

1 : A LONG STORY

January 2013

Dear FDA,

My name is Jennifer Msumba and I attended the Judge Rotenberg Center. I am writing to ask you to please reconsider your approval of the Graduated Electronic Decelerator (GED) for use on ANY human being. I was placed on the GED about 2 months after arriving. I started out on the GED-1, and during my last few years I was placed on the GED-4. There are so many of us that were tortured with these devices, this “treatment.” I believe the reason why more ex-students haven’t spoken out is because they are either non-verbal, afraid, or believe that no one cares about us or it will not make a difference. Parents and families that speak and rally in favor of the GED, are not the ones who have to experience it, the pain and anxiety, day after day for years on end.

The GED is harmful, even the GED-1. I was burned many times, and I still have scars on my stomach from being repeatedly shocked there, by the FDA approved GED-1. The electrodes had actually burned into my skin. I experienced long term loss of sensation and numbness in my lower left leg, after getting a shock there. I felt searing pain all the way down to the bottom of my foot and was left with no feeling in my skin from the knee down for about a year . . . Also, I would like you to know that the devices have a tendency to malfunction and go off all by themselves. The Judge Rotenberg Center (JRC) refers to this as a “misapplication.” It happened to me and other students so many times I cannot count. Sometimes the GEDs will just start to go off and shock you by themselves. Other times the staff shocked one student but the remote can also set off someone else’s device at the same time. I have also gotten accidentally shocked from staff mixing up my device with another student’s device, shocking me instead.¹ Then there are the times when

staff intentionally misused the GED. I have had staff who became angry with me and started pushing more than one remote at a time, shocking me several places on my body at once. I have had staff intentionally give me shocks for things I didn't do in places like the bus where there was no camera to prove it. I have had numerous staff over my years there threaten me with a GED, antagonize me to try and get me to have a behavior they can then shock me for, merely for the sport of it. Staff can and DO use the GED to scare non-verbal students into doing what they want them to by pretending they are about to shock them. Some even laugh when they do this.

Many of the things I and others get shocked for at JRC were very small things. They would often shock us for things simply because staff found them annoying and they would keep writing therapy notes until our psychologist added it to our program. I got shocked for tic like body movements, for which I have no control over, and which don't hurt me or anybody else. I would be shocked for waving my hand in front of my face for more than 5 seconds, for closing my ears with my fingers, which I do when things get too loud, because I cannot tolerate too much noise. I would be shocked for wrapping my foot around the leg of my chair, for tensing up my body or my fingers, and the list goes on and on. There was a period of time where I and many of the other students were getting shocked for having 5 verbal behaviors in an hour. A verbal *behavior* is a minor behavior like talking to yourself, noises (such as clearing your throat), or talking without permission. Every hour would start a new block. And if you were pinpointed more than 4 times in that hour, on the 5th you would get a shock, and then for EVERY minor verbal behavior after that you would be shocked. If you talked out a 6th time, shock. If you had to go to the bathroom, and you had to go really bad, but you asked more than once, that would be nagging, which is a verbal behavior. And these were the things we were getting shocked for.

. . . I was paralyzed with fear every day. No matter what I did I was doomed. I ask those who read my letter to think to themselves about how often they do some of these things while they are working. Twirl their pens, talk to yourself or think out loud, ask a question to someone nearby, hum a song that's in

your head, laugh at something funny in the room. These are things humans do. And they are not harmful. Yet we were being subjected to terrible pain and fear for doing these simple things . . . People NEED to know these things happened . . .

There was a time when I was there that I was on the portion program. This is where JRC starves you as a punishment for having a behavior. For example, my first plan was that for every time I had a minor behavior, such as talking to myself, rocking, wiggling my fingers, I would lose a part of my next meal. My meals came to the classroom cut into tiny pieces and divided into portions inside of a little plastic cup. Every time I had one of these little behaviors, I was forced to stand up and throw one cup away. There were many days I would lose most of my meals. And the hungrier I got, the more frantic and restless my body became. This caused me to have more behaviors like tics and rocking, and in turn I would lose more food. My mind clouded and I could no longer concentrate. I would often become so frustrated from this I would end up hurting myself. At the end of the day, at 7pm, I was offered “LOP” (loss of privilege) food. This was made intentionally to be completely unappetizing. It was ice cold, and it was made up of chicken chunks, mash potato, spinach, and then doused with liver powder, then set to sit in the refrigerator for days. The smell alone made me sick. And I never once was able to eat it, no matter how hungry I got.

Most of us on GED’s had to sleep with the devices on. That means locks and straps that get all tangled around you and make it very hard to lay down in a comfortable way. I was very anxious to close my eyes, always fearing a shock for something I might not have even known I did. My fears came true one day, and I was given a GED-4 shock while I was asleep. It was not explained to me why I got this shock. I was terrified and angry. I was crying. I kept asking why? And they kept telling me “No talking out.” After a few minutes Monitoring called and told the staff to shock me again for “Loud, repetitive, disruptive talking out.” The next day I asked the supervisor why I had gotten that GED. She explained that staff had found a small piece of plastic in my self-care box, which contained my shampoo bottles etc., and that they considered this a hidden weapon. I could not believe it. I did not hide anything in my self-care box. I had not

done anything wrong. Yet I was shocked for it . . . That piece of plastic, which I was never shown, had probably broken off of one of the plastic containers inside the box. And I was severely punished for this. After this incident I really stopped sleeping. Every time I closed my eyes they would jump open, anticipating that jolt somewhere in my body.

