### THE MORAL AND LEGAL BASES FOR BANNING AVERSIVE CONDITIONING DEVICES USED FOR CONTINGENT ELECTRIC SHOCK

*Comments submitted to the Neurological Devices Panel of the Medical Devices Advisory Committee, U.S. Food and Drug Administration, relative to Docket No. FDA-2014-N-0238* 

### Lydia Brown April 2014

#### I. Introduction

I am writing regarding the forthcoming meeting scheduled to convene on April 24, 2014 to discuss the safety and effectiveness of aversive conditioning devices. I am an autistic advocate for people with disabilities presently serving on the Board of Directors of TASH<sup>1</sup> New England, as well as a current member of the District of Columbia Autism Task Force, and the Consumer Advisory Council for the Georgetown University Center for Excellence in Developmental Disabilities. TASH New England is the regional chapter of TASH National, an international association of people with disabilities, family members, and professionals devoted to equity, opportunity, and inclusion for people with the most significant disabilities and a founding coalition partner of the Alliance to Prevent Restraints, Aversive Interventions, and Seclusion (APRAIS). Previously I worked for the Autistic Self Advocacy Network<sup>2</sup> for over two years, and served on the Adult Services Subcommittee of the Massachusetts state autism commission. My work has primarily focused on issues of violence against people with disabilities, including the abusive use of restraints, seclusions, and aversives.

I am submitting these comments to present the argument that historical and current practices with respect to contingent electric shock constitute both a moral and legal imperative for the FDA to ban aversive conditioning devices used for this purpose. Under 21 C.F.R. § 895.21, in order to ban a device, the Commissioner of the Food and Drug Administration must make a finding "that the continued marketing of the device presents a substantial deception or an unreasonable and substantial risk of illness or injury."<sup>3</sup> Based on the nature, purpose, and current usage of contingent electric shock, aversive conditioning devices that administer a noxious electrical stimulus to modify undesirable behavioral characteristics meet both of the conditions stipulated in the regulatory requirements for banning medical devices.

#### II. Factual Background

At this time, there is only one facility or treatment provider in the United States known to use contingent electric shock as an aversive behavioral intervention as part of their program—the Judge Rotenberg Educational Center (JRC) in Canton, Massachusetts, a residential institution

<sup>&</sup>lt;sup>1</sup> TASH was originally founded in 1975 as The American Association for the Education of the Severely and Profoundly Handicapped. In 1980, the name changed to The Association for the Severely Handicapped, and in 1983, to The Association for Persons with Severe Handicaps (TASH). In 1995, the Board of Directors discontinued the full name, but maintained the acronym. *See* TASH, ABOUT US, *available at* http://tash.org/about.

 $<sup>^{2}</sup>$  The Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for Autistic people. ASAN advocates for systems change and the inclusion of Autistic people in the policymaking process, while working to educate communities and improve public perceptions of autism.

<sup>&</sup>lt;sup>3</sup> 21 C.F.R. § 895.21(a) (2011).

housing people with psychiatric and developmental disabilities.<sup>4</sup> In addition to the dubious distinction of being the only facility to use contingent electric shock in its program, the JRC is also the only manufacturer of electric shock aversive conditioning devices at this time.<sup>5</sup> The JRC administers contingent electric shock through use of several devices manufactured in-house that are known collectively under the name Graduated Electronic Decelerator (GED). As of 2013, the JRC has included the use of the GED or other aversives in the behavior plans for 38% of 213 students - approximately 80 people.<sup>6</sup> The ostensible purpose of aversive behavioral interventions in general, as well as contingent electric shock in particular, is to reduce or eliminate undesirable behaviors, especially severely self-injurious and destructive behaviors considered to be the most challenging to treat in clinical settings.

The concept for the GED derived from the Self-Injurious Behavior Inhibiting System (SIBIS), which was a much less powerful aversive conditioning device available on the open market in the late 1980's and early 1990's.<sup>7</sup> The SIBIS delivered a skin shock lasting 0.2 seconds with amperage of 3.5 milliamperes.<sup>8</sup> Between 1988 and 1990, the JRC used the SIBIS to shock 29 students, including Brandon Sanchez, who is autistic and has severely self-injurious behaviors.<sup>9</sup> Following an incident in which Brandon received over five thousand shocks in one day, the JRC inquired as to whether Human Technologies, SIBIS's manufacturer, would be willing to develop a device with increased voltage and amperage.<sup>10</sup> When Human Technologies refused, the JRC invented the original GED on their own.<sup>11</sup> The original GED (also known as the GED-1), delivers a skin shock lasting two full seconds with amperage of 15.5 milliamperesmore powerful than commercially available stun guns used for self-defense and law enforcement purposes.<sup>12</sup> In the last twenty years, the JRC has also developed the significantly more powerful GED-4 (skin shock lasting two seconds with amperage of 45.5 milliamperes), a "holster" that shocks the wearer's hands if removed, and a GED "cushion" that delivers shocks for standing up from a chair.<sup>13</sup> In 1994, the FDA cleared the original GED for marketing based on its similarity to its predecessor, the SIBIS.<sup>14</sup> Despite the "cleared" status of the first iteration of the GED, none of the JRC's other GED devices have also been cleared, and not one of the GED devices has ever received full FDA approval.<sup>15</sup>

Prior to 2011, the JRC's ability to include use of the GED in a student's treatment plan was governed by the terms of a settlement between the state of Massachusetts and the JRC, as

<sup>9</sup> Gonnerman, *supra* note 7.

<sup>&</sup>lt;sup>4</sup> Laurie Ahern & Eric Rosenthal, Mental Disability Rts. Int'l, *Torture Not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center: Urgent Appeal to the United Nations Special Rapporteur on Torture* 3 (2010) [hereinafter "MDRI"]. <sup>5</sup> Id.

<sup>&</sup>lt;sup>6</sup> Isaac Borenstein, REPORT BY MONITOR JUDGE ISAAC BORENSTEIN (RET.) FOR THE JUDGE ROTENBERG EDUCATIONAL CENTER (JRC) 126 (2013) [hereinafter "BORENSTEIN"].

<sup>&</sup>lt;sup>7</sup> Jennifer Gonnerman, School of Shock, Mother Jones, Aug. 20, 2007, *available at* 

http://www.motherjones.com/politics/2007/08/school-shock (last visited 12 Apr. 2014).

<sup>&</sup>lt;sup>8</sup> Thomas R. Linscheid, *et al.*, *Clinical Evaluation of the Self-Injurious Behavior Inhibiting System*, in 23 J. OF APPLIED BEHAVIOR ANALYSIS 53, 56 (1990).

<sup>&</sup>lt;sup>10</sup> Paul Kix, The Shocking Truth, in BOSTON MAGAZINE, July 2008, available at

http://www.bostonmagazine.com/articles/2008/06/the-shocking-truth/ (last visited 13 Apr. 2014). <sup>11</sup> Id.

<sup>&</sup>lt;sup>12</sup> See id.; MDRI, supra note 4, at 13-14.

<sup>&</sup>lt;sup>13</sup> See MDRI, supra note 4, at 8; N.Y. State Educ. Dep't, OBSERVATIONS AND FINDINGS OF OUT-OF-STATE PROGRAM VISITATION: JUDGE ROTENBERG EDUCATIONAL CENTER 7-8 (2006) [hereinafter "NYSED"].

<sup>&</sup>lt;sup>14</sup> Polyxane Cobb, A SHORT HISTORY OF AVERSIVES IN MASSACHUSETTS 2 (2005).

<sup>&</sup>lt;sup>15</sup> See NYSED, supra note 13, at 7-8.

well as regulations regarding the use of highly intrusive aversive interventions including contingent electric shock.<sup>16</sup> Prior to permitting the JRC to include the GED or other aversive interventions in a student's individual treatment plan, the state regulations required the informed consent of the student (or the student's parent or guardian), the consent of the court in a substituted judgment hearing, and the approval of the JRC's peer review and human rights committees.<sup>17</sup> The regulations also required an annual review of any individual treatment plan containing the GED or other aversive interventions.<sup>18</sup> After 2011, new regulations promulgated by the Massachusetts Department of Developmental Services prevented any state-licensed facility from using contingent electric shock on any student whose individual treatment plan did not already include the GED.<sup>19</sup> Under the revised regulations, the JRC has still been able to use the GED on approximately 80 students who were already subject to the device.<sup>20</sup>

# III. The continued marketing of aversive conditioning devices is substantially deceptive because current best practices in service provision for persons with significant disabilities offer multiple alternatives to electric shock aversives.

