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November 25, 2024

Xavier Becerra
Secretary
U.S. Department of Health and Human Services

Robert Califf
Commissioner
Food and Drug Administration

Shalanda Young
Director
Office of Management and Budget

Sent via electronic mail

Re: FDA proposed rule banning electrical stimulation devices

Dear Secretary Becerra, Commissioner Califf, and Director Young,

We the undersigned write to express our deep appreciation for the Food and Drug Administration's (FDA's) continued efforts to ban the use of electrical stimulation devices (ESDs) used to treat self-injurious or aggressive behavior, and to urge the FDA to take all necessary steps to release the final rule banning these devices as soon as possible. For nearly eight years since the FDA initially released its Proposed Rule to ban these devices, and for almost ten years since a panel of experts recommended that they be banned, people with disabilities have continued to suffer from painful and dangerous electric shocks. We appreciate that the FDA has, across three presidential administrations, recognized what people with disabilities, families, disability advocates, researchers, medical professionals psychiatrists and psychologists, and the United Nations have long known: these are devices of torture and abuse, and their use must end. While we have seen support across multiple Administrations, the further delay that will be caused by a change in Administration and bringing



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them up to speed necessitates a release of the final rule as quickly as possible to ensure that members of our community are protected.

Given the extensive time the FDA has taken to develop the final rule and the fact that there have been no material changes to the science underlying the FDA's original 2020 decision to ban these devices, there is no need to delay this final rule further. Following the rule's issuance, we expect the FDA to take prompt action to enforce the ban and ensure the safety and well-being of individuals known to have been subject to ESDs. **Secretary Becerra and Commissioner Califf, we ask that you devote all necessary resources to finalize the rule without further delays.** Additionally, we call on the White House to take all steps necessary to ensure that the rule is expeditiously finalized and released.

The FDA is mandated to protect the health and safety of these individuals and must not delay further. We appreciate the actions the FDA has taken under Commissioner Califf's leadership to continue to protect the health and safety of individuals with disabilities and urge you to complete this work. In the fourteen years since this issue was first raised to the FDA, some of our nation's most vulnerable people have been subjected to unbearably painful electric shocks for such harmless behaviors as getting out of their seats, interrupting, whispering, slouching, swearing, or failing to maintain a neat appearance. As the previous rule recognized and the proposed ban continues to note, disabled people are experiencing dramatic short and long-term harm from this abusive treatment every day. They cannot afford to wait any longer. **We the undersigned urge HHS and the White House to prioritize and take all actions necessary to ensure this critical rule is immediately finalized and implemented.**

If you have any questions about this letter, please contact Gregory Robinson of the Autistic Self Advocacy Network at grobinson@autisticadvocacy.org, or (202) 891-6500.

Signed,

10 Minutes A Day

A Better Life LLC



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Access Ready Inc

ACLU

ADAPT

ADAPT Montana

ADAPT Montana

ADVOCACYDENVER

AHRC NYC

Alliance Against Seclusion and Restraint

American Academy of Developmental Medicine and Dentistry

American Academy of Pediatrics

American Association of People with Disabilities

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Foundation for the Blind

American Network of Community Options and Resources (ANCOR)

Amnesty International Group 151-Boston, MA

Arc of West Central Colorado

Association for Autism and Neurodiversity (AANE)

Association of University Centers on Disabilities

Atlantis ADAPT

Autism National Committee (AutCom)

Autism Society of America

Autism Society of Minnesota



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Autism Speaks

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Blue Fire, Inc.

Boston Center for Independent Living

Caldwell Family Services Inc.

Caring Across Generations

Center for Law and Social Policy (CLASP)

Center for Learner Equity

Center for Public Representation

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

Citizens Commission on Human Rights New England Chapter

Citizens Commission on Human Rights, National Affairs Office

City University of New York (CUNY) School of Law, Disability Rights and Social Justice Clinic

Collaborative for Citizen Directed Supports-New Jersey

CommunicationFIRST

Communitas, Inc.

Community Connections, Inc.

Community Systems Inc. - Virginia

Community Systems Inc. — Massachusetts

Community Systems Inc. CT



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Community Systems Support and Management Services, Inc.

Community Systems, Inc.

Community Systems, Inc. - Delaware

Council of Parent Attorneys and Advocates

CQL | The Council on Quality and Leadership

Deaf Equality

Detroit Disability Power

Developmental Disabilities Coalition, Inc.

