



Nothing about us without us!

July 8, 2024

Honorable Members of the House Appropriations Committee

Dear Representative:

We, the undersigned, engage in advocacy and education on the rights, autonomy, and wellbeing of people with disabilities. Physical and psychological harm to persons with intellectual and developmental disabilities are issues of great concern to us. We were consequently disturbed to learn about a rider in the subcommittee markup of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies funding bill prohibiting the FDA from banning medical devices or uses of medical devices to the extent that they are court-ordered. We write to voice our **opposition to Sec. 722 of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Appropriations Act, 2025.**

This provision would prevent the FDA from banning skin shock devices for behavior modification, something the FDA has been attempting to do for a number of years.<sup>1</sup> This practice is widely disavowed by the medical, behavioral intervention, disability advocacy, and developmental disability support communities.<sup>2</sup> However, it continues at a single facility in the United States despite the research likening its effects to those of torture.<sup>3</sup> Indeed, the practice has received United Nations condemnation as a violation of the Convention Against Torture.<sup>4</sup> In that facility, people are subject to skin shocks for conduct including not removing a jacket on command, saying “no” when shocked, or

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<sup>1</sup> Banned Devices; Proposal To Ban Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior, 89 Fed Reg 20882, 20882-20897 (proposed Mar 26, 2024) (to be codified at 21 C.F.R. § 882 & 21 C.F.R. § 895).

<sup>2</sup> 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>

<sup>3</sup> Seligman, M. E., & Maier, S. F. (1967). Failure to escape traumatic shock. *Journal of Experimental Psychology*, 74(1), 1–9. <https://doi.org/10.1037/h0024514>

<sup>4</sup> Méndez, J. E. (2013). *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan E. Méndez (GE.13-11820). United Nations. 84–85. [https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A-HRC-22-53-Add4\\_EFS.pdf](https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A-HRC-22-53-Add4_EFS.pdf)



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tensing their bodies in anticipation of a shock.<sup>5</sup> In its latest attempt to end this horror, the FDA has included findings that the device is both unsafe- due to the physical and emotional harms it causes- and ineffective at its stated purpose of behavioral modification.<sup>6</sup>

Because all current victims are subjected to skin shocks by court order, this provision would end the FDA's efforts to protect them from further suffering. While we respect the knowledge and skill of judges in their chosen field, legal professionals rarely have medical qualifications. Decisions about the safety and efficacy of medical devices are best left to people of relevant education, training, and experience such as those who fill the ranks of the FDA. These are not choices the courts are well-equipped to make. Abrogating the FDA's authority in this way could have dangerous consequences beyond even these weighty concerns.

**For these reasons, we call on you to oppose torture and leave decisions about the safety and efficacy of medical devices in the hands of the FDA.**

Please do not hesitate to contact John Poulos or Greg Robinson from the Autistic Self Advocacy Network at [jpoulos@autisticadvocacy.org](mailto:jpoulos@autisticadvocacy.org) or [grobinson@autisticadvocacy.org](mailto:grobinson@autisticadvocacy.org) for further information regarding this or related concerns.

Sincerely,

### **National Organizations**

Access Ready

Alliance Against Seclusion and Restraint

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union (ACLU)

American Network of Community Options and Resources (ANCOR)

Arizona Developmental Disabilities Planning Council

Association of University Centers on Disabilities

Autism Society of America

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<sup>5</sup> Neumeier, S. (2012, April 16). *The Judge Rotenberg Center on Trial, Part One*. Autistic Self Advocacy Network. <https://autisticadvocacy.org/2012/04/the-judge-rotenberg-center-on-trial-part-one/>

<sup>6</sup> See Footnote 1



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Autism Speaks  
Autistic People of Color Fund  
Autistic Self Advocacy Network  
Autistic Women & Nonbinary Network  
Blue Fire, Inc.  
Breaking Code Silence  
Caring Across Generations  
Center for Popular Democracy  
Center for Science in the Public Interest  
Coalition on Human Needs  
Colorado Neurodiversity Chamber of Commerce  
CommunicationFIRST  
Council of Parent Attorneys and Advocates  
Disability Rights Pennsylvania  
Division on Career Development and Transition  
Home and Community Positive Behavior Support Network  
Human Services Research Institute  
Justice in Aging  
Lakeshore Foundation  
MadFreedom, Inc.  
NADD  
National Association for Rights Protection and Advocacy  
National Association of Councils on Developmental Disabilities  
National Association of State Directors of Developmental Disabilities Services  
National Center for Self-Determination  
National Council on Independent Living  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Health Law Program  
Not Dead Yet  
Public Citizen  
Queerability  
Restraint Free World  
Roustabout Media  
Stop the Torture  
TASH New England  
The Advocacy Institute



