Dear Secretary Azar, Commissioner Gottlieb and Director Mulvaney,

We the undersigned write to once again urge the Federal Drug Administration (FDA) to finalize its proposed ban of electrical stimulation devices (ESDs) used to treat self-injurious or aggressive behavior. For two years since the FDA initially released its Proposed Rule to ban these devices, and for four years since a panel of experts recommended that they be banned, children and adults with disabilities have continued to suffer from painful and dangerous electric shocks. We urge you to take action now to end this abuse.

Concerned citizens and advocacy organizations first wrote to the FDA in March 2010 and again in January 2013, urging that the FDA ban these dangerous and unnecessary devices. In addition, in December 2012, the Centers for Medicare and Medicaid Services issued a letter making clear that use of the graduated electronic decelerator device, and other Level III aversive techniques, is prohibited for individuals receiving Medicaid-funded services. Advocates met with FDA representatives in April 2013. A year later, on April 24, 2014, the FDA held a day-long hearing and convened an advisory panel to seek scientific and clinical expert opinion on the risks and benefits associated with other treatment options, the risks and benefits of ESDs for aversive conditioning, and on whether these devices present a substantial and unreasonable risk of illness or injury. For a month before and a month after that meeting – from March 27 to June 24, 2014 – the FDA gave the public the opportunity to comment, and the FDA received almost 300 comments at that time (posted on Docket FDA-2014-N-0238, available at https://www.regulations.gov/document?D=FDA-2014-N-0238-0001).

The FDA took a full two years before announcing on April 22, 2016 that it had determined that these devices present an unreasonable and substantial risk of illness or injury that cannot be corrected or eliminated by labeling. We were pleased that the FDA finally recognized what the United Nations, disability advocates, researchers, psychiatrists and psychologists, families and people with disabilities have long known – these are devices of torture and abuse – and that their use would finally be ended. However, despite having already had multiple public comment periods related to the device, FDA allowed an extension of the comment period on the rule from a deadline of May 25 to July 25, 2016. It has now been nearly twenty-one months since that comment period ended. This delay raises significant concerns.

The FDA is mandated to protect the health and safety of these individuals and must not delay further. In the eight years since this issue was raised to the FDA and in the two years it took for the FDA to release a proposed rule in response to the April 2014 hearing, many vulnerable people with disabilities were subjected
to unbearably painful electric shock for such harmless behaviors as getting out of one’s seat, interrupting, whispering, slouching, swearing, or failing to maintain a neat appearance. As the proposed rule recognizes, innocent and vulnerable children and adults are experiencing dramatic short and long term effects from this abusive treatment every day.

We the undersigned urge HHS and the White House to prioritize and take all actions necessary to ensure these critical rules are finalized. Secretary Azar and Commissioner Gottlieb, we ask that you devote any and all resources necessary to swiftly review comments and finalize the rule with an immediate effective date and no further delays. Additionally, we call on the White House to take all steps necessary to ensure that the final rule is shepherded through the Office of Information and Regulatory Affairs.

If you have any questions about this letter, please contact Sam Crane of the Autistic Self Advocacy Network at scrane@autisticadvocacy.org, (202) 509-0135.

Sincerely,

A Better Life, LLC
ACHIEVA
ACCSES
Access Living
ADAPT
ADAPT Chicago
ADAPT DC Metro
ADAPT Georgia
ADAPT Kansas
ADAPT Montana
ADAPT Utah/ Disabled Rights Action Committee
The Advocacy Institute
Advocates
Alliance
The Alliance for the Betterment of Citizens with Disabilities (ABCD)
Alliance for Citizen Directed Supports
Alliance for Person-Centered Accessible Technologies
Allies for Independence
American Academy of Developmental Medicine and Dentