5,300 electric shocks in one day. In his testimony, he stated that over a 24-hour period, this student, a teenager who weighed only 52 pounds, was strapped to a board and subjected to an average of one shock every 16 seconds.²⁵

And sometimes, according to media reports, shocks are given in error. In a December, 2007 article titled, “A Shocking Error in Treatment”, The Boston Globe stated: “The Judge Rotenberg Educational Center is the only school in the nation that routinely uses skin shocks to control self-destructive and violent behavior by autistic, retarded, and emotionally disabled patients. But the Canton-based center is too error-prone to be allowed to keep using aversive therapy without intensive and ongoing oversight by state health officials.”²⁶ The article goes on to describe a well publicized incident that occurred in the middle of the night on August 26th, 2007. The staff at a Judge Rotenberg Center group home received a call from a person who said he was a quality control monitor. Staff were told to awaken two residents, secure them to 4-point restraint boards and shock them. One resident was shocked 77 times and the other 29 times. Later it was discovered that the call was a hoax perpetrated by a former student, but staff did not question the logic of punishing the students for some unknown behavior that allegedly occurred hours previous to the punishment.^{27, 28}

The Graduated Electronic Decelerator has been known to malfunction and deliver what the Center’s director calls, “spontaneous activations²⁹”; that is, people are shocked in error. The Mother Jones article sites a “Trouble Report” that reads, “Jamie Z was getting his battery changed, Luigi received a shock”³⁰ In 2006, the Boston Globe reported: “from 1992 until last year, state investigators identified 10 occasions when students received shocks when they had done nothing, either because the device malfunctioned or the staff accidentally shocked the wrong person. Most of the complaints were dismissed because the injuries weren’t serious enough, but the Disabled Persons Protection Commission determined that the school abused one student who received five to 10 spontaneous shocks due to a malfunction. Commission records also show that one student was seriously injured as a result of shocks. The man was admitted to Children’s Hospital in Boston in 2002 with ‘acute stress response’ after receiving 30 shocks while strapped to a board for six hours. Witnesses told investigators the student stopped eating and drinking afterward and cried about his punishment, but investigators dropped the complaint because the shocks were part of a court-approved treatment plan”.³¹

²⁴ Miller, G. *I Wonder if Parents Really Know What Happens to their Children at Judge Rotenberg Center*, April 17, 2006.

²⁵ *School of Shock*, Jennifer Gonnerman, Mother Jones, August 20, 2007

²⁶ *A Shocking Error in Treatment*, Boston Globe, December 21, 2007

²⁷ Ibid

²⁸ Rotenberg Center Blasted By Gov. Eliot Spitzer and Media After A Prankster Gets Employees to “Accidentally” Shock Kids 100 Times, Mother Jones, December 19, 2007

²⁹ *School of Shock*, Jennifer Gonnerman, Mother Jones, August 20, 2007

³⁰ Ibid

³¹ Scott, Allen. State checking burn claims at school: 10 complaints about shocks in past six months. Boston Globe, June 26, 2006

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Electric shock is not JRC's only method of behavioral intervention. The New York State investigation team noted,

“With mechanical movement limitation the student is strapped into/onto some form of physical apparatus. For example, a four-point platform board designed specifically for this purpose; or a helmet with thick padding and narrow facial grid that reduces sensory stimuli to the ears and eyes. Another form of mechanical restraint occurs when the student is in a five-point restraint in a chair. Students may be restrained for extensive periods of time (e.g., hours or intermittently for days) when restraint is used as a punishing consequence. Many students are required to carry their own “restraint bag” in which the restraint straps are contained.”³² (p.8) The same report notes, “Some of these students were observed to be fully restrained in restraint chairs and wearing movement limiting helmets. One student left the school building in full restraint (hands and feet restrained with Velcro straps in a restraint chair), clearly agitated and upset, and returned the following morning carried to the conference room fully restrained in what appeared to be the same chair.”³³(p.17)

The New York State investigation team further reported,

“GED skin shock and restraint are also used together when the Behavior Rehearsal Lesson (BRL) is practiced on a student. The BRL is used when a student exhibits a high risk, low frequency behavior. As described by a JRC staff person, during a BRL, the student is restrained and GED administered as the student is forcibly challenged to do what the procedure seeks to eliminate. If the student attempts to pull away he receives a GED skin shock; if the student attempts to follow through with the high-risk behavior he receives multiple GED skin shocks at closer intervals.”³⁴ (p.9)

The New York State Education Department report described an additional procedure used at the Judge Rotenberg Center. The procedure is known as the Contingent Food Program. According to the report:

