

#StopTheShock Wait-In Guidebook

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The FDA has been saying for years that they will end the use of shocks at the Judge Rotenberg Center. On April 24th, 2014, the FDA held a hearing on the GED shock devices used at the JRC. The testimony of medical experts and JRC survivors led the FDA to conclude that the devices cannot be used without causing harm, and to recommend a ban. This ban is closer than ever to being finalized, but our work isn't done - we need to keep up the pressure until the FDA acts to #StopTheShock for good.

Wait-in leaders are a key part of our strategy to push the FDA to #StopTheShock this year. The wait-ins, held on the anniversary of the FDA hearing, are to remind them that #WeAreStillWaiting and we demand the rule's immediate release.

Leaders are responsible for coordinating a group event, such as tabling or physically waiting in a public place, and getting the word out about their event on social media. To learn more about what kind of work is involved in coordinating a wait-in, please read this guide! We'll cover step-by-step how to coordinate a wait-in and provide some examples for events you could hold. **If you will be holding a wait-in, please sign up to receive technical support and materials from ASAN [here](#).** If you have any questions about leading an event, please email rcaplan@autisticadvocacy.org

First, decide what kind of wait-in you want to do. This can depend on a lot of factors, including location, if you're working with a group, what activities you and people you know are good at. You'll want to think about what would be best for your group and your situation.

Some examples:

- Set up an information table in a public place
- Host a letter-writing and/or calling event
- Making a poster or art display in your community
- Asking passersby to take a selfie and share the word
- Create a wall of post-it-notes at a place of power, or make one near you and share it on social media
- And more!



Example Events and Tips:

Set up an information table in a public place

Sometimes people will set up tables in public places like malls, main streets, or universities and talk to people who walk by about social issues. This is a really good way to tell others in your community about how important it is to #StopTheShock. You'll want to look at the guidance for finding a location in a public place.

Tips:

- Have an eye-catching poster or banner to draw people's attention. A wall of post-it-notes is a great way to do this!
- Find out who is okay talking to strangers and assign roles ahead of time. People who don't want to talk to passerby could organize flyers and materials in advance.
- Write scripts. You'll want to figure out a quick way to explain to people the issues and what you want them to do. Try to write a script that's around 30 seconds.
- Have an action planned. Decide in advance what you want each person who stops to do. For example:
 - If you want them to take a selfie, think about making a selfie frame, or signs people can hold. Have people ready to take pictures.
 - If you want them to call the Congresspeople or the FDA, give them a paper with scripts written on it.
- Have candy that you can give out. It's a good way to get people to stop and listen.
- Figure out if you need to bring a table/chairs. If so, see if you or anyone you know has foldable table and chairs. If not, you may be able to rent them.

While you table, you can also ask people to take selfies. You can also use a wall of post-it-notes or a piece of art to draw people to your event.

Host a letter-writing and/or calling event

These events are where you get together to all call the government or elected officials. In this case, you could call the FDA and your Congresspeople. You can get together with your student group, friends, family, community organization or another group to all call. Calling as a group makes it more likely that people will call. It also helps people who are nervous about calling or can't use phones themselves. It also can be fun to do things together as a group.

Tips:

- Find a place without a lot of background noise for people to call and talk about what they're writing
- If you're in a group, you may want to do this during a regular meeting.
- Reach out to other social justice and advocacy organizations in your community and explain the issues and ask them to attend.
- Come up with scripts and examples beforehand for people to refer to. You can use our scripts for calling or writing to [Congress](#) and [the FDA](#).
- Have volunteers who would be okay making a call on behalf of someone who has disabilities that affects making phone calls.

- If people are writing letters, bring postage, envelopes and other materials. Offer to mail all of the letters at once.
- You can call after the offices of your Congresspeople and the FDA are closed and leave a voicemail.