I truly believe that the judges that approve us for the GED have no idea what it really is like. All they have to go on is what JRC claims. The GED does not feel like a “hard pinch” or a “bee sting.” It is a horrible pain that causes your muscles to contract very hard, leaving you sore afterward. I would often have a limp for one or two days after receiving a GED. The devices JRC puts on us are not the same ones they show to the outside world when they let outsiders try the GED. Students wear a different electrode, a long one with 2 metal electrodes that radiate the electricity across a large area.

Besides the physical pain, life with GEDs is a life of constant anxiety. I experienced heart palpitations daily, had a very hard time sleeping and eating, and became paranoid, always wondering if I was about to get shocked and constantly alert in all directions. I eventually became very depressed there and contemplated suicide every night. Now, after having been gone almost 4 years, I am still having nightmares and flashbacks during the day, especially when I hear certain noises that remind me of GEDs and JRC.

I want to mention, similar to many other students, I was also tied to the 4-point restraint board and given multiple shocks for a single behavior. And if I screamed out in fear while on the board, I would be shocked for that as well. I was shocked for behaviors I had no control over, such as tensing up and tic-like body movements. We were always having to watch others getting shocked in the room. Hearing others scream, cry, beg to not be shocked. Students would scream “I’m sorry, No, Please!!” all day. I, like other students, would cringe and feel sick and helpless while watching others getting shocked. I was so anxious about getting shocked that I would many times bang my head just to get it over with. The GED often was the cause of my behavior problems. The students that get shocked the most at JRC are non-verbal. So, they cannot speak up. I feel that

just because we were born different, we are not given the same rights to be protected from tortures like the GED.

We are at the mercy of guardians and judges. When I was brought to court to be approved for the GED, I was not told where we were going or why. I was brought into the courtroom wearing a helmet and restraints on my wrists and ankles. I was not questioned by the judge. All he had to go on was my appearance in those restraints, testimony from JRC officials, and charts of provoked behaviors. These behaviors came from being forced to sit in isolation with a straight upright posture, in the center of a hard restraint board, day after day, week after week, for two months. I received no real help and no socialization. For those two months I was not allowed to sit in a chair, at the classroom or residence. I was to sit on the board. Also, JRC provoked me by not allowing me to shower during those two months. Instead of showers, I was bathed tied to a restraint board, naked, while staff washed me, putting their hands all over me. All in front of cameras, where Monitoring watched, including men. Being tied on a restraint board, naked, with my private areas exposed to the staff in the bathroom and the cameras was the most horrible, vulnerable, frightening experience for me. I would scream out “rape, rape!” And these were recorded as major behaviors for me.

When I first arrived at JRC, I was immediately subjected to humiliation and provocation by them forcing me to wear a diaper. I in NO WAY needed or have ever needed a diaper as an adult. I am completely independent in all toilet and hygiene skills. And they knew that. I had NEVER worn a diaper up until that day, except of course when I was a little baby. And that is exactly how they made me feel, like a little baby. I was embarrassed and confused and angry. I took that diaper off constantly. When I would take the diaper off they would mark that down on my chart that they would later show the judge as destructive behavior. I would often get restrained on the 4-point board for taking off the diaper and fighting staff not to make me put it back on. In these ways and more, JRC provoked many behaviors in me that were shown on a chart to the judge. There is no way the judge could know what was provoking my behaviors. JRC told the judges that their program was the only

thing that could help me. That theirs is the only last resort treatment.

I was considered a difficult case. I would like you to know that I am doing very well in a new program that is nothing like JRC. I don't get shocked or put in restraints, and I am given help by staff and doctors that I can talk to. I am not drugged up as JRC claims I would be if I left. JRC made no attempt to understand me. Feelings do not matter to JRC and we were specifically not allowed to express them. I felt like an animal test subject there. My new program does not punish me for my problems, that are the result of having Asperger's Syndrome. I have gotten so much better from getting real help instead of constant punishment and pain.

I ask you to please investigate carefully into the GED. The ones that are actually being used on the students, not the samples JRC provides, as I have experienced them to be extremely manipulative in all things. There are no doctors overseeing us with the GED. Every few years they would drive me to a doctor's office near Framingham and not tell me why. In his office he would literally walk in, say hi how are you, and before you can answer he has signed their papers and you are shown the door.

I hope [this] will share a new perspective for you, the perspective of the ones that should matter the most, the human beings on which these devices are being used.

Sincerely,
Jennifer Msumba²

THE BEGINNING

On the night of October 19, 1976, two children were playing in the parking lot of the old St. Anthony's School in Providence, Rhode Island. They happened to look in a basement window, then rushed home and told their parents that they saw a man being beaten in the church basement. The parents immediately contacted police. The Providence Police Department report stated, "The children had observed through a window in the basement in the building a white male juvenile handcuffed to a chair in gym shorts being beaten by several adults to the degree that it was leaving red marks. At this time the po-