“The Contingent Food Program is also widely applied and designed to use hunger to motivate students to be compliant. This intervention requires that a student “earn” a portion of his or her daily prescribed calories by not engaging in identified target behaviors (as per his/her behavior contract). If the student passes each of the behavioral contracts that are set for him/her, he/she will earn 100 percent of the planned calories for each meal served. If the student fails to pass one or more of his/her contracts, the student is not given the food portion(s) that is (are) the potential reward(s) for that contract. Food portions not earned are discarded by the staff and/or student. If the student does not earn the minimum daily total of calories by 7:00 PM, then the balance necessary to bring the total calories eaten to the student's targeted calories is dispensed to him in the form of nonpreferred staple food (e.g., consisting of mashed food sprinkled with liver powder).

The Specialized Food Program is more restrictive. For students on the Specialized Food Program, JRC does not offer make-up food to compensate for food that the student missed by failing to pass his or her contracts unless the student has eaten 20 - 25 percent or less of his normal daily caloric target. If the student has eaten 20 - 25 percent or less, he/she is offered make-up food to bring him up to the 20 - 25 percent level.”³⁵(p.10)

³² *JRC Program Visitation Report – 6/9/2006*. New York State Education Department. Based on visits: 4/25, 4/26, 5/16, 5/17, and 5/18 2006.

³³ Ibid

³⁴ Ibid

³⁵ Ibid

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The Mother Jones article reported that six children have died in the care of the Judge Rotenberg Center, “prompting numerous lawsuits and government investigations”³⁶. The following, from a report of The Disabled Person's Protection Commission and the Massachusetts Department of Mental Retardation, describes one of these deaths:

“The Disabled Person's Protection Commission and the Massachusetts Department of Mental Retardation released the report of an extensive investigation into the death of a 19-year old woman who died in 1990 at the Judge Rotenberg Center (JRC, formerly the Behavior Research Institute, or BRI). The investigation, which included interviews of 72 witnesses, review of hundreds of documents, and reports by four experts, concluded that JRC/BRI direct care staff, nursing staff, and administration, as well as several specific staff members, took actions that were ‘egregious’ and ‘inhumane beyond all reason’ and constituted not only violations of legal standards but violations of ‘universal standards of human decency’. The woman, who was mentally retarded and could not speak, began showing symptoms of illness on December 15 and 16, 1990: she refused her food (she had always had a hearty appetite), she was restless and fidgety and made unusual noises. By December 17, she was pale, disoriented, had ‘glassy eyes’, and kept attempting unsuccessfully to vomit. During this time, because staff mistook her attempts to communicate her discomfort for ‘target behaviors,’ she was punished repeatedly -- forced to smell ammonia, spanked, pinched, and forced to eat ‘taste aversives’ -- either a vinegar mix, or jalapeno peppers or hot sauce. By 7:00 p.m. she had received 8 spankings, 27 finger pinches, 14 muscle squeezes and had been forced to inhale ammonia at least five times and given several taste aversives, even though she was ‘obviously ill’. She received a total of 61 aversives on the day that she died. At 8:00 p.m. on December 18, she was lying on the floor of the bathroom and unable to get up, pale with a bluish tinge to her skin. Although a registered nurse was notified, she refused to call an ambulance until a medical technician arrived and confirmed the need for it half an hour later. By the time the 19-year old woman reached the hospital, her blood pressure was zero and she was in shock. She died on the operating table at 1:35 a.m. on December 19. The autopsy revealed that her stomach had been perforated, (and) that she had extensive ulcers. On the specialized food plan, she had to earn her daily meals by not engaging in certain behaviors and/or working on a computer. Ironically, staff confirmed that although her meals depended on her getting right answers on a computer, she neither understood the relationship between getting fed and getting the right answer on the computer, nor how to get the right answer on the computer. ‘If she didn't earn her food, it was thrown out. She got real thin, she was skinny,’ said one staff member. Staff also said that she was ‘always wanting to eat.’ The program allowed the 19-year old to be limited to as few as 300 calories a day, 20% of her minimum calorie intake for the day. In addition, although DMR regulations permit the use of intrusive and severe aversives such as spanking and ammonia for ‘seriously dangerous behaviors’, the woman was punished when she displayed the following behaviors: ‘Drooling, spitting, nagging, topping work, refusing, and silly laughing. She was deprived of food for merely having the wrong answer on the computer.’³⁷

In 2008, an article in Boston Magazine reported the following relevant to the conditions and deaths at Judge Rotenberg:

“In 1979, the state of New York issued two reports from agencies that oversaw the Behavior Research Institute. Fifteen New Yorkers at that time attended the school. (New Yorkers today still account for the highest percentage of the school's student body.) The bright red buttocks and

³⁶ *School of Shock*, Jennifer Gonnerman, Mother Jones, August 20, 2007

³⁷ *The Communicator* (1995), vol. 6, no. 1.) ; excerpted from bulletins of the Coalition for the Legal Rights of People with Disabilities.