You can also take pictures of your event and post them on social media with #WeAreStillWaiting and #StopTheShock. You may want to have a poster that people can write post-it-notes with phrases like We Are Still Waiting, and attach them to the poster. Then you can share pictures of a poster that everyone made collaboratively and/or display it in your community.

Making a poster or art display in your community

Posters and other art displays can be a very good way to draw attention to a cause. If you post your posters or art in a public place, it can potentially reach more people than tabling because it can be there longer.

Tips:

- Provide a way for people to find out more about #StopTheShock, through flyers or linking the ASAN website.
- If you are a student, talk to your college or university about posting your art there.
- Share your work on social media with #StopTheShock and #WeAreStillWaiting so that people can see it on there.

You can also display your art while you table, or create it collaboratively with your friends or group members at a call-in or letter-writing event.

Asking passersby to take a selfie and share the word

Selfies and social media posts are very good ways to show that many people are invested in this issue, and ensure that the FDA knows that we are watching them to make sure that they pass this ban. We want to have as many people as possible tweeting about it.

Tips:

- Prepare templates and sample posts that people can refer to when they post selfies. See the social media section of this guide for examples.
- Write the hashtags very large on a poster so that people make sure that they use them
- Offer to take people's pictures on their phone so they can post it
- Make a frame with the hashtags written on it that people can pose with, or signs that say things like "I want the FDA to #StopTheShock because....." and give people an option to fill in why.
- Hand out ASAN's StopTheShock one-pager and template posts so that people can learn more and take action.

You may want to combine this with tabling, since they both would work best in public places and you will want to explain to people why banning the GED is so important. If you have also made a poster or art project, you may want to ask people to take their pictures.

Create a wall of post-it-notes at a place of power, or make one near you and share it on social media

Disability rights activists have fought hard to get the rule on the GED on the 2019 FDA agenda, their to-do list, so to speak. Now, we are using post-it-notes as a symbol to remind them to pass this ban. Creating a wall of post-it-notes serves as a powerful reminder to the FDA that we are holding them accountable for passing this ban. Creating a wall of post-it-notes can draw attention to your cause and demonstrate the importance of this issue.

Is it legal?

We have looked into whether it is legal to affix post-it-notes to the sides of buildings. There is no one definitive answer; it depends on your area. Thus, it is up to you whether you want to do this in your community. You can look into your local laws to see if they say anything about this. You may want to reach out to activism organizations in your local community and ask if they have done “post-it protests” before and if so, how did it go for them. You can also bring a poster on an easel or stand (a chair could serve as an easy stand) and then attach the post-it-notes to the poster, instead of to the wall of the building itself.

Tips:

- Have different color post it notes to create an eye-catching aesthetic. You can also bring different color markers.
- Allow people to write their own post-it-notes and stick them on the wall.
- Apply for a permit if you are planning this at a place of power. That way you have all your permissions in order to hold an event there.

While you are creating this wall and holding your wait-in, you can talk to passerby and ask them to take selfies or give them more information. You can also ask them to add a sticky note to the wall.

And more!

There are many different kinds of events that you could hold that we haven't mentioned here. You might want to combine all or some of these different kinds of events together. Think about what kind of event would be best for your community. Feel free to email ASAN if you have any questions.

These are all things that you could organize in your local community. **Think about what would work best in your community.** You may want to think about locations to hold an event, ways to draw the attention of people in your community. If you're working with a group, you may want do multiple of these things. You also want to think about what you and your friends like to do are passionate about. For example, if you and your friends and/or group members like art, then think about covering a poster with art and slogans to display in your community and share on social media. If you and your friends know how to call Congress and the FDA, then you can do that as a group, and ask other people you know. **There are many different ways to show that #WeAreStillWaiting to #StopTheShock!**

Choosing your location

Next, you'll want to find a location. If you are holding an event where you want to get the attention of passerby, you'll want to find a public place. If you are holding an event where you want to call the FDA and your Congresspeople, you'll want to find a place that is quieter.

