



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.¹ This practice is widely disavowed by the medical, behavioral intervention, disability advocacy, and developmental disability support communities.² However, it continues at a single facility in the United States despite the research likening its effects to those of torture.³ Indeed, the practice has received United Nations condemnation as a violation of the Convention Against Torture.⁴ In that facility, people are subject to skin shocks for conduct including not removing a jacket on command, saying “no” when shocked, or

¹ 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).

² 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>

³ 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>

⁴ 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



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tensing their bodies in anticipation of a shock.⁵ 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.⁶

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 or 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

⁵ 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/>

⁶ 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