



Plain Language Edition

#StopTheShock

**What is it, and how can
you help? (2024)**

Words To Know

Judge Rotenberg Center (JRC)

An institution in Massachusetts. People with intellectual and developmental disabilities (I/DD), mental health disabilities, and learning disabilities live there. Both kids and adults live at the JRC. Many autistic people live there.

Aversive

A kind of punishment. Aversives get used when someone wants someone else to stop doing something. The point of aversives is to make someone feel pain or uncomfortable. Aversives get used against people with disabilities at the JRC.

Bill

An idea for a law. A bill has to get enough votes in Congress to become a law. If the bill becomes a law, people have to follow it.

Electric shock device

A device used to punish the person wearing it. The device punishes people by giving them electric shocks. These electric shocks are very painful. The electric shock device the JRC uses is called the Gradual Electronic Decelerator (GED). The GED is a kind of aversive.

Food and Drug Administration (FDA)

A government agency. They are in charge of making sure food and medicine are safe. They are also in charge of medical devices.

#StopTheShock

A campaign to end the use of electric shock devices to change someone's behavior.

Public comments

A way for people to share ideas to the government. Public comments let the government know what everyday people think about a rule or law.

Public comment periods are the time that people can make public comments. Public comment periods are usually between 1 and 3 months long.

Proposed rule

An idea or draft of a rule. That means people don't have to follow the rule yet. They only have to follow the rule if it gets passed.

Rider

Something that gets added to a bill. Sometimes, legislators add riders to bills that are about a different topic. This is because they want to make something a law without making a separate bill about it.

For example: Senator Apple wants to make a law that says everyone can get one pound of chocolate per year for free. Instead of writing a new bill that says everyone can get one pound of chocolate per year for free, Senator Apple adds that rule to a different bill about public education. If the public education bill becomes a law, the rule about chocolate will become a law, too. The rule about chocolate is called a rider because it is attached to, or "riding", the public education bill.

Self-care

Anything you do on-purpose to make yourself feel better. These can be things that help with your physical, mental and/or emotional health.

To sue/Suing

When someone tries to bring someone else to court for not following the law. This also gets called "filing a lawsuit."

Sources

Proof that shows what you are saying is true. Things like research papers and news reports are kinds of sources.

To Start

The **Judge Rotenberg Center (JRC)** is an institution in Massachusetts. People with intellectual and developmental disabilities (IDD), mental health disabilities, and learning disabilities live there. Both kids and adults live at the JRC. Many autistic people live there.

Some people at the JRC get forced to wear an **electric shock device**. This device gets used to punish the person wearing it. The device punishes people by giving them electric shocks. These electric shocks are very painful.

The JRC shocks people for:

- Standing up
- Swearing
- Not taking off a coat
- Flapping their hands
- Noises or movements that they make because of their disability
- Screaming in pain while being shocked

People with disabilities and our allies have been fighting to stop the JRC. We want to stop people at the JRC from getting shocked. We've been working together to try and stop the JRC for more than 10 years. We call our campaign **#StopTheShock**. We have tried many things to make the JRC stop using electric shocks. In this guide, we will talk about one way to stop the use of electric shocks.

What is Happening Now?

The **Food and Drug Administration (FDA)** is a government agency. They are in charge of making sure food and medicine are safe. They are also in charge of medical devices. That means the FDA is in charge of the electric shock devices.

The FDA says if a food or medicine is safe. If a medicine is not safe, they can ban it. This means that no one in the US can use or sell the medicine. They can do the same thing for medical devices. If the FDA bans a device, no one can use it in the US.

ASAN and our allies asked the FDA to ban the electric shock device. Right now, the FDA is working to ban electric shock devices. The JRC will not be able to use the devices if they get banned. To ban electric shock devices, the FDA must make a rule. A rule tells people what they are allowed to do. It also tells people what they are not allowed to do.

The FDA has put out a **proposed rule**. A proposed rule is an idea or draft of a rule. That means people don't have to follow the rule yet. They only have to follow the rule if it gets passed.

The FDA asked for **public comments** on the proposed rule. Public comments are a way for people to share ideas with the government. Public comments let the government know what everyday people think about a rule or law.

People told the FDA what they think about the proposed rule. Many people said they want the FDA to ban electric shock devices.

Some people don't want the FDA to ban electric shock devices. Those people are trying to get Congress to stop the FDA from banning electric shock devices. One way that Congress can do this is by putting a **rider** in a **bill** that would take away the FDA's power to ban devices that a court says is okay to use. This is a problem because courts have said it is okay for the JRC to use electric shock devices on many residents. **If the bill passes through Congress with this rider, the FDA will not be able to stop the JRC from shocking people.**

#StopTheShock Timeline– How Did We Get Here?

2014 - The Food and Drug Administration (FDA) held a big meeting. It invited lots of people. They invited autistic self-advocates. They also invited the JRC itself. The FDA listened to everyone at the meeting. Then, the FDA decided the electric shock devices were too dangerous to use.

2016 - The FDA made a **proposed rule** that would ban the electric shock devices. The government asked for public comments on the proposed rule. Lots of people commented on the rule about the electric shock devices.

