VIA EMAIL

July 8, 2024

U.S. House Appropriations Committee
H-307 The Capitol
Washington, DC 20515

Dear Chairman Tom Cole, Ranking Member Rosa DeLauro, and Committee Members,

We, the undersigned members of the Health and Rights Task Forces and fellow members of the Consortium for Constituents with Disabilities (CCD), are writing to you today to express strong opposition to section 722 of the Agriculture, Rural Development, Food and Drug Administration, and Related Agencies funding bill.[1] This rider provision would prohibit the Food and Drug Administration (FDA) from banning devices or their use to the extent that they are authorized or ordered by a court, and thus circumvent decades of advocacy against the use of contingent electric shock on people with disabilities.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. CCD members include disability professionals, national organizations, provider associations, self-advocates, and other allies of individuals with disabilities.

As members of a coalition of disability rights and justice organizations, ensuring the physical and psychological well-being of people with disabilities is an issue of paramount concern to us. As such, we are deeply alarmed by this rider provision, which would serve to insulate from FDA oversight and regulation a single facility – The Judge Rotenberg Center (JRC) – that employs painful electric shocks for the alleged purposes of behavior modification in people with disabilities. The FDA has conducted an extensive public review for more than a decade[2] and determined that the devices used to deliver these powerful shocks – which are designed and manufactured by the same and only facility that uses them in the United States – should be banned due to an unreasonable risk of harm to those receiving shocks. Members of CCD

[1] *See* page 93, lines 6-11, https://docs.house.gov/meetings/AP/AP01/20240611/ 117433/BILLS-118-SC-AP-FY2025-Agriculture-FY245AgSubcommitteeMark.pdf

[2] 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.

recently expressed strong support for the FDA's plans to implement this long-overdue ban,[3] and those plans must not be further impeded.

The individuals who are receiving these shocks frequently are people who have intellectual and developmental disabilities, are subject to guardianship and barred from making their own treatment decisions, and have disabilities that make it more difficult to communicate or withdraw assent or to express harms as they occur. This means this population is especially vulnerable to additional harm from these devices, which they have little-to-no power to escape or avoid. In fact, efforts to do so are frequently punished with additional shocks. At JRC, people are subject to skin shocks for conduct including not removing a jacket on command, saying "no" when shocked, or tensing their bodies in anticipation of a shock.[4]

This practice is widely disavowed by the medical, behavioral intervention, disability advocacy, and developmental disability support communities[5] and denounced by the United Nations as a violation of the Convention Against Torture.[6] Yet, despite this condemnation, this practice continues at JRC. 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.[7]

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. This provision would serve no present purpose other than to shield the one facility that designs, manufactures, and uses these devices on disabled people from FDA regulation. These are technical questions of fact, not law, and thus are not choices the courts are well-equipped to make. Decisions about the safety and efficacy of such devices are best left to people steeped in the subject matter and who have relevant education, training, and experience, like those who fill the ranks of the FDA who have already conducted and documented a thorough and lengthy investigation. The FDA's proposed rule rests on factual premises within the agency's expertise. Abrogating the FDA's authority in this way could have dangerous consequences beyond even these weighty concerns.

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[3] *See* CCD Comments on FDA's Proposed Ban on Electrical Stimulation Devices, Docket No. FDA-2023-N-3902 (May 28, 2024), https://www.c-c-d.org/fichiers/CCD-Comments-on- FDA-ESD-Regulation-sign-ons.pdf

[4] 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/

[5] 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

[6] 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

[7] See Footnote 3

For these reasons, we call on you to oppose torture and leave decisions about the safety and efficacy of these devices in the hands of the FDA. We ask that you **remove Section 722 from the Ag-FDA Appropriations bill**.

Sincerely,

Access Ready Inc.
American Academy of Pediatrics
American Association for Health and Disability
American Association of People with Disabilities
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Civil Liberties Union (ACLU)
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
Amputee Coalition
Association of Assistive Technology Act Program
Association of University Centers on Disabilities (AUCD)
Autism Society of America
Autism Speaks
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Center for Public Representation
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Communication 4 ALL
CommunicationFIRST
Council of Parent Attorneys and Advocates
Council of State Administrators of Vocational Rehabilitation
Disability Rights Education & Defense Fund
Epilepsy Foundation
Huntington's Disease Society of America
Justice in Aging
Lakeshore Foundation
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services

National Center for Learning Disabilities

National Council on Independent Living

National Disability Rights Network (NDRN)

National Down Syndrome Congress

National Health Law Program

Respectability

TASH

The Arc of the United States

The Kelsey

United States International Council on Disabilities

World Institute on Disability

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The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQI+ based discrimination and religious intolerance.