The FDA's regulations provide two bases upon which the agency can ban a medical device. The first basis is a finding that the continued marketing of the device is substantially deceptive, and that the deception is "important, material, or significant in relation to the benefit to the public health from its continued marketing" to meet the standard for substantiality.<sup>21</sup> The JRC's framing of the necessity and use of the GED, as well as the associated risks with its implementation, constitutes substantial deception of consumers and decision makers. The JRC's distinct treatment methodology hinges upon the ability to claim that in cases of the most severe, complex, and challenging behavior, aversive behavioral interventions, including contingent electric shock through the GED, are the only effective treatment. Despite the JRC's representations, however, service providers and other treatment professionals who work with people with the most significant disabilities have found the greatest long-term efficacy and least risk of harm in positive, non-punitive or aversive interventions that assess the antecedents and function of existing behavior while emphasizing the introduction and development of replacements for dangerous behaviors.<sup>22</sup> Positive methods have demonstrable results even for people with the most severely aggressive and self-injurious behaviors, including some people who previously received the GED and other aversives at the JRC.<sup>23</sup>

<sup>&</sup>lt;sup>16</sup> See Settlement Agreement, *Behavioral Research Inst. v. Leonard*, No. 86E-0018-GI at 2-6, 9-10 (Mass. Sup. Ct. Jan. 7, 1987) [hereinafter SETTLEMENT AGREEMENT]; Matthew L. Israel, HISTORY OF JRC,

http://web.archive.org/web/20120308165343/http://www.judgerc.org/history.html (last visited 12 April 2014). <sup>17</sup> SETTLEMENT AGREEMENT, *supra* note 16, at 2-6, 9-10. *See also* NYSED, *supra* note 13, at 5.

<sup>&</sup>lt;sup>18</sup> Id.

<sup>&</sup>lt;sup>19</sup> 114 MASS. CODE REGS. 5.14(4)(b)(3), (4) (2011).

<sup>&</sup>lt;sup>20</sup> See id.; BORENSTEIN, supra note 6, at 126.

<sup>&</sup>lt;sup>21</sup> *Id.* at § 895.21(a)(1).

<sup>&</sup>lt;sup>22</sup> See Massachusetts Department of Developmental Services, RESPONSE TO TESTIMONY AND WRITTEN COMMENTS TO PROPOSED AMENDMENTS TO BEHAVIOR MODIFICATION REGULATIONS: 115 C.M.R. 5.14 8, 10-11, 14 (2011); Polyxane S. Cobb, A DISCUSSION OF AVERSIVES: WHY THEY DON'T SUCCEED AND WHAT DOES 8 (2005); Fredda Brown, Ph.D., CONSULTATION REPORT: [NAME REDACTED] 3-4 (1999).

<sup>&</sup>lt;sup>23</sup> See generally Frank L. Bird & James K. Luiselli, *Positive behavioral support of adults with developmental disabilities: assessment of long-term adjustment and habilitation following restrictive treatment histories*, 31 J. OF BEHAVIORAL THERAPY AND EXPERIMENTAL PSYCHIATRY 5, 14-18 (2000).

The JRC further engages in substantial deception through self-publication of internal research without external validation intended to give the illusory appearance of legitimacy and evidence-based practice. For example, the JRC represents on its website a self-published follow-up study on treatment and outcomes of sixty-five JRC students as evidence and data-based research.<sup>24</sup> Nevertheless, no related paper was accepted for peer review, there is no explanation or context for the methods of data collection, there is no mention of either informed consent or approval from any institutional review board (IRB).<sup>25</sup> The veneer of scientific legitimacy and relevance that the JRC cultivates through its carefully maintained public image and self-published research will certainly have undue influence on parents and school district officials responsible for making the decision to send students to the JRC. When parents and other public officials make placement decisions under the false impression that the JRC uses scientifically validated treatment methods accepted by professionals working with people who have significant behavioral challenges, they have been deceived as to the nature of the program and the device.

Contingent electric shock has no demonstrated long-term efficacy in treating the destructive and self-injurious behaviors that it seeks to reduce or eliminate while non-aversive behavioral interventions do have proven long-term efficacy. The Judge Rotenberg Center frequently claims that peer-reviewed literature has demonstrated that contingent electric shock is effective; however, all of the papers that the JRC proffers to this effect were published internally with the sole involvement of their own personnel or those closely connected to their facility with no meaningful external review. At a minimum, the existing literature demonstrates only that electric shock aversives have inconsistent short-term efficacy with absolutely no long-term efficacy in reducing or eliminating destructive and self-injurious behaviors.<sup>26</sup> The evidencebased research and practice data clearly demonstrate that unlike positive interventions, punitive aversive interventions merely temporarily suppress behaviors without any long-term efficacy.<sup>27</sup> Professionals and researchers specializing in service provision for people with the most significant disabilities have found that the use of aversives not only has no long-term efficacy, but also that aversives fail to aid in the development of functional skills and non-dangerous behaviors.<sup>28</sup> In 1990, several researchers specializing in nonaversive behavior interventions for people with the most challenging aggressive and self-injurious behaviors wrote that