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scrapes across the cheek; the plaintive cry of a student who said, "Take me home, I want to go home"; the weird, oft-repeated, and grammatically challenged cheers from teachers ("Good working without stopping") — it led the authors of one report to write that the school's "rigidly implemented" program was the "singular most depressing experience that team members have had." That was not the worst of it, though.

On July 17, 1981, at BRI's sister school in Northridge, California, staffers restrained 14-year-old Danny Aswad face-down on his bed. Aswad died in that position. The autopsy report concluded that he died of natural causes, but the state of California placed the school on a two-year probation anyway. In 1982, the state's Department of Social Services filed a 63-page legal complaint alleging abuse at the school. The complaint claimed, among other things, that BRI withheld meals; showed staff how to hide students' injuries from regulatory agencies; and, strangely, encouraged students to act out for a film crew, the footage to be used later to demonstrate how the children had behaved before BRI. Later that year the state reached a settlement with BRI in California. The school couldn't use anything more punishing than a water spray. The state also forbade Israel—who says he'd turned over control of the campus before Aswad's death—from stepping foot on the Northridge property. But this, too, was not the worst of it.

In 1985, Vincent Milletich died. The 22-year-old from Queens, New York, attended the school in Providence, as did, by that time, roughly 60 others. On July 23, for acting out at the BRI residential home in Seekonk, Milletich was restrained in a chair, his hands and feet tied by plastic cuffs, his face masked and his head helmeted, the earphones inside it emitting white noise. He suffocated in there, asphyxiation. Though BRI was not found to have caused Milletich's death, a district court judge ruled it was negligent for approving the therapy and not carrying it out with sufficient supervision."³⁸

Although the Judge Rotenberg Center has been using painful procedures on children with disabilities since its inception almost forty years ago,³⁹ no advocacy organization, state law enforcement agency, or legislative committee has been able to halt these practices, though many have tried. The Judge Rotenberg Center spent over 2.8 million dollars on legal fees according to its 2007 IRS 990 form (for the July '07 – June '08 fiscal year), the most recent IRS report that has been made public⁴⁰. The explanation that The Judge Rotenberg Center includes on the same form to explain the amount spent on legal fees states, "During the year ended June 30, 2008, the Judge Rotenberg Center, Inc. retained attorneys and staff to represent them and act on their behalf in opposing legislation introduced into the State Legislatures which would have eliminated educational funding for schools which utilize certain aversive behavioral techniques. If this legislation passed, substantially all funding for JRC Inc. would be eliminated unless JRC dramatically altered its method of instruction and treatments"⁴¹ It is of concern to the signers of this letter that the Judge Rotenberg Center spent almost three million dollars of public funds (Medicaid and state education funds) on its lobbying efforts to continue the practices described in government reports.

³⁸ Kix, P. *The Shocking Truth*, Boston Magazine, July, 2008.

³⁹ Israel, M. History of JRC, Judge Rotenberg Center website: <http://www.judgerc.org/>

⁴⁰ Judge Rotenberg Center, 2007 Form 990 (<http://www.guidestar.org/FinDocuments/2008/042/489/2008-042489805-050ee456-9.pdf>)

⁴¹ Judge Rotenberg Center, 2006 990 Form. Schedule A, Part IIA.

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Contrary to the assertion that the use of painful procedures is necessary to control dangerous or disruptive behaviors⁴², a wide range of methods are available which are not only more effective in managing the dangerous or disruptive behaviors of children and adults with disabilities, but which do not inflict pain or dehumanize⁴³. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that will achieve the individual's needs. David Coulter M.D., a neurologist at the Children's Hospital Boston and past President of The American Association on Intellectual and Developmental Disabilities, states, "In 28 years as a clinical child neurologist, during which I have personally cared for approximately 15,000 (or more) children and youth with developmental disabilities, served as the onsite neurologist for two state schools in Texas from 1982-1985, and currently serve as the neurologist for two private schools in Massachusetts (one for students with blindness and other disabilities and the other for students with autism), I have never seen anyone who, in my medical opinion, needed electric shock as a form of behavior management."⁴⁴

