



Nothing about us without us!

A Letter of Support for Legislation Banning Electric Stimulation Devices

Dear Member of Congress:

We, the 34 undersigned organizations, write in support of Section 811 of H.R. 7667, the Food and Drug Amendments of 2022 and of the similar section adopted during markup of S. 4348, the Food and Drug Administration Safety and Landmark Advancements Act of 2022, which ban “electrical stimulation” devices that “apply a noxious electrical stimulus to a person’s skin intended to reduce or cease self-injurious behavior or aggressive behavior.” The use of these devices as aversive treatment is widely recognized as cruel, harmful, and ineffective.

In 2020 the Food and Drug Administration (FDA) banned the use of these devices as aversive therapy, in a well-reasoned position that is consistent with the overwhelming weight of scientific literature on this topic, and actual treatment practices across the country.¹ Unfortunately, FDA’s proposed ban was reversed on a technicality related to the FDA’s regulatory authority.²

The disability community has worked for years to ban the use of this device and we now ask Congress to include a ban of the use of this device in the FDA User Fee bill. The medical evidence that this is an ineffective and harmful intervention is clear. When the FDA’s judgment was questioned, the American Academy of Pediatrics, the American Academy of Developmental Medicine and Dentistry, the American Association on Intellectual and Developmental Disabilities, the International Association for the Scientific Study of Intellectual and Developmental Disabilities, the National Association for the Dually Diagnosed, the National Association of State Directors of Developmental Disabilities

¹ Food and Drug Administration. 21 CFR Parts 882 and 895. Banned Devices; Proposal To Ban Electrical Stimulation Devices Used To Treat Self-Injurious or Aggressive Behavior; Proposed Rule

<https://www.govinfo.gov/content/pkg/FR-2016-04-25/pdf/2016-09433.pdf>

² No. 20-1087,

Judge Rotenberg Educational Center, Inc., et al v. U.S. Food and Drug Admin., et al (Jul. 6, 2021) (hereinafter JRC v. FDA),

[https://www.cadc.uscourts.gov/internet/opinions.nsf/C32A7577ED02127D8525870A00555511/\\$file/20-1087-1905079.pdf](https://www.cadc.uscourts.gov/internet/opinions.nsf/C32A7577ED02127D8525870A00555511/$file/20-1087-1905079.pdf)

Services, and the National Association of State Directors of Special Education all agreed that the medical evidence was clear that the use of this device was ineffective and should be banned.³ As Manfred Nowak, the UN's Special Rapporteur on Torture, has bluntly stated: "This is torture."⁴

The undersigned organizations oppose the use of electro-shock devices on persons with intellectual and developmental disabilities, including autism. As the FDA found, use of these devices "present[s] a number of psychological and physical risks: Depression, fear, escape and avoidance behaviors, panic, aggression, substitution of other behaviors (e.g., freezing and catatonic sit-down), worsening of underlying symptoms (e.g., increased frequency or bursts of self-injury), pain, burns, tissue damage, and errant shocks from device misapplication or failure. Based on literature for implantable cardioverter defibrillators, FDA has determined that ESDs present the risks of posttraumatic stress or acute stress disorders, shock stress reaction, and learned helplessness. That literature provides additional support for the risks of depression, anxiety, fear, and pain. Experts in the field of behavioral science, State agencies that regulate the use of ESDs, the sole current manufacturer and user of ESDs, and individuals who were subject to ESDs corroborate most of these findings, and they attest to additional risks."⁵

We acknowledge that these devices are typically used on individuals with intellectual or developmental disabilities who struggle with dangerous and distressing behaviors. Thousands of individuals with these challenges are successfully served with evidence-based practices that do not involve electro-shock. Medical evidence is clear that all behavior is communication. For people with disabilities who have yet to be given another effective means of expressing their wants and needs, such harmful behaviors may be the only method of communication available. In fact, research shows that many people with developmental disabilities who struggle with self-injury and/or aggression are experiencing understandable frustration and distress associated with limited

³ No. 20-1087 JRC v FDA, Brief of Amici Curiae (Jan. 22, 2021),

<https://www.iassidd.org/wp-content/uploads/2021/02/As-filed-Amicus-Brief.pdf>

⁴ <https://abcnews.go.com/Nightline/shock-therapy-massachussetts-school/story?id=11047334>

