

April 11, 2014

Avena Russell Center for Devices and Radiological Health Food and Drug Administration 10903 New Hampshire Ave., Bldg. 66, Rm. 1535 Silver Spring MD 20993-0002

Dear Ms. Russell,

On behalf of APRAIS, the Alliance to Prevent the Use of Restraint, Aversive Procedures, and Seclusion, I write to urge the FDA to ban the use of electric shock for behavior modification.

As many of our organizations have made numerous requests in the past related to our concerns for the health, safety, and welfare of the young people in the care of the Judge Rotenberg Center in Massachusetts, the undersigned write to you with a renewed call for action; the immediate and complete cessation of approval of the use of electric shock devices as a form of behavior control.

The Judge Rotenberg Center has been cited for numerous violations of FDA regulations due to its ongoing modifications to the Graduated Electronic Decelerators. These modifications have consistently increased the allowable voltage used to shock patients. In the hands of Judge Rotenberg Center staff, these GED devices deliver brutal electric shocks to young people. It is important to note that the Judge Rotenberg Center is not only the *only* facility in the United States to use such a device; the Judge Rotenberg Center is also the sole manufacturer of this machine.

A significant body of research refutes the effectiveness of these extreme techniques when attempting to address behavioral concerns of those with significant disabilities. Not only are these strategies damaging for the recipients, they are also dangerous for the staff who are implementing them. Only seven states send students to the Judge Rotenberg Center – the other 43 states include citizens with equally challenging behaviors, but rely on other, more humane and less traumatic means to educate and treat them.

In addition to the evidence supporting the ban of such violent and inhuman "treatments" for individuals with challenging behaviors, numerous oversight bodies have launched investigations into the Judge Rotenberg Center due solely to the use of these devices. In the summer of 2010 the Department of Justice commenced an investigation into the Center, which is ongoing. Additionally, in the summer of 2012 the United Nations' Special Rapporteur on Torture, Juan Mendez, brought a formal request to investigate the Judge Rotenberg Center's use of electric shock with children. Mr. Mendez stated, "The use of electricity on anyone's body raises the question of whether this is therapeutic or whether it inflicts pain and suffering tantamount to torture in violation of international law." The United Nations' investigation is also ongoing, and while these investigations are important procedures in gathering information to affect change, the children who are victims of this inhumane treatment cannot wait any longer.

In 1990 – *twenty four years ago* – many of the nation's leading scientists on behavior management for people with the most complex and challenging behaviors wrote: "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 dehumanizing (facial sprays, shaving cream in mouth, foul smells) are no longer acceptable." (Horner, R. H., Dunlap, G., Koegel, R. L., Carr, E. G., Sailor, W., Anderson, J., Albin, R. W., O'Neill, R. E., (1990) Towards a technology of 'nonaversive behavioural support', *Research and Practice for Persons with Severe Disabilities*. 15, 125-132.)

Finally, continuing to allow for such procedures is deeply inconsistent with work of other federal departments to prevent and eliminate the use of aversive behavioral interventions. Continuing to allow the use of GED devices is in direct conflict with the Department of Education's recently released Restraint and Seclusion Resource Document. SAMHSA's National Center for Trauma-Informed Care's development of evidence-based behavioral health interventions and de-escalation techniques have also made these devices completely unnecessary.

It is with these considerations that we call upon your respective authority to immediately and completely ban the use of electric shock devices for behavior management. History has proven that the administration at the Judge Rotenberg Center has made little to no effort to eliminate the use of techniques akin to torture, or that they have any intention of eliminating these techniques, in the face of a large and growing body of science on the effectiveness of positive approaches for people with behavior challenges. It is time to end this dangerous and painful "treatment" of some of the most vulnerable young people in our country. An immediate ban of federal approval of electric shock is the only conscionable action.

APRAIS: The Alliance to Prevent Restraint, Aversive Intervention and Seclusion was founded in 2004 with a mission to prevent the use of restraint, seclusion and other

aversive interventions that deny people their humanity and rob them of their dignity. To learn more, visit <u>www.tash.org/aprais</u>.

We thank you for your attention to this serious matter and we look forward to your reply at your earliest convenience.

American Association of People with Disabilities Association of University Centers on Disabilities Autism National Committee Autistic Self Advocacy Network Autism Society Bazelon Center for Mental Health Law Children and Adults with Attention Deficit/Hyperactivity Disorder Council of Parent Attorneys and Advocates **Disability Rights Education & Defense Fund** Families Against Restraint and Seclusion Family Alliance to Stop Abuse and Neglect Gamaliel Foundation National Alliance on Mental Illness National Association of State Mental Health Program Directors National Autism Association National Council on Independent Living National Disability Rights Network National Down Syndrome Congress National Down Syndrome Society Parent 2 Parent USA RespectAbility Law Center TASH The Arc of the United States

APRAIS Allies: Autism Women's Network Statewide Parent Advocacy Network