Sadly, the problem of traumatizing children in the name of treatment is not limited to one institution or to the use of electric shock or food deprivation. A recent report by the U.S. Government Accountability Office (GAO) on the treatment of children in public and private schools across the country documents cases in which students were pinned to the floor for hours at a time, handcuffed, locked in closets, and subjected to other acts of violence. The GAO found hundreds of cases of alleged abuse and death related to the use of restraint and seclusion on school children over the past two decades. Examples of these cases include a seven year old dying after being held face down for hours by school staff, five year olds being tied to chairs with bungee cords and duct tape by their teacher and suffering broken arms and bloody noses, and a thirteen year old hanging himself in a seclusion room after prolonged confinement. The GAO found no federal laws restricting the use of restraints and seclusion in public or private schools and widely divergent laws at the state level.⁴⁵

A 2009 report from the National Disability Rights Network⁴⁶ describes cases in almost every state in which the abusive use of restraint or seclusion in schools resulted in injury, trauma or death to children with disabilities. The report notes that because there is no mandated system to report or collect data on these abuses, the cases described are just the tip of the iceberg. While there are frequent news stories and significant public concern about bullying and student violence, as a country we have ignored these sanctioned abuses, and as the NDRN report states, we have allowed "children with disabilities to be victimized in our nation's schools at the hands of the professionals who are entrusted to keep them safe. The restraint or seclusion of children, and the physical and emotional harm which these practices cause, should frighten every parent in America, not only parents of children with disabilities." Cases are reported in which children are strapped to chairs; pinned to the floor by several adults (sometimes for hours at a time); grabbed and dragged into rooms; held in arm locks or handcuffed; placed in coffin-like boxes and cells; locked in closets; and subjected to other physically and psychologically traumatizing acts of violence by school personnel and others. Below are some examples from this report:

42 Judge Rotenberg Center Website: <http://www.judgerc.org/introtojrc.html>

43 TASH Statement on Positive Behavioral Approaches, http://www.tash.org/IRR/positive_behavior_supports.html;

LaVigna, G.W. and Donnellan, A.M. (1986). Alternatives To punishment: Solving behavior problems with non-aversive strategies. New York: Irvington. 186-187.; The Association for Positive Behavior Support (<http://www.apbs.org/index.html>)

44 Email communication

45 <http://www.gao.gov/products/GAO-09-719T>

46 School is Not Supposed to Hurt: Investigative Report on Abusive Restraint and Seclusion in Schools. National Disability Rights Network; January, 2009 (<http://www.napas.org/sr/SR-Report.pdf>)

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- Students with disabilities who misbehaved at a public school in Tennessee were placed in plywood seclusion boxes measuring 4 ft. x 3 ½ ft.(p.20)
- In Pennsylvania, a young boy, now eight years old, was kept strapped to a positional support chair for two to three hours every day for over two years by his teacher. A tray and three straps were placed across the boy’s chest, waist and legs to keep him from moving. He received no instruction while restrained.(p.25)
- A 15 year old Michigan boy with autism died while being physically restrained at school by four school employees who pinned him down for 60-70 minutes on his stomach, with his hands held behind his back and his shoulders and legs held down. He became non-responsive after 45 minutes but the restraint continued and he eventually stopped breathing. He was the second child in Michigan to die from the use of restraint.(p.14)
- In Wisconsin, a seven year old girl was suffocated and killed at a mental health day treatment facility when several adult staff pinned her to the floor in a prone restraint for blowing bubbles in her milk.(p.14)

It has been our experience that when people hear about practices like those described in this letter, most are amazed that these practices could be legal. Certainly it is not legal for a parent to do any of these things to his or her own child under any circumstances. Advocates have sought policy changes through federal, state and local regulatory agencies as well as through the criminal justice system but we see no hope on the horizon. We have pursued each of these avenues with rigor and purpose for over twenty years with some small steps forward in state regulations that remain spotty and insufficient, but ultimately resulting in no overarching federal mandate to protect people from these abuses. Disability advocates cannot begin to match the millions of dollars that facilities like the Judge Rotenberg Center spend in defense of their right to continue these practices. Our most vulnerable children suffer as a result.

Even if state regulations are enacted that prevent facilities from using aversive procedures, they can move their operation to another state. If Federal regulations are promulgated, facilities can simply change their designation from an Intermediate Care Facility (ICF/MR), regulated by The Centers for Medicare and Medicaid Services (CMS); to a Residential Treatment Center (regulated by The Children’s Health Act of 2000); to a “school”, which can operate with almost no Federal programmatic oversight. Fewer than half of the states in the U.S. have specific regulations addressing the use of aversive procedures, restraint, and seclusion in public schools and only six states require that the use of such procedures be reported⁴⁷.

