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## National Council on Disability Letter to the FDA on Taking Action Against Judge Rotenberg Center

March 27, 2014

Commissioner Margaret A. Hamburg, M.D.  
U.S. Food and Drug Administration  
10903 New Hampshire Avenue  
Silver Spring, MD 20993

### **RE: Neurological Devices Panel of the Medical Devices Advisory Committee**

Dear Commissioner Hamburg:

The National Council on Disability (NCD) writes about the forthcoming Neurological Devices Panel of the Medical Devices Advisory Committee meeting, scheduled to convene on April 24, 2014 to discuss the safety and effectiveness of aversive conditioning devices. As an independent federal agency charged with advising the President, Congress, and other Federal agencies regarding laws, policies, practices, and procedures affecting people with disabilities, NCD submits this letter as a sister Federal agency. NCD strongly opposes the use of aversive treatments, including the use of all GEDs and other painful skin shock devices, and expressed this longstanding position in recent correspondence to the Department of Justice and Commonwealth of Massachusetts.<sup>[i]</sup> NCD reiterates these views and recommendations here, as we believe it has great bearing on your deliberations.

On March 22, 2013, NCD met with several FDA key officials, including Elizabeth Dickinson, Chief Counsel, to discuss the FDA's investigation on the use of Graduated Electronic Decelerators (GEDs) at the Judge Rotenberg Center (JRC). At the meeting, NCD strongly urged the FDA to expedite its investigation and quickly move forward with its findings.

NCD has a longstanding history of opposing aversive treatments.<sup>[ii]</sup> As stated in NCD's 1995 Report, *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children*,

While it is possible to understand the desperation of these parents, to share their exasperation with ineffective programs and treatments, and to sympathize with them in their frustration to locate appropriate programs, there are limits to what society can permit in the name of treatment. There are those in our society who would advocate for severe physical punishment or even the mutilation of prisoners convicted of what everyone would agree are heinous crimes. Yet these prisoners are afforded protection under the law from this treatment, even though there are those who would claim that such treatment would “teach them a lesson.” Students with severe behavioral disabilities are not criminals, and yet present law allows them to be subjected to procedures which cannot be used on the most hardened criminals, or, in some cases, even on animals. [\[iii\]](#)

In 2011, the Massachusetts Department of Developmental Services (DDS) took an important step in protecting the rights of future JRC students by adopting regulations that greatly restrict the intentional use of pain as a form of treatment – including the use of electric shock, seclusion, and restraints on young children and adults with disabilities. While the Massachusetts regulations are laudable, JRC is still permitted to subject students that were previously admitted to aversive treatment. Further, there is nothing stopping JRC from moving their facility to a different state to avoid the new Massachusetts regulations. In fact, JRC has already moved twice since its inception: first from California to Rhode Island, following a student’s death and subsequent investigation by the state of California, and then from Rhode Island to Massachusetts, where it is located today. [\[iv\]](#)

Recent media attention has shed light on a long and horrifying history of abuse at JRC. One such incident occurred at a JRC group home in August 2007, when a prank phone call directed staff to pull two children out of their beds in the middle of the night and shock them, while restrained, over 100 times combined, resulting in the need for hospital care due to burns caused by the GED device. [\[v\]](#) Moreover, in 2012, video footage was released by a court showing an incident at JRC in which Andre McCollins, an autistic teenager, was strapped to a table and screaming in pain, while staff administered 31 shocks to his body, for failing to remove his jacket. [\[vi\]](#) This disturbing video has created worldwide outrage.

Recent correspondence sent to NCD further reveals the alarming treatment JRC subjects its students to. [\[vii\]](#) In this email, a former student who was at JRC for seven years recounts the long-lasting and devastating results from the GEDs. This former student reports being burned many times, some which have caused permanent scarring, long-term loss of sensation and numbness. She recalls several instances where the GED devices malfunctioned. She also reports JRC staff inappropriately using the GED devices. Recalling these ghastly experiences, the former student states, “I was paralyzed with fear every day” and asserts “life with GEDs is a life of constant anxiety.” The former student reports still experiencing frequent nightmares and flashbacks.

Unequivocally, the use of GEDs at JRC has many negative physical and emotional consequences. Indeed, JRS’s own administrators have admitted that the GED devices are intended to “hurt.” [\[viii\]](#) Not only are the GED devices extremely painful for the students forced to wear them, but they have caused skin damage. Nearly one-third of the students who wear the GED device experience painful skin burns, some of which blister (second degree burns). [\[ix\]](#)

The use of electric shock is not a legitimate method of treatment for any person. Such measures – whose use against non-disabled individuals is already recognized as illegal and immoral – are contrary to the letter and the spirit of the Americans with Disabilities Act and the Developmental Disabilities Assistance and Bill of Rights Act.

