

# #StopTheShock - What is it, and how can you help? (2024)

## Words to Know

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**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.

**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.

**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

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The **Judge Rotenberg Center (JRC)** is 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.

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.

## *How do we stop the shock?*

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 is asking 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.

The FDA wants to know what people think of their proposed rule. We must tell the FDA that we want them to pass the rule. We want the FDA to ban electric shock devices.

## *How does a rule get made?*

1. A government agency **decides to make a rule**. The agency might ask for more information to help them write a draft of the rule. The agency could ask the public or other agencies.
2. The government agency **writes a proposed rule**. Remember, people do not have to follow a proposed rule unless it gets passed. The FDA has already written their proposed rule about electric shock devices.
3. The agency **collects public comments on the rule**. This is the step the FDA is at right now!
4. Anyone can write a public comment. You do not need to be an expert on something to write a public comment about it. The government wants to hear from everyday people.
5. The agency **reads and answers the public comments**.
6. The agency has to read every comment. They need to write an answer to every comment. But, they can group similar comments together and answer them all at once. That's why it is important to write your own unique comment. We will talk about how to make comments unique later.
7. After answering all public comments, the agency **decides if they will issue the rule**. To "issue" a rule means to make or pass the rule.
8. If they decide to issue the rule, the rule starts to get **implemented**. **Implementing a rule** means making sure that the rule is followed.

Sometimes, people sue when a rule gets issued and implemented. **Suing** is when someone tries to bring someone else to court for not following the law. This also gets called “filing a lawsuit”.

Some reasons people might sue after a rule gets issued are:

- If they think the agency ignored their public comments
- If they think the agency didn't follow the rule-making steps the right way
- If they think the agency broke another law by making their rule

# #StopTheShock Timeline

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**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. These are called omnibus bills. ASAN and the disability community advocated for a new rule to get put in the 2022 omnibus bill. This new rule gave the FDA the power to ban the electric shock device.

**NOW** - The FDA has created a new proposed rule to ban the electric shock device. The FDA is asking for public comments on the draft of the rule.

# About Public Comments

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People in the government have to read the public comments. Then, they decide whether or not to make the rule.

Anyone can write a public comment. The government made public comments to try and hear everyone's opinions. You do not need to be an expert to write a comment.

Usually, everyday people don't send in public comments. Most people don't even know what a public comment is! Sending in a public comment can be confusing, but it is important.

The government needs to hear from people it doesn't usually hear from. For example, the government doesn't usually hear from autistic people. The government needs to hear from autistic people. That is how the government can make policies that help us.

People only have a short time to make public comments. This is called a public comment period. **Public comment periods** are the time that people can make public comments. Public comment periods are usually between 1 and 3 months long.

Public comments need to be unique. That means your comment needs to be different from everyone else's. That's because the FDA will only read unique public comments. That means if two people send the same comment, the FDA will only read it once. Even though they are 2 comments, the FDA will act like they are only 1 comment.

We want to show the FDA that lots of people want to ban electric shock devices. That means everyone needs to send different comments from each other. ASAN has templates you can follow to submit a comment. But you will need to fill in the blanks with your own ideas. This way, the FDA counts each comment separately.



When writing your comment, here are the most important things to explain:

- Why do you think the FDA should ban electric shock devices?
- How does the electric shock device hurt people?
- How would banning the electric shock device help people?

Here are some other tips for writing your public comment:

- Write 1000 words or less for your comment. The FDA might not read more than the first 1000 words.
- Do not put private information about your life in your comment. Do not write your address or other contact information. Don't send pictures or videos.
- Do not write about ECT.
  - ECT is short for electroconvulsive therapy. ECT is not the same as the electric shock devices the JRC uses. You can just say "electric shock device."
- Don't talk about other problems people with disabilities have. Focus on just talking about electric shock devices. Don't talk about Applied Behavioral Analysis (ABA). This rule is only about electric shock devices.
- Don't say that there are children at the JRC getting shocked. Right now, the JRC only uses the electric shock device on adults.
- Try to add personal details about why #StopTheShock matters to you. That will help people working for the government to remember your story.