Disability Belongs

Disability Law Center

Disability Law Center (MA)

Disability Law Colorado

Disability Policy Consortium

Disability Rights Arizona

Disability Rights Arkansas

Disability Rights California

Disability Rights Center - NH

Disability Rights Center of Kansas

Disability Rights Education and Defense Fund

Disability Rights Florida

Disability Rights Idaho

Disability Rights Maine

Disability Rights Maryland



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Disability Rights Michigan

Disability Rights Mississippi

Disability Rights Montana

Disability Rights MS

Disability Rights New Jersey

Disability Rights New York

Disability Rights North Carolina

Disability Rights North Carolina

Disability Rights of West Virginia

Disability Rights Ohio

Disability Rights Oregon

Disability Rights Pennsylvania

Disability Rights South Carolina

Disability Rights Texas

Disability Rights Vermont

Disability Rights Washington

Disability Rights Wisconsin

Downstate New York ADAPT

DQIA Disabled Queers in Action

DQIA: Disabled Queers In Action

Echoing Hills Village, Inc.

Epilepsy Foundation of America

Equip for Equality



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Family Voices NJ

FIRSTwnc

Frontier Community Services

Garden Center Services

Georgia ADAPT

Georgia Council on Developmental Disabilities

Governor's Advisory Council for Exceptional Citizens (GACEC) - DE SAP

Hawaii Disability Rights Center

Home and Community Positive Behavior Support Network

Huntington's Disease Society of America

IdeaBlizzard Productions

Imagine

Indiana Disability Rights

ICAPA Network

Judith Creed Horizons for Achieving Independence (JCHAI)

Justice in Aging

Kentucky Protection and Advocacy

Kupenda for the Children

Lakeshore Foundation

Law Project for Psychiatric Rights (PsychRights)

Learning Disabilities Association of Delaware

Liberty Resources

Life Enrichment Advancing People



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lifempowered

Little Lobbyists

Living Strong of Salem, NH

Maryland Coalition for Inclusive Education (MCIE)

Michigan Developmental Disabilities Institute

Michigan Disability Rights Coalition

Minnesota Autistic Alliance

Minnesota Council on Disability

Minnesota Neurodivergent Education Advocacy and Therapy Services

Multicultural Autism Action Network

NADD

National Alliance for Direct Support Professionals, Inc.

National Alliance on Mental Illness (NAMI)

National Alliance on Mental Illness of Massachusetts

National Association of Councils on Developmental Disabilities

National Association of Rights Protection and Advocacy

National Center for Parent Leadership, Advocacy, and Community Empowerment
(National PLACE)

National Center on Disability, Equity, and Intersectionality

National Disability Rights Network (NDRN)

National Down Syndrome Congress

National Health Law Program

National Leadership Consortium on Developmental Disabilities



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Native American Disability Law Center

Neighborhood Access

Neurodiversity Manitoba

Nevada Disability Advocacy & Law Center

New Disabled South

New Horizons Resources, Inc.

North Dakota Protection & Advocacy Project

Oak Hill/EasterSeals-Ct.

Oklahoma Disability Law Center

Ollibeau

Open Road Inclusive Community Consulting

Options in Community Living, Inc.

Partnership for Inclusive Disaster Strategies

Pennsylvania Developmental Disabilities Council

Place of Mind LLC

Queerability

Resources for Organizing and Social Change

Roots and Wings Therapeutic Services LLC

Second Thoughts MA: Disability Rights Advocates against Assisted Suicide

SPAN Parent Advocacy Network

Staten Island Center For Independent Living

Suburban Connections for Collective Liberation

Syntiro



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TASH

TASH New England

The Advocacy Institute

The Alliance for Citizen Directed Supports

The Arc - Jefferson, Clear Creek & Gilpin Counties

The Arc Arapahoe, Douglas & Elbert Counties

The Arc MN

The Arc of Adams County

The Arc of Aurora

The Arc of Massachusetts

The Arc of Northeast Colorado

The Arc of Pennsylvania

The Arc of Pueblo Colorado

The Arc of Southwest Colorado

The Arc of the United States

The Arc Pikes Peak Region

The Autistic People of Color Fund

The Center for Learner Equity

The Charles Lea Center Inc

The Coelho Center for Disability Law, Policy and Innovation

The Glenn Report

The Harford Center, Inc.

The Julian Way



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The LISTEN Center

The Minnesota Disability Law Center at Mid-Minnesota Legal Aid

The National Leadership Consortium on Developmental Disabilities

The Progress Center

The RespectABILITY Law Center

Together We Care GA

United Spinal Association

University of Cincinnati Center for Excellence in Developmental Disabilities

Uplift, Inc.

Values Into Action-Pennsylvania

Vision for Equality

West Bay RI

Wildflower Alliance