Clearly, the time has come for limiting the use of stimuli and procedures that are painful, damaging, and dehumanizing. The debate should be not on whether to limit our use of the most severe forms of behavioral intervention, but on how that limitation should occur. [...] The routine use of procedures that deliver pain (shock, pinching, slaps), procedures that result in harm (bruises, cuts, broken bones), and procedures that are disrespectful or

<sup>&</sup>lt;sup>24</sup> See generally Judge Rotenberg Ctr., FOLLOW-UP STUDY: 65 STUDENTS BEFORE AND AFTER ATTENDING JRC (2012), available at http://judgerc.org/images/uploads/Follow\_up\_study\_2012-1.pdf.

<sup>&</sup>lt;sup>25</sup>See id.

<sup>&</sup>lt;sup>26</sup> Fredda Brown *et al.*, Personal Paradigm Shifts Among ABA and PBS Experts: Comparisons in Treatment Acceptability, 10 J. OF POSITIVE BEHAVIORAL INTERVENTIONS 212, 216-226 (2008).

<sup>&</sup>lt;sup>27</sup> The Am. Acad. of Dev. Med. and Dentistry, POSITION PAPER ON THE USE OF FARADIC AVERSIVE SHOCK TREATMENT STRATEGIES IN BEHAVIORAL MODIFICATION SCHEMES IN VULNERABLE POPULATIONS (April 2014) (on file with author).

<sup>&</sup>lt;sup>28</sup> See Cobb, supra note 22, at 7-8; Massachusetts Department of Developmental Services, supra note 22, at 8-11; Brown, supra note 22, at 1-2.

### *dehumanizing (facial sprays, shaving cream in mouth, foul smells) are no longer acceptable.*<sup>29</sup>

Not long afterward in 1993, renowned behaviorist Ole Ivar Lovaas reversed his position and publicly criticized the practice of aversive interventions on CBS, thereby repudiating his own prior work as one of the pioneers of electric shock aversives on autistic people.<sup>30</sup> These statements, issued over twenty years ago, further underscore the reality that experts in the field have thoroughly rejected aversive interventions as outdated, unnecessary, and ineffective.

In the field of complex and challenging behaviors, there are alternatives to overprescription of psychotropic medication other than contingent electric shock. The JRC discusses contingent electric shock as though there are only two possible options for addressing severe behavioral challenges—the overuse of psychotropic medication as a means of chemically inducing compliance, or the implementation of electric shock aversive conditioning. The existing literature in the field of service provision for people with the most significant disabilities disputes this false dichotomy. For example, a 1991 study evaluating the efficacy of functional communication training to reduce challenging behaviors found a substantial reduction in the targeted behaviors as well as transference to new settings for up to 24 months afterward.<sup>31</sup> That study's finding were later confirmed in a 2011 literature review on functional communication training in which the authors argued that this nonaversive method is now a well-established treatment for challenging behaviors in people with developmental disabilities.<sup>32</sup> In a second example, a 2007 study of two children with intellectual disabilities who had severely aggressive behaviors demonstrated significant decrease in aggression and other problematic behavior when they were given supported choices.<sup>33</sup>

# IV. The continued marketing of aversive conditioning devices is substantially deceptive because the Judge Rotenberg Center fundamentally misrepresents the nature and usage of the GED devices.

The Judge Rotenberg Center claims that contingent electric shock is only used to treat individuals with the most challenging destructive or self-injurious behaviors; however, by their own admission, they administer the GED for behaviors that cannot be credibly construed as dangerous to self or others. The justification for this practice is that these are "antecedent" behaviors that if unpunished will lead to behaviors such as attacking staff, severely damaging property, or seriously injuring oneself.<sup>34</sup> Yet at the same time, in any ordinary educational setting, these behaviors would at most result in a written reprimand or after-school detention. An

<sup>&</sup>lt;sup>29</sup> Robert H. Horner, Glen Dunlap, Robert L. Koegel, Edward G. Carr, Wayne Sailor, Jacki Anderson, Richard W. Albin, & Robert E. O'Neill, *Toward a Technology of "Nonaversive" Behavioral Support*, in 30 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 125, 131 (1990).

<sup>&</sup>lt;sup>30</sup> GONNERMAN, *supra* note 7; Dan Moser & Alan Grant, *Screams, Slaps, and Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples*, in LIFE MAGAZINE 90-96 (May 7, 1965).

