

26 July 2011

Senator Michael Rodrigues, Chair
Representative Kay Khan, Chair
Honorable Committee Members
Joint Committee on Children, Families, and Persons with Disabilities
State House, Room 213B and Room 146

Dear Chairman Rodrigues and Chairman Khan,

I am writing to respectfully urge the Joint Committee on Public Safety and Homeland Security to favorably report Senate, No. 49, An Act relative to level IV treatment interventions; Senate, No. 50, An Act creating a special commission on behavior modification; Senate, No. 51, An Act relative to the humane treatment of disabled persons; and House, No. 77, An Act relative to the humane treatment of disabled persons, favorably from committee. These bills will be heard before your Committee on 26 July 2011.

I belong to the Autistic Self-Advocacy Network, which fully supports these bills, and the Autism Women's Network, in addition to being a developmentally disabled person. I am Autistic.

At the heart of the matter today is the Judge Rotenberg Center (JRC), a residential and day institution for the developmentally disabled and behaviorally challenged in Canton, Massachusetts. The Judge Rotenberg Center has been open since at least 1977, when it was originally called the Behavior Research Institute until a 1986 ruling by a Judge Rotenberg allowing the use of electrical shock as a therapy. Afterward, it was renamed in honor of this judge.

The Judge Rotenberg Center is the only institution in the entire country that uses what are termed "shock aversives," as well as other forms of aversive therapy including depriving students of up to three-quarters of their daily nutrition.

The supposed purpose of aversive therapy is to create a mental association in the patient's head between an undesirable behavior or outcome and an unpleasant stimulus. For example, if you sprayed a dog with water every time it barked, you are using an aversive behavioral intervention by creating a mental association between an unwanted behavior (barking) and an unpleasant stimulus (being sprayed with water.) Less painful or extreme aversives like time-outs or verbal reprimands are often used with children, including non-disabled children.

Those of coming to testify today in support of these bills are doing so because we believe the Judge Rotenberg Center's use of electric shock aversives on developmentally disabled people is morally wrong, inhumane, and ineffective in rectifying behavioral problems. But the Judge Rotenberg Center's staff will attempt to rebut our arguments with stories about past and current students at their institution. They will argue that the patented GED skin-shock device that they use is necessary for their students who receive it, that the only alternative to shock aversives is heavy doses of psychiatric medication, and that regulating or banning aversives is a civil rights violation. But these arguments are gross falsifications.

Firstly, the Judge Rotenberg Center's supporters will argue that level III aversives, such as their GED skin-shock device, can be "a life-saving intervention" in the cases of individuals with

maladaptive behavioral problems like severe head-banging, skin-picking, hitting or punching themselves, biting others, spitting at others, or attacking others. Perhaps in a true emergency, when used *solely* as a *temporary* measure, in the most severe cases of self-injurious or destructive behavior that threatens imminent, life-threatening harm to self or others, such aversives like electric shocks *may* have *some* level of efficacy.

That is why I support Senate Bills 49, 50, and 51 (as well as House Bill 77, which is a total ban on aversives), which create a compromise, *permitting* the use of these kinds of aversives under the assumption that they *might* be effective with a *few* people while creating more oversight and stricter regulations that do not currently exist. For these three bills, it is inconceivable that the Judge Rotenberg Center, which ostensibly exists to improve the lives of its students, would oppose measures that will protect the rights of their students and ensure they are receiving a quality level of care by appropriately trained staff, as well as allowing the Judge Rotenberg Center to provide for alternative means of behavioral intervention and support and to seek alternative remedies. Instead, the Judge Rotenberg Center's supporters make another fallacious argument in response to this speculation.

The Judge Rotenberg Center's second fallacious argument is that because positive behavioral interventions failed with these individuals, the only possibly effective alternative to these types of aversives is heavy dosages of psychotropic medications that will result in disabled individuals being in "a catatonic state." This is not true. Despite the Judge Rotenberg Center's efforts to paint opponents of shock aversives as promoters of overmedication, many people who oppose the use of these kinds of aversives also do not support arbitrary and ineffective psychiatric prescriptions for any or all developmentally or intellectually/cognitively disabled people. For some people, medications may be effective in the long-term and in the short-term; for others, such medications may be effective and necessary as a temporary short-term measure; and for still others, these medications may be unnecessary and should be not prescribed.

There are other institutions that care for individuals with the most severe, self-injurious or destructive behaviors *without* using chemical restraints *or* shock aversive therapy, and whose residents have good outcomes. The Judge Rotenberg Center does not provide transitional planning for its students to prepare for leaving the Judge Rotenberg Center and returning to the community. Instead, it advocates that its students belong at the Judge Rotenberg Center and must be given shock aversive therapy for the rest of their lives. There exists an implied threat that without the Judge Rotenberg Center, its students will be returned to their parents' doorsteps without *any* behavioral supports and without other options for support and services. This is entirely unfounded and untrue.