- Only send in a comment you write yourself. You can start from ASAN's template, but you need to change it to be your own words.
- You won't hear anything back from the FDA when you send your comment. You might not hear back from the FDA at all. But your public comments will still get read by the FDA.

## ***What Can I Put in My Comment?***

### **Introduce Yourself**

Say who you are and why the problem or rule is important to you. Here are some examples of things you could say:

- I have a disability.
- I am autistic.
- I take care of someone with a disability.
- I have a family member with a disability.
- I work with a group of self advocates.
- I work with a disability rights group.

Then, say why you care about this problem. Here are some examples of things you could say:

- I do not want disabled people to be in pain.
- I do not want students to be punished by getting shocked.
- I want disabled people to be safe from getting hurt.

Say “I want the FDA to pass a rule banning the use of electric shock devices for behavioral modification.”

It's important that you use this exact sentence, or one very close to it. It helps make clear the specific problem you want the FDA to fix. You can copy the above sentence into your comment.

## **Explain Why**

Talk about why you want the FDA to pass this rule. Here are some examples of things you could say:

- It is painful for people who get shocked. The electric shock device is more powerful than a taser.
- People get shocked for things like not taking off their coat. They get shocked for screaming out in pain after being shocked.
- The electric shock device is inhumane. People should not get treated that way.
- It is scary that people with disabilities like me can be painfully shocked.
- The United Nations said the electric shock device was torture.
- There are lots of other ways to help people with disabilities without shocking them. People with disabilities across the U.S. don't get the device used on them.

## Tell a Story

If you would like to, you can share a personal story. Your story can help the FDA understand why they should ban electric shock devices. If you have questions about how to share your story, check out our [toolkit](#). Make sure to only share your story if it relates to the electric shock device. Here are some examples of things you could tell a story about:

- A time an electric shock device was used on you:
  - To get you to stop doing something
  - To punish you in some way
- A time someone you know was hurt by an electric shock device
- A time someone helped you to stop hurting yourself without using an electric shock device. For example, some autistic people will bang their heads into walls or hurt themselves in other ways. The JRC says that the only way to stop this is with the electric shock device. This is wrong. You can tell the FDA about your experiences.

## Sources

- **Sources** are proof that shows what you are saying is true. Things like research papers and news reports are kinds of sources.
- Sharing sources that are true and have facts can make your comment stronger. Here are examples of some good sources:
  - Fact-checked news articles (like those from the Associated Press)
  - Articles that have been “peer reviewed”
  - The ASAN website or this toolkit.

- You can copy and paste links to your sources in your comment.
- You can also share things that are less “formal”. For example, you can share blog posts. But the government might take blog posts less seriously, since anyone can write one. The government might not think a blog post is true.

### **Example Comment 1:**

Johann writes a comment. He says:

I am a person with a disability. I want the FDA to pass a rule banning the use of electric shock devices for behavioral modification. It is painful for the people being shocked. There are many other ways to help disabled people stop hurting themselves. We don't need to use electric shock. Please pass this ban.

### **Example Comment 2:**

Rashida writes a comment. She says:

I am autistic. I want the FDA to pass a rule banning the use of electric shock devices for behavioral modification.

I used to hurt myself when there was too much going on around me. I got help to learn other ways to calm down when overwhelmed. I did not need electric shock to help me do this. There is no reason for these devices to be used on disabled people. I want the FDA to ban electric shock devices.

You can also look at ASAN's [statements and comments](#) for ideas about what to put in your comment.

## *What do I do after I send in my comment?*

- After you send in a comment, please send us your comments. We want to see what you have said. This helps us understand the kinds of comments people are sending in. Email your comment to [info@autisticadvocacy.org](mailto:info@autisticadvocacy.org)
- Tell your friends, family, and others to also put in comments. You can also ask organizations that you are a part of to make comments. For example, you can ask a self advocacy group or college disability group.

## **Take care of yourself**

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

Here are some ways to take care of yourself after sending in comments.

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