The Children’s Health Act of 2000 does provide solid protection against the use of these practices by restricting seclusion and restraint to emergency use only, and establishing administrative regulations and reporting procedures, and possible termination of funding for failure to comply – but these regulations apply only to certain types of facilities⁴⁸ and the Catch-22 is that the facility itself can choose its designation. There is no federal law that says, if you provide a certain type or array of services, you are a psychiatric treatment facility, and as such must operate under the Children’s Health Act. Until federal legislation prevents the abuse of our most vulnerable citizens, practitioners who choose to do so will be able to continue to cause harm to children and adults with disabilities in the name of treatment.

⁴⁷ *Fact Sheet: A Call to United Action*, The Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS), www.tash.org/dev/tashcms/ewebeditpro5/upload/APRAIS_Fact_SheetFInal708.doc -

⁴⁸ Children’s Health Act (CHA) of 2000, H.R. 4365. Part H - Requirement relating to the rights of residents of certain facilities; Part I - Requirement relating to the rights of residents of certain non-medical, community-based facilities for children and youth. Engrossed Senate Amendment.

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As of August, 2007, the Judge Rotenberg Center was reported to be serving 234 students⁴⁹. According to a December 25, 2007 New York Times article, states pay about \$228,000 per child, per year⁵⁰. This translates to about 53 million tax-payer dollars a year. Money like this might be a good investment if these vulnerable children were getting quality support and help, but in the view of the signers below, students with disabilities should not be subjected to painful and dehumanizing practices. We, the undersigned believe it is time to end these practices wherever they occur in programs and facilities across the country; to accomplish this, we need your help.

Electric shock, prolonged restraint, and food deprivation in any other context, administered to any other population, would be considered torture. If Americans were told that these abuses were being imposed upon the elderly, prisoners, non-disabled school children, or even animals, there would be public outcry. But when told these techniques are being used on children and adults with disabilities, many people are willing to turn away. We have been told, “we are not doctors; we don’t know what people like this need.” We, the undersigned, don’t believe that one needs any particular degree or background to know that all people should be treated humanely.

Some people with developmental disabilities have dangerous or disruptive behaviors and may need considerable help to change their behaviors. However, painful or aversive procedures, seclusion, or prolonged restraint are not effective, necessary or conscionable treatment methods. The people subjected to these procedures comprise one of the most devalued segments of the population. Their plight is often magnified by the nature of their condition which hinders their ability to speak out against mistreatment and makes them vulnerable to abuse.⁵¹

We cannot condone treating persons with disabilities in a manner that would not be tolerated if applied to other segments of the population. Anyone who is concerned with human rights and with the ethical treatment of all people should express outrage at the continued use of behavior change procedures that cause pain and are dehumanizing. This report calls on **the Office of Disability, U.S. Department of Health and Human Services; the Secretary of the Department of Health and Human Services; the Secretary of the U.S. Department of Education; the Attorney General of the United States; the U.S. Department of Justice; the House Committee on Education & Labor; the Senate Committee on Health, Education, Labor, and Pensions; Amnesty International; Human Rights Watch; and Physicians for Human Rights** to publicize these practices and to take action against the continued abuse of persons with disabilities.

For additional information, to discuss proposed action, or to contact the organizations that signed the attached letter, please contact Nancy Weiss by phone: 410-323-6646 or e-mail: nweiss@udel.edu

The attached letter is signed by 29 disability organizations including: The American Association on Intellectual and Developmental Disabilities; the Association of University Centers on Disabilities; The Arc of the U.S.; the Autism National Committee; the Autistic Self Advocacy Network; the Center on Human Policy, Law, and Disability Studies, Syracuse University; the Disability Rights Education and Defense Fund; Easter Seals; the National Association of County Behavioral Health and Developmental Disability Directors; the National Association of Councils on Developmental Disabilities; National Association for the Dually Diagnosed; the National Disability Rights Network; Self Advocates Becoming Empowered; TASH; United Cerebral Palsy; the University of Medicine and Dentistry of New Jersey, School of Nursing and the University of San Diego Autism Institute.

⁴⁹ *School of Shock*, Jennifer Gonnerman, Mother Jones, August 20, 2007

⁵⁰ Parents Defend School’s Use of Shock Therapy, Leslie Kaufman, New York Times, December 25, 2007

⁵¹ Sobsey, R., & Sobon, S. (2006) Violence, protection and empowerment in the lives of children and adults with disabilities. In R. Alaggia & C. Vine (Eds.).