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The Alliance for Citizen Directed Supports  
The Arc of the United States  
The Autistic People of Color Fund  
The Center for Outcome Analysis  
The National Leadership Consortium  
The National Leadership Consortium on Developmental Disabilities  
The National Organization for Interdisciplinary Research and Evaluation (NOIRE)  
The Partnership for Inclusive Disaster Strategies  
United Spinal Association  
World Institute on Disability

**State, Territorial, and Local**

504 Democratic Club  
ADAPT Montana  
AdvocacyDenver  
Alaska Governor's Council on Disabilities and Special Education  
Amnesty International Group 151, Boston  
Another Way, Inc.  
Arc West Central Colorado  
Autism Alliance of MI  
Bridges Supports Coordination LLC  
Bright Futures Advocacy and Counseling LLC  
Childhood Communication Services  
Citizens Commission on Human Rights, New England Chapter.  
Colorado Cross-Disability Coalition  
Colorado Developmental Disabilities Council  
Community Legal Aid Society, Inc.  
Delaware County Advocacy & Resource Organization  
Disability Law Center of Utah  
Disability Law Center of Massachusetts  
Disability Law Center of Alaska  
Disability Law Colorado  
Disability Policy Consortium  
Disability Rights Arizona  
Disability Rights Arkansas  
Disability Rights California  
Disability Rights Center of New Hampshire



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Disability Rights Center of Kansas  
Disability Rights Florida  
Disability Rights Idaho  
Disability Rights Maine  
Disability Rights Maryland  
Disability Rights Michigan  
Disability Rights Mississippi  
Disability Rights Montana  
Disability Rights New Jersey  
Disability Rights New Mexico  
Disability Rights New York  
Disability Rights North Carolina  
Disability Rights West Virginia  
Disability Rights Ohio  
Disability Rights Oregon  
Disability Rights Pennsylvania  
Disability Rights Rhode Island  
Disability Rights South Carolina  
Disability Rights South Dakota  
Disability Rights Tennessee  
Disability Rights Vermont  
Disability Rights Washington  
Disability Rights Wisconsin  
El Grupo Vida  
Empowering Lives Foundation  
Equip for Equality  
Family Voices Colorado  
Friends Meeting at Cambridge  
Golden Heart Advocacy  
Green Mountain Self-Advocates  
Idaho Council on Developmental Disabilities  
InVision Human Services  
Kansas Council on Developmental Disabilities  
Kentucky Protection and Advocacy  
Keystone Muscle Therapy  
Law Office of Matthew Engel  
Loren Esposito LICSW LLC



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Maine Developmental Disabilities Council  
Mental Health Association in Michigan  
Michigan Developmental Disabilities Institute  
Native American Disability Law Center  
Neighbours Inc.  
Neurodivergent Academy  
New Village  
North Dakota Protection & Advocacy Project  
Office for Pastoral Ministry with Persons with Disabilities, Archdiocese of Newark  
Oklahoma Disability Law Center  
Open Road Inclusive Community Consulting  
PA Coalition for HCBS  
Paths to Self Direction  
Pennhurst Memorial & Preservation Alliance  
Public Awareness Committee  
Public Justice Center  
Ripple Recovery  
Seeking Employment Equality and Community  
SPIN  
Syntiro  
The Arc - Jefferson, Clear Creek & Gilpin Counties  
The Arc Michigan  
The Arc of Adams County  
The Arc of Colorado  
The Arc of Massachusetts  
The Arc of Pueblo Colorado  
The Arc of Weld County  
The Arc, Westwood, MA  
The Collaborative for Citizen Directed Supports- NJ  
The Provider Alliance  
The RespectABILITY Law Center  
Uplift, Inc.  
Values Into Action New Jersey  
Values Into Action- Pennsylvania  
Vermont Center for Independent Living  
Vermont Coalition for Disability Rights  
Virginia Board for People with Disabilities



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Vision For Equality

West Virginia Developmental Disabilities Council

**Individuals**

Cheryl McCollins - Andre McCollins' mother

Dr. Algernon Lutwak - Medical Resident and Autistic Advocate

Jane Nisbet - Co-Author of Pain and Shock in America

Karen L. Davis - Disability Research and Advocate

Krista Cormier - Former resident of the Judge Rotenberg Center

Shain Neumeier - Autistic Lawyer and Advocate