

To: Michael Yudin, Acting Assistant Secretary, Office of Special Education and Rehabilitative Services

Cindy Mann, Deputy Administrator/Director, Center for Medicaid and CHIP Services (CMCS), Centers for Medicare and Medicaid Services

Re: Ongoing funding of Judge Rotenberg Center

Date: January 10, 2013

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 funding for the Center considering the US Food and Drug Administration's recent Warning Letter dated December 6, 2012.

The FDA's letter dated December 6, 2012—the third warning letter to the Judge Rotenberg Center in 19 months—cites the Judge Rotenberg Center for 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 so-called caregivers who are implementing 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. In the summer of 2010 the Department of Justice commenced an investigation into the Center, and has yet to release findings. 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.

Finally, continuing to allow federal funds to be provided for such procedures is deeply inconsistent with work of your departments to prevent and eliminate the use of aversive behavioral interventions. Continuing to fund the use of GED devices flies in the face of the excellent work of SAMHSA's National Center on Trauma Informed Care, and is in direct conflict with the Department of Education's recently released Restraint and Seclusion Resource Document.

It is with these considerations that we call upon your respective authority to immediately and completely suspend federal funding for the Judge Rotenberg Center. 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. Additionally, the Judge Rotenberg Center administration seems to flout the continued intervention of the FDA and other regulatory bodies regarding its continued use of shock "therapy" for the individuals in their care. It is time to take drastic and significant action in order to compel the Judge Rotenberg Center to change its treatment of some of the most vulnerable young people in our country. An immediate suspension of federal funding for the Judge Rotenberg Center 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. APRAIS is comprised of 24 national non-profit organizations. To learn more, visit www.tash.org/aprais.

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

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 Maryland Disability Law Center National Alliance on Mental Illness National Autism Association National Centers for Independent Living National Down Syndrome Congress National Down Syndrome Society Parent 2 Parent USA RespectAbility Law Center TASH The Arc of the United States