No matter where you hold it, make sure your location is accessible to people with a variety of disabilities. For example, people should be able to get to your wait-in location using wheelchairs or other mobility devices, blind and partially sighted people should be able to navigate to your location, etc. For more information about ensuring your event is accessible, check out ASAN's [Accessible Event Planning guide](#). Your location should also be accessible by public transportation, to ensure that people who want to attend can.

For public events: Think about places in your community with a lot of foot traffic.

Here are some potential venues to approach:

- **Colleges and universities.** Many colleges and universities have opportunities for students and student organizations to “table” in high traffic areas.
- **On busy streets.** For example, outside of a mall or another area with a lot of people that walk by.
- **Outside a place of power.** For example, outside of town hall or a courthouse

If you plan to hold your wait-in outdoors, make sure you have a backup location reserved in case of rain or snow.

For indoor events: You'll want to find a location with a space you can reserve for the event.

Try contacting local nonprofits or community meeting spaces, explaining the purpose of the wait-ins, and asking if they might be willing to let you use their space.

Here are some possible venues to approach:

- **Public colleges and universities.** Especially if you already have a connection to a university, these can be good places to hold events provided it is accessible to the public.
- **Public libraries.** Not all libraries offer free meeting spaces, but some do.
- **City buildings.** Some city-owned buildings may offer free meeting space for organizations.
- **Community centers,** particularly those for marginalized communities, for example, LGBTQ+ community centers.
- **Local community performance spaces.**

You should confirm your location **as soon as possible**. If you have to apply for a permit or reserve the space, you should do that soon to ensure that you have the space.

You can also hold an event virtually! You can do this over email, Twitter, Facebook or other forms of social media. If you make a email thread, group, hashtag or channel, you can talk about the event, offer advice and encouragement, and do the event together without meeting in person.

People will be holding events all around the country on Wednesday, April 24th. The time of day doesn't matter, choose the time that works best for your situation. The date is important since it marks five years since the FDA held their original hearing.

Get a permit

If your event will be on public property, **you will probably need a permit**. Your city may not require a permit to hold events on public property, or may not require a permit for small gatherings. Even if you are not legally required to get a permit, if your city issues permits for assembly, you should still get one, in case you are asked about it during the wait-in.

There is often a wait to get a permit - it can take anywhere from two weeks to over a month to approve or deny a permit. Therefore, **wait-in coordinators should apply for a permit as soon as possible** after deciding on a venue.

The process of getting a permit, and the requirements for permits and public gatherings, are different in different places. Because of this, we cannot include very detailed instructions in this guidebook. To find out your city's permit policy, you can use a search engine on the web and search "[**your city or town**] + [**gathering or assembly permit**]". You can also call the local police department, using their non-emergency number, and ask about permit requirements.

Sample script for this call: "Hi, I'm planning an event at [**place**] at [**day/time**]. It's an event to draw attention to the use of electric shocks against disabled people. I'm calling to ask how I can get a permit for this event." If you need help navigating the permit process or the permits website for your city, contact ASAN.

It often helps to have the permit document materials you may be bringing, for example, folding tables or chairs, easels and posters, etc. In some areas, you may not be allowed to set up tables or easels if this is not included in your permit. If you want to use any amplification, including a megaphone, specify this in your permit as well.

Finally, **remember to take your permit with you to the event**. If you can, bring a physical copy of the permit. If this is not possible, have the phone number of the city office that issued the permit so they can confirm it.

Use Facebook to announce your wait-in

Once you have your time and location, you can start spreading the word about your event. Begin by making a Facebook event page.

Add ASAN as a co-administrator of the Facebook event. You can find instructions on how to do that [here](#).

Advertise your event

As well as using Facebook to invite people you personally know, reach out to local organizations and ask them to send the link to their members. You don't need to stick to disability rights organizations – other groups focused on social justice issues, such as LGBT groups, may be willing to help promote the event as well.