<sup>&</sup>lt;sup>31</sup> V. Mark Durand & Edward G. Carr, *Functional Communication Training to Reduce Challenging Behavior: Maintenance and Application in New Settings*, in 24 J. OF APPLIED BEHAVIOR ANALYSIS 251, 251 (1991).

<sup>&</sup>lt;sup>32</sup> Patricia F. Kurtz, et al., An analysis of functional communication training as an empirically supported treatment for problem behavior displayed by individuals with intellectual disabilities, in 32 RES. IN DEV. DISABILITIES 2935, 2935 (2011).

<sup>&</sup>lt;sup>33</sup> Brian McClean, Ian M. Grey, & Margaret McCracken, *An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings*, in 11 J. OF INTELLECTUAL DISABILITIES 281, 281 (2007).

<sup>&</sup>lt;sup>34</sup> Judge Rotenberg Ctr., JRC RESPONSES TO ALLEGATIONS IN NYSED JUNE 9, 2006 REPORT, 23-25 (2006).

investigative team from the New York State Education Department (NYSED) found that JRC uses aversive interventions, including GED shocks, for many students "without a clear history of self-injurious behaviors" as well as "behaviors that are not aggressive, health dangerous or destructive, such as nagging, swearing and failing to maintain a neat appearance."<sup>35</sup> In support of these findings, Gregory Miller, a former teacher's assistant at the JRC, has also openly discussed multiple situations in which students were shocked for behaviors that do not align with the JRC's claims that use of the GED is necessary to treat dangerous behaviors such as banging one's head into the floor, biting off pieces of one's own tongue, or violently attacking others.

One student was shocked for stopping work for more than 20 seconds. A second, a girl with cerebral palsy, was shocked for moaning and reaching out to hold a staffer's hand. A third was shocked for closing his eyes for more than five seconds. A fourth was shocked for urinating in her pants; Miller says she'd asked for over two hours to go to the bathroom. A fifth was shocked because he yelled when he saw another student about to be shocked. [...] One day, Miller claims, a student he knew well was shocked for attempting to go to the bathroom without permission, then for refusing a teacher's order, then for trying to take the GED off his arm.<sup>36</sup>

Numerous such incidents further evidence the lack of any real substance to the JRC's claim that the GED is only used to treat severely aggressive or self-injurious behaviors.

Furthermore, the JRC claims in their literature that the GED delivers a fairly mild shock akin to the pain of "a bee sting."<sup>37</sup> To offer a comparison, the two electronic restraint devices approved for usage by the U.S. Marshals Service to control prisoners in transport and court settings are capable of delivering incapacitating, immobilizing shocks with amperages of anywhere from 3 to 6 milliamperes.<sup>38</sup> In the training video marketed by Stun Tech, the manufacturer of the most common stun belt used for prisoner restraint, the film depicts twenty-five police officers who each experience the activation of the stun belt of only 3 to 4 milliamperes of current.<sup>39</sup> Each officer collapses to the floor in pain.<sup>40</sup> Compared to the stun technology used in the correctional setting, the GED-1 has an amperage of 15.5 milliamperes (over three times greater than Stun Tech's belt) while the GED-4 has an amperage of 45.5 milliamperes (over fifteen times greater than Stun Tech's belt).<sup>41</sup> The JRC's founder, Matthew Israel, has admitted that the GED is intended to "hurt."<sup>42</sup> Given that the GED-4 is in more common usage than the GED-1, and that both devices have significantly higher current than those used in the correctional setting ostensibly to control potentially violent and aggressive

<sup>41</sup> MDRI, *supra* note 4, at 8.

<sup>&</sup>lt;sup>35</sup> NYSED, *supra* note 13, at 3.

<sup>&</sup>lt;sup>36</sup> Paul Kix, *The Shocking Truth*, in BOSTON MAGAZINE, July 2008, *available at* http://www.bostonmagazine.com/2008/06/the-shocking-truth

<sup>&</sup>lt;sup>37</sup> GONNERMAN, *supra* note 7.

<sup>&</sup>lt;sup>38</sup> See Anne-Marie Cusac, Stunning Technology, in THE PROGRESSIVE (Aug. 10, 2010), available at

http://progressive.org/mag\_cusactech; Amnesty Int'l, CRUELTY IN CONTROL? THE STUN BELT AND OTHER ELECTRO-SHOCK EQUIPMENT IN LAW ENFORCEMENT, (1999), available at: http://www.refworld.org/docid/3ae6a9c90.html;

Band-It Electronic Restraint, from KARBON ARMS INC., OFFICER.COM, available at

http://www.officer.com/product/10046602/karbon-arms-inc-band-it-electronic-restraint; U.S, Marshals Svc., Policy Directives: Less than Lethal Device 2.1(E)(1)(d), *available at* 

http://www.usmarshals.gov/foia/Reading\_Room\_Information/Contracts/cso\_forms\_policy/less\_than\_lethal\_devices.pdf.