2020 - The FDA **issued the rule that banned electric shock devices**. But the JRC did not start to follow the rule. Instead, the JRC sued the FDA so they could keep hurting people with disabilities. The JRC took their lawsuit to the DC Circuit Court.

2021 - The DC Circuit Court got rid of the rule. They said that the FDA could not ban the device. That means the JRC can keep using the electric shock devices.

2022 - Every year, Congress makes new laws to figure out how to spend money for the next year. These are called omnibus bills. ASAN and the disability community advocated for a new rule to get put in the 2023 omnibus bill. This new rule gave the FDA the power to ban the electric shock device. The omnibus bill had bipartisan support, meaning both Democrats and Republicans voted for the bill.

March 2024 - The FDA created a new proposed rule to ban the electric shock device. The FDA is asked for public comments on the draft of the rule. Hundreds of people wrote public comments to the FDA about the proposed rule.

NOW - Someone in Congress added a rider to a funding bill. The rider would stop the FDA from being able to ban devices that a court has said are okay to use, including the electric shock devices. This goes against what Congress said in 2022, when they gave the FDA the power to ban the electric shock device. We need to make sure that the rider is taken out of the bill before the bill becomes a law.

How do we get the rider taken out of the bill?

We need members of Congress who can vote on the bill to take the rider out! The part of Congress voting on the bill is called the House Appropriations Committee. They will vote on the bill on July 10th. We have between now and July 10th to stop this rider and save the FDA's power to ban electric shock torture.

What Can I Do to Help?

Call Your Representative

First, check to see if your House Representative is on the Appropriations Committee. Check if they are on the member list [here](#). If you are not sure who your Representative is, you can find out by putting in your ZIP Code [here](#).

If your Representative is on the Appropriations Committee, call the House switchboard at (202) 224-3121 and ask to be connected to your Representative's office. You can say "Please connect me to Representative [first and last name]'s office."

Once you are connected to your Representative's office, you can use our script:

*My name is [your full name], and I am from [your city]. I am a constituent of Representative [Name]. I'm calling to ask Representative [Name] to oppose Section 722 of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Appropriations Act. This rider takes away the FDA's ability to ban the use of electric skin shock for behavior modification. Only one institution in the country still uses electric shocks this way, and the UN found the practice to be torture in 2013. The FDA's proposed rule to ban the devices this year received hundreds of public comments in support of the ban, and this bill would take that decision away. The House must make sure the people they represent are heard. **Can I count on Representative [Name] to oppose this rider?***

If your Representative is not on the House Appropriations Committee, there is still something you can do! You can call the staff leads of the Agriculture, Rural

Development, Food and Drug Administration, and Related Agencies subcommittee. These staff members help Representatives working on the bill. Their contact information is:

Pam Miller (202-225-2638) and
Martha Foley (202-225-3481).

You can use this script to plan what you will say:

*My name is [your full name], and I am from [your city]. I am a constituent of Representative [Name]. I'm calling to oppose Section 722 of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Appropriations Act. This rider takes away the FDA's ability to ban the use of electric skin shock for behavior modification. Only one institution in the country still uses electric shocks this way, and the UN found the practice to be torture in 2013. The FDA's proposed rule to ban the devices this year received hundreds of public comments in support of the ban, and this bill would take that decision away. The House must make sure the people they represent are heard. **Please do whatever you can to get this rider removed!***

Email Your Representative

If your House Representative is on the [Appropriations Committee](#), please use [this form](#) to tell your Representative to remove Section 722 of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Appropriations Act!

This form uses your address to figure out where to send the email. If your Representative is on the Appropriations Committee, the form will automatically email your Representative. If your Representative is not on the Appropriations Committee, the form will automatically email the correct Congressional Staff Leads: Pam Miller, Chris Bigelow, Susan Avcin, and Martha Foley.

The form will send a pre-written email. You can edit or add to the pre-written email if you want to, but you do not have to.

What do I do after I call or email my representative?

Tell your friends, family, and others to also call or email their representatives. You can also ask organizations that you are a part of to call or email their representatives. For example, you can ask a self advocacy group or college disability group.

Take care of yourself

You might feel tired or frustrated after calling or writing an email. It is stressful to talk about people with disabilities getting hurt.

Here are some ways to take care of yourself after calling or writing an email:

1. Remember that your feelings are okay and important, whatever they are.

People feel things in different ways. You might not feel things in the same way as the person next to you. That doesn't mean either of you is wrong. You might feel really sad or angry. Or, you might feel numb, or feel not much at all. That is okay.

2. Listen to your body. If you need to cry, then cry. If you need to talk to someone, find someone who will listen. If you need to go somewhere to be alone for a while, do that.

3. Give yourself a break. Writing about things like this can take a lot of energy. It's okay if you need a break for a while afterwards.

4. Take time for self-care. Self-care is anything you do on-purpose to make yourself feel better. These can be things that help with your physical, mental and/or emotional health. Self-care looks different to everybody. Some examples of self-care are:

- creating art
- stimming
- exercise

- going outside
- journaling
- writing blog posts about other things
- playing with pets or getting support from service/support animals
- watching TV shows and movies
- watching funny videos on the Internet