You can also create and spread flyers with the time and location of your event. Leave stacks of them with friendly organizations, and post flyers around your area. You can post flyers about your wait-in event, as well as ASAN's [#StopTheShock flyer](#).

You can also use other forms of social media like Twitter to share information about your wait-in and the campaign to #StopTheShock.

Reach out to the press

Getting media presence at your wait-in is very important. We need to show the country and the FDA that #WeAreStillWaiting.

The first step is to create a press list. Look up your local newspapers, radio and TV stations – they should have a “contact us” or “report a news tip” page on their website which will tell you where to send a press release. You can also contact local non-profits and ask them if they have a list of press contacts they would be willing to share with you.

If you are planning your wait-in for more than two weeks out, send the first press release to everyone on your press list 1-2 weeks before the event. If you do not have time to send individual emails, you can enter every email address on your list into the “BCC” field of a message, and then begin it with a generic salutation such as “To whom it may concern”. If you can, follow up with another email one week before the event, or on a shorter timeline, a few days before. In the few days immediately before your event, you should also make some phone calls to the offices of local newspapers and TV stations. See the next page for a template press release. Please note that this template press release requires customization.

For Immediate Release

[the date you are sending out the press release]

Local Contact: [your name]

Phone: [phone number where you can be reached during the day]

Email: [your email]

Local Disability Community Calls on FDA to Stop the Shock

[YOUR CITY] – As part of a nation-wide effort, disability rights advocates in the [your city] area will be holding a event on April 24th to urge the FDA to release a rule banning electric shock devices used to punish people with disabilities at the Judge Rotenberg Center (JRC).

Children and adults at the JRC, an institution in Massachusetts, are forced to wear an electric shock device called a Gradual Electronic Decelerator (GED) on their bodies. Using a remote control, someone else can use the GED to give an electric shock to the person wearing it. The JRC uses the GED as an “aversive:” they use the pain of the electric shock to punish people for doing certain things.

The JRC says that they need to use the GED on the people who live there because they struggle with aggression and self-injury. **But the JRC is the only place in the United States that uses electric shocks to punish people with disabilities.** All across America, people with the exact same disabilities as the people at the JRC are being supported to deal with the exact same problems, without any kind of aversives. Research shows that positive supports for people with disabilities are better than aversives at helping people keep from hurting themselves or others.

Using the GED doesn’t only hurt people with disabilities by shocking them. It can burn skin, or make someone unable to move. Getting shocked also makes people more likely to develop mental health disabilities because of their bad experiences with the GED. People with disabilities who were shocked by the GED have developed PTSD, depression, and anxiety disorders.

After a hearing on April 24th, 2014 about the use of GED, the FDA found that the devices are not safe to use, do not help the people they are used on, and cause serious harm. This conclusion led the FDA to recommend that the GED be banned. Since then, JRC survivors and disability rights advocates have fought hard at every step to move the FDA closer to banning the device. In 2016, the FDA wrote a final rule banning the GED, but they have not released it.

It’s been five years since the first hearing, and on April 24th, 2019, disability activists nation-wide are calling on the FDA once again to ban this shock device once and for all. In communities around the country, people are holding events to spread the word and hold the FDA accountable for finalizing this rule.

The [your city] wait-in will be held at [location], and begins at [time]. Speakers will be [if you have a list of speakers, put it here, making sure to include job titles if relevant].

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

Collect any materials that you will need for the event.

The materials that you need for the event depend on what kind of event you are coordinating.

Some materials that might be useful:

- [#StopTheShock flyers](#) to handout
- Scripts for calling or writing to [Congress](#) and [the FDA](#).
- Posters with slogans (for example, #StopTheShock) or blank posters to cover with post-its
- Tables and chairs if you're tabling and they are not provided
- Any art supplies you might need

Event Signups:

ASAN will provide support and materials in the weeks leading up to your wait-in event. We also want to hear what all of the site-coordinators are planning, and share your event on our website. Please sign up using the [form here](#) so we can support your event.