<sup>&</sup>lt;sup>39</sup> Cusac, *supra* note 35.

<sup>&</sup>lt;sup>40</sup> Id.

<sup>&</sup>lt;sup>42</sup> ABC Nightline, *Feds Warn School Featured in ABC News Report: Shock Devices Violate Law*, Dec. 19, 2012, *available at* http://abcnews.go.com/Blotter/feds-warn-school-abc-news-report/story?id=18018135.

prisoners, it is obvious that the usual claim that the GED should be compared to a bee sting is patently false. This misrepresentation is simply another example of the JRC's substantive deception with regard to the nature of the GED device.

### V. The use of aversive conditioning devices as a tool for behavioral modification presents an unreasonable and substantial risk of injury.

The second basis on which the FDA may make a decision to ban a device is a finding that the continued marketing of the device presents an unreasonable and substantial risk of illness of injury. The GED meets this standard on several counts. The use of GED devices is inherently and unreasonably punitive and degrading. The form of behaviorism that characterizes the JRC's treatment methodology is based in the philosophy of indistinguishability, which emphasizes the appearance or emulation of "normal" behavior as the optimal treatment goal for people with disabilities.<sup>43</sup> The philosophy undergirding the JRC's treatment methodology is an extreme form of behaviorism that almost completely rejects any potential validity or usefulness of any other forms of treatment.<sup>44</sup> The ultimate goal is absolute compliance with artificial behavioral norms rather than meaningful, self-determined futures and functional skills or coping mechanisms. For this reason, application of the GED is inherently discriminatory and punitive, as the painful shocks will target behaviors merely associated with disability even in the absence of any real danger to self or others.

In one example, Michael Famolare, a student at the JRC, is permitted to leave the facility for home visits accompanied by his GED device and activator, which his mother uses as a control mechanism to ensure compliance with any commands.

Marguerite Famolare brought her son Michael to the Rotenberg Center six years ago, after he attacked her so aggressively she had to call 911 and, in a separate incident, flipped over a kitchen table onto a tutor. Michael, now 19, suffers from mental retardation and severe autism. These days, when he comes home for a visit, Marguerite carries his shock activator in her purse. All she has to do, she says, is show it to him. "He'll automatically comply to whatever my signal command may be, whether it is 'Put on your seatbelt,' or 'Hand me that apple,' or 'Sit appropriately and eat your food,'" she says. "It's made him a human being, a civilized human being."<sup>45</sup>

While using her son's fear of shock from the GED may have successfully resulted in his obedience, the reality is that the use of fear and threats have induced robotic behavioral responses in lieu of any meaningful and voluntary changes in Michael's behavior. The GED did not make Michael "more human;" it exerts control through fear and coercion. The knowledge that at the push of a button one will receive an extremely painful, incapacitating electric shock—whether or not the device is actually activated—is sufficient grounds for intimidation.

The history of the JRC evidences a clear pattern of abuse, particularly with application of the GED shock device without any legitimate treatment purpose. In one example, Antwone

<sup>&</sup>lt;sup>43</sup> Lydia Brown, *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, in* TORTURE IN HEALTHCARE SETTINGS: REFLECTIONS ON THE SPECIAL RAPPORTEUR ON TORTURE'S 2013 THEMATIC REPORT 181, 182-183 (Juan E. Méndez & Hadar Harris, eds., 2014).

<sup>&</sup>lt;sup>44</sup> Matthew L. 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 7, 10 (2010). <sup>45</sup> GONNERMAN, *supra* note 7.

