

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*