⁵ U.S. Food and Drug Administration, Final Rule: Banned Devices; Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior, 85 Fed. Reg. (Mar. 6, 2020), 13,312 <https://www.govinfo.gov/content/pkg/FR-2020-03-06/pdf/2020-04328.pdf>.

communication (Kripke, 2016a, 2016b, 2016c, 2018; Smull & Harrison, 1992).⁶ Attempting to suppress behaviors that may indicate that an individual is experiencing physical or emotional pain by shocking them when they express themselves via behavior rather than exploring and addressing the underlying causes of that behavior will leave people with intellectual and developmental disabilities to languish in misery, receiving repeated shocks for behavior that is an expression of suffering.

The only facility in the United States that utilizes these devices as an aversive is the Judge Rotenberg Center (JRC) in Massachusetts. Testimony from former residents of the JRC, including before the FDA, report that electroshocks were administered for many things completely unrelated to self-injurious behavior, include things like flapping their hands, standing up without permission, swearing, not taking off a coat, involuntary noises or movements that they make because of their disability, and screaming in pain while being shocked⁷ as well as failing to be neat, using the bathroom without permission, and closing their eyes for more than five seconds.⁸ Subjecting people with disabilities to electrical shocks for non-dangerous conduct that others find disruptive, troublesome, or annoying is morally and medically unjustifiable.

⁶ Kripke, C. (2018). Adults with Developmental Disabilities: A Comprehensive Approach to Medical Care. *American Family Physician*, 97(10), 649–656.

Kripke, C. (2016a). Capsule Commentary on Fortuna et al., Health Conditions and Functional Status in Adults with Autism: A Cross Sectional Evaluation. *Journal of General Internal Medicine*, 31(1), 106. <https://doi.org/10.1007/s11606-015-3537-6>

Kripke, C. (2016b, January 9). Understanding Autism, Aggression and Self-Injury—Transcribed Presentation. When Autistic Children Are Aggressive or Self-Injurious: Best Support Practices, San Francisco, CA.

<https://odpc.ucsf.edu/training/best-practices-behavior-support/understanding-autism-aggression-and-self-injury-transcribed>

Kripke, C. (2016c). Evaluation of Behavior Change in Patients with Developmental Disabilities. *American Family Physician*, 93(8), 686–692.

Smull, M., & Harrison, S. B. (1992). Supporting People With Severe Reputations in the Community. National Association of State Directors of Developmental Disabilities Services. http://www.nasdds.org/uploads/documents/Supporting_People_with_Severe_Reputations_in_the_Community.pdf

⁷ ASAN [#StopTheShock](#) Factsheet

⁸ Unsilenced. Judge Rotenberg Educational Center.

<https://www.unsilenced.org/program-archive/us-programs/massachusetts/judge-rotenberg-educational-center/>

The undersigned 34 organizations urge every member of Congress to vote to ban this device and protect the rights, dignity, and humanity of people with disabilities.

If you have any questions, please reach out to AJ Link at the Autistic Self Advocacy Network at ajlink@autisticadvocacy.org.

Sincerely,

Access Ready

American Academy of Pediatrics

American Association on Health and Disability

American Network of Community Options and Resources (ANCOR)

Autism Society of America

Autism Speaks

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Caring Across Generations

Center for Public Representation

Children and Adults with Attention-Deficit/Hyperactivity Disorder

CommunicationFIRST

Council of Parent Attorneys and Advocates

Disability Rights Education and Defense Fund

Epilepsy Foundation

Family Voices

Idaho Council on Developmental Disabilities

Justice in Aging

Lakeshore Foundation

National Association of Councils on Developmental Disabilities

National Association of State Directors of Special Education

National Disability Rights Network (NDRN)

National Down Syndrome Congress

National Down Syndrome Society

National Health Law Program

NeuroClastic

Partnership for Inclusive Disaster Strategies

RespectAbility

TASH

The Advocacy Institute
The Arc of the United States
United States International Council on Disabilities
World Institute on Disability