Nicholson,<sup>46</sup> a former JRC resident, was repeatedly shocked for swearing and getting out of his seat without permission.<sup>47</sup> He was also shocked after refusing to take a shower, with his mother describing the incident as follows:

He said that one time a new worker told him it was time to go to bed. He told him that he had extra time to stay up but he said "you are going to bed and I want you to take a shower." So they ripped his clothes off him and he said they said "now we are going to hang you up like Jesus Christ" and they shocked him while he was in the shower.<sup>48</sup>

In a separate incident in October 2002, former JRC resident Andre McCollins received thirty-one shocks over a period of six hours while in four point restraints.<sup>49</sup> After refusing to remove his jacket when told to do so by staff, Andre received a GED shock for non-compliance by refusing to follow instructions.<sup>50</sup> When he screamed and attempted to escape by diving under a table, four adults physically dragged him into the main part of the room before securing him face-down on the restraint board.<sup>51</sup> According to the charts documenting each application of the GED on this date, all but one of the shocks were administered for yelling/screaming or full body tense-up, which were presumably in fear and anticipation of additional shocks.<sup>52</sup> Three days after the incident at the urging of his mother, Andre was transported to Boston Children's Hospital, where he was diagnosed with acute post-traumatic stress and his mother described his state as catatonic.<sup>53</sup> In April 2012, an excerpt of surveillance footage depicting this incident was played in open court during a jury trial as part of a lawsuit that Andre's mother filed against the JRC.<sup>54</sup> In a third example, a former student phoned one of the JRC's group homes in 2007 claiming to be a staff supervisor monitoring the home's surveillance cameras and instructing staff to rouse two residents from bed and administer GED shocks for supposed earlier offenses.<sup>55</sup> One of the two students received 30 shocks, while the other received 77, resulting in a stage II ulcer and several first-degree burns from multiple shocks.<sup>56</sup> The staff member's obedience to these instructions only further emphasizes the normalization of shocking students as punishment at the JRC, as the request was not questioned.

In addition to the inherently punitive and degrading nature of the GED, contingent electric shock is unsafe and inconsistent even within the confines of its supposed purpose. The New York State Education Department report on the JRC's general practice of using the GED for students with a broad range of diagnoses in lieu of any alternative treatment measures

<sup>&</sup>lt;sup>46</sup> It is possible to identify this student by comparing different sources that narrate the same story. *See* GONNERMAN, *supra* note 7 (mentioning Antwone Nicholson); Fredda Brown & Dina A. Traniello, *The Path to Aversive Interventions: Four Mothers' Perceptions*, 35 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 128, 133 (2010) (referring to him by a pseudonym, "Andrew," but discussing the same incident covered in Gonnerman's *Mother Jones* article).

<sup>&</sup>lt;sup>47</sup> Brown & Traniello, *supra* note 46, at 133.

<sup>&</sup>lt;sup>48</sup> *Id.* at 133.

<sup>&</sup>lt;sup>49</sup> Jennifer Gonnerman, *The Rotenberg Center's Controversial Behavioral-Modification Program*, in NEW YORK MAGAZINE, Sep. 2, 2012, *available at* http://nymag.com/news/features/andre-mccollins-rotenberg-center-2012-9/index.html (last visited 13 Apr. 2014).

<sup>&</sup>lt;sup>50</sup> Id.

<sup>&</sup>lt;sup>51</sup> Id.

<sup>&</sup>lt;sup>52</sup> See Judge Rotenberg Ctr., GED Recording Sheet Andre McCollins, Oct. 25, 2002 (on file with author).

<sup>&</sup>lt;sup>53</sup> Gonnerman, *supra* note 49.

<sup>&</sup>lt;sup>54</sup> Shain Neumeier, The Judge Rotenberg Center on Trial, Part One, Apr. 16, 2012, *available at* https://autisticadvocacy.org/2012/04/the-judge-rotenberg-center-on-trial-part-one/.

<sup>&</sup>lt;sup>55</sup> See BORENSTEIN, *supra* note 6, at 24, 31-33; MASS. DEP'T OF EARLY EDUC. & CARE, INVESTIGATION REPORT 3 (2007) [Hereinafter "DEEC"].

<sup>&</sup>lt;sup>56</sup> DEEC, *supra* note 52, at 3, 8-9.

suggests that the JRC acts with reckless disregard for potential side effects of contingent electric shock, including those with higher incidence in the JRC's population.

There is no evidence that JRC considers the potential negative effects, such as depression or anxiety, that may result from the use of aversive behavioral strategies with certain individual students. Several students from NYS came to JRC with diagnoses of Post-Traumatic Stress Disorder (PTSD), yet their behavior programs call for skin shock. Skin shock has the potential to increase the symptoms associated with PTSD, yet there is no evidence of data measuring these possible side effects or therapies designed to treat these symptoms.<sup>57</sup>