In light of the effect on children and youth and with disabilities nationwide, NCD is gravely concerned by the use of aversive treatments at JRC – the only known school in the United States to provide such treatment. We are aware that students from an estimated 18 other states and the District of Columbia attend JRC and are therefore potential recipients of such aversive treatments. [\[x\]](#) As such, NCD views this as a significant issue of national importance and FDA’s actions will have a national impact.

The treatment being provided at JRC is contrary to federal policy and the findings of mental health research. The 2003 *President’s New Freedom Commission on Mental Health* stated that restraint will be used only as safety

interventions of last resort, not as treatment interventions.[\[xi\]](#) Similarly, the US Department of Health and Human Services Substance Abuse (HHS) and Mental Health Administration (SAMHSA) has found that seclusion and restraints are detrimental to the recovery of persons with mental illnesses.[\[xii\]](#)

The practices of JRC are equally contrary to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) which states in part:

...The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that... meet minimum standards relating to— provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to ***no greater risk of harm than others in the general population***... and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program... (emphasis added).[\[xiii\]](#)

The objectionable practices at JRC have not only attracted national attention but have also been scrutinized internationally. In June 2010, the United Nations Special Rapporteur on Torture stated that the practices of the Judge Rotenberg Center in Canton, Massachusetts equate to torture and urged the US government to appeal.[\[xiv\]](#)

FDA must take immediate action and protect children and adults with disabilities across the nation by prohibiting the use of all GED devices and other skin shock devices currently used by JRC. NCD understands that in order to ban a device, FDA must make a finding that a device “presents substantial deception or an unreasonable and substantial risk of illness or injury” based on all available data and information.[\[xv\]](#) Unequivocally, the information provided in this letter, as well as significant social science research, demonstrates the substantial risk of injury encountered by students at JRC. Accordingly, NCD urges FDA to take swift action to ban the use of all GEDs.

Thank you for your anticipated attention to this critical issue. NCD stands ready to assist you in ways that our collaboration can best benefit students with disabilities and their families while promoting safe learning environments for all students across America. We are available to discuss these matters at your earliest convenience. Please contact me through NCD’s offices at (202) 272-2004.

Respectfully,

Jeff Rosen  
Chairperson

cc:

Jill Hartzler Warner, Acting Associate Commissioner for Special Medical Programs

James Swink, Medical Devices Advisory Panel Coordinator

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[\[i\]](#) National Council on Disability, *Letter to DOJ Disability Rights Section Chief Allison Nichol on the Judge Rotenberg Center* (April 12, 2012), available at [/publications/2012/DOJApril132012/](#); National Council on Disability, *Comments of the National Council on Disability in Support of Proposed Amendments to Regulations on Behavior Modification at 115 CMR 5.14*, (July 18, 2011), available at [/publications/2011/July182011](#).

[\[ii\]](#) National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (2002), available at [/publications/2000/Jan202000](#); National Council on Disability, *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children* (1995), available at [/publications/1995/09051995](#).

[iii] *Id.*

[iv] 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), 6, available at <http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/USReportandUrgentAppeal.pdf>.

[v] TIME, 'Shock' School Trial: Where Is the Evidence that Abuse Helps Treat Autism? (2012), available at <http://healthland.time.com/2012/04/23/shock-school-trial-where-is-the-evidence-that-abuse-helps-treat-autism/#ixzz2IFduZZLs>.

[vi] Politico, *Teen Electrocuted for Refusing to take of his Coat*, available at <http://www.politicalnews.com/teen-electrocuted-for-refusing-to-take-off-his-coat/>.

[vii] Email sent to NCD from Nancy Weiss, Director of the National Leadership Consortium on Developmental Disabilities at the University of Delaware, on behalf of former JRC student, January 17, 2013.

[viii] ABC Nightline, *Feds Warn School Featured in ABC News Report: Shock Devices Violate Law*, December 19, 2012, <http://abcnews.go.com/Blotter/feds-warn-school-abc-news-report/story?id=18018135>.

[ix] Polyxane S. Cobb, *A Short History of Aversives in Massachusetts*, available at <http://www.arcmass.org/Portals/0/JRC%20History%202005.pdf>.

[x] 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](http://articles.cnn.com/2006-06-21/politics/shock.therapy.school_1_shock-therapy-electric-shock-geds?s=PM:EDUCATION).

[xi] 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), 12, available at <http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/USReportandUrgentAppeal.pdf>.

[xii] *Id.*

[xiii] 42 U.S.C. § 15009(a)(3)(B)(i-iii) (2000).

[xiv] ABC Nightline, *UN Calls Treatment at Mass. School 'Torture'* (2010), available at <http://abcnews.go.com/Nightline/shock-therapy-massachusetts-school/story?id=11047334>.

[xv] 21 U.S.C. § 360f.

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**National Council on Disability** 1331 F Street, NW, Suite 850 Washington, DC 20004