There are other institutions that serve the same population as the Judge Rotenberg Center, which do not use shock aversives or similar behavioral interventions, and which have been successful in reducing and eliminating dangerous behaviors. Additionally, there are public and private providers of a variety of supports and services for disabled people, including people with severe, challenging maladaptive behavior problems. There is no dearth of resources.

We know that aversives, consistent with the theory of Pavlovian conditioning, only address the actual maladaptive behaviors. They do not address the root causes of why these people engage in these harmful behaviors. Take a weed, for instance. If you pull a weed's leaves, the roots remain. The weed may appear to be gone for awhile, but check back in a few days or weeks, and voila! It's back. If you don't take the time to search for the roots and remove them, you will not kill the weed.

Likewise, if you do not address the *causes* of maladaptive behavior—sensory overload, inability to communicate, etcetera—you are not addressing the real problem. It's the tip of the iceberg, so to speak. Aversives cannot do that. Aversives cannot remove offending sensory stimuli, and aversives cannot provide people with a means of expressive communication, be that verbalizing speech or otherwise. All aversives can do is induce fear and pain in a person who may or may not be able to communicate that terror.

We also know from psychology that an aversive, once removed (such as upon release or “graduation”), will cease to have its effect. Given sufficient time, the mental association of the aversive with the undesirable behavior will fade, and the frequency of the undesirable behavior will actually increase again. This alone should be enough to refute the arguments in favor of the efficacy of aversive therapy. As a long term measure, it has no effect, and while used, it is a band-aid over a bullet wound at best.

The Judge Rotenberg Center’s third argument will be that implementing regulations or a ban on aversives will deprive the families of disabled people of their civil rights. But this is not the 1950’s, where disabled people only existed as extensions of their families, and where their parents or siblings alone had the right to speak for them, putting words in their mouths about their wants and needs. This is the twenty-first century, where disabled people from all walks of life, and who require various levels of daily support for their needs, publicly and privately advocate for themselves and their peers. If the legislature does not take steps against these kinds of aversives, there *will* be a civil rights violation—a violation of the civil rights of every disabled person in Massachusetts.

The Judge Rotenberg Center will argue that the a restriction or ban violates the civil right of parents to make decisions for their children. Our courts have upheld the rights of parents to make decisions for their children without state intervention except when there is a compelling interest on the part of the State to act in the interest of the child's benefit, such as in cases of abuse. In 2009, Minnesota Judge John Rodenberg ruled that thirteen year old Daniel Hauser's parents could not choose to deny their son necessary chemotherapy in favor of alternative treatments; Daniel was provided with child protective services.

Whenever a child's rights are in danger, and in particular, whenever a disabled child or adult's rights are in danger, our government does have a moral and legal obligation to prevent the infringement of that individual's rights. All people have certain rights, including the right to be free from fear of inhumane or cruel treatment. You would think that our most vulnerable citizens, if anyone, would be protected by the government. I, and other disabled people and advocates across the state, am begging you to put an end to the abuses of the last few decades. If the government does not intervene to protect these essential rights, they allow for the rights of any disabled person to be trumped by the agendas of others. Disabled people have civil rights too, and those rights must be not merely recognized and paid lip service, but must also be upheld and protected.

The Judge Rotenberg Center uses painful aversive “treatments” when there is scientific and empirical evidence that supports the effectiveness of non-painful interventions in reducing and eliminating self-injurious and destructive behaviors. Instead, its staff subjects disabled people to electrical shocks, and the State allows them to do so.

For well over twenty years, legislators in the Massachusetts General Court have tried to pass bills to completely ban shock aversive therapy; however, each time, they are met with the millions of dollars

the Judge Rotenberg Center has in legal retainers and lobbying power. Further, as most elected legislators are not experts on psychology or developmental disabilities, it can be easy to be intimidated into compliance by the endless train of Judge Rotenberg Center staff.

Based on the appearance of close to forty Judge Rotenberg Center staff or administrators at the Department of Developmental Services's regulatory hearing last Friday, I am certain that the same people will appear before you today, shepherding dozens of staff members before your Committee in order to repeat what has always been successful in the past—intimidating our legislators into complying with their agenda against proven science and the voices of disabled people and their advocates. Do not let a chorus of voices drown out the voices of people who may not be able to express themselves as eloquently, but who certainly have feelings and rights. If you cannot ban aversives, at least impose regulations to protect the people who receive them. Prevent the opportunity for abuse of the most vulnerable members of our community. If the government does not take action, who will?

Lydia Brown