Furthermore, given that autistic people, who represent a significant portion of the JRC's population, have a particularly high incidence of epileptic disorders, the risk of inducing seizures posed by application of the GED further illustrates the unnecessary dangerousness of the device and its unreasonable risk of injury.<sup>58</sup> Additionally, despite the JRC's claims to the contrary, the GED has a substantially high risk of causing first and second degree burns. Not only is it common practice for JRC staff to rotate the position of electrodes to avoid burns from repeated shocks to the same area, but they also use a specific term, "GED vacation," to denote a period of time of up to several weeks during which a student is taken off the GED in order to allow injuries to heal.<sup>59</sup> Almost one-third of the students who receive GED shocks subsequently suffer from painful skin burns, some of which graduate into second-degree burn territory.<sup>60</sup> Additionally, the nature of the GED's design causes the device to spontaneously activate (referred to as a "misapplication") without any protections in the product design against external interference.<sup>61</sup> As of 2013, the GED continues to pose a threat of malfunctions and unintentional shocks to JRC students.<sup>62</sup> The JRC deliberately designed the GED to inflict pain and suffering. and has failed to address crucial engineering flaws in the device that cause unintentional shocks. The inordinately high amperage emitted by both the GED-1 and the GED-4, compounded by the inherently degrading nature of the device as well as the high frequency of burn injuries caused by the GED's shocks, constitute both substantial and unreasonable risk of injury to the students who receive GED shocks.

<sup>&</sup>lt;sup>57</sup> NYSED, *supra* note 13, at 13.

<sup>&</sup>lt;sup>58</sup> See generally Paul M. Levisohn, The Autism-Epilepsy Connection, *in* 48 EPILEPSIA 33 (2007); Amy Brooks-Kayal, Epilepsy and Autism Spectrum Disorders: Are There Common Developmental Mechanisms?, *in* 32 BRAIN DEV. 731 (2010); Frank M.C. Besag, The Relationship Between Epilepsy and Autism: A Continuing Debate, *in* 98 ACTA PAEDIATRICA 618 (2009); Sarah J. Spence & Mark T. Schneider, The Role of Epilepsy and Epileptiform EEGs in Autism Spectrum Disorders, *in* 65 PEDIATRIC RES. 599 (2009); Thierry Deonna & Eliane Roulet, Autistic Spectrum Disorder: Evaluating a Possible Contributing or Causal Role of Epilepsy, *in* 47 EPILEPSIA 79 (2006); Anne T. Berg, *et al.*, Risk and Correlates of Autism Spectrum Disorder in Children with Epilepsy: A Community-Based Study, *in* 26 J. OF CHILD NEUROLOGY 540 (2011).

<sup>&</sup>lt;sup>59</sup> See Judge Rotenberg Ctr., *supra* note 34, at 31; Letter from Gregory Miller, former JRC Teacher's Assistant, to Muthar S. Shamsi, FDA District Director, and Karen Archdeacon, FDA Compliance Officer (16 Jan. 2013) (on file with author), *available at* http://www.autistichoya.com/2013/01/letter-from-former-teacher-at-torture.html [hereinafter "MILLER"]; NYSED, *supra* note 13, at 21-22 ("The rotation of electrodes is necessary to prevent skin burns that may result from repeated application of the shock to the same contact point on the student's body."); BORENSTEIN, *supra* note 6, at 52; ISRAEL, *supra* note 44, at 110 ("The electrode site is checked each hour, when the electrode is rotated, and also after each application.").

<sup>&</sup>lt;sup>60</sup> CNN, New York Education Officials Ban Shock Therapy (2006), *available at* http://articles.cnn.com/2006-06-21/politics/shock.therapy.school\_1\_shock-therapy-electric-shock-geds?\_s=PM:EDUCATION.

<sup>&</sup>lt;sup>61</sup> GONNERMAN, *supra* note 7; MILLER, *supra* note 44; BORENSTEIN, *supra* note 6, at 86-87.

<sup>&</sup>lt;sup>62</sup> BORENSTEIN, *supra* note 6 at 86-87.

### VI. Conclusion

The JRC's repeated pattern of abuse with the GED, coupled with the clear evidence that continued marketing of the GED presents both substantial deceptions and substantial risk of injury, present a compelling and urgent case for an outright ban on all aversive conditioning devices used for contingent electric shock. The use of electric shock aversives for behavioral modification is completely inconsistent with the current literature and best practices in the field of treating the most severe behavioral challenges. Furthermore, shocking disabled people in the name of treatment is a profoundly disturbing practice that does not belong in any civilized society. I urge the panel to recommend a full and total ban on aversive conditioning devices used for contingent electric shock.

If you have any questions, please do not hesitate to contact me to discuss this further at your convenience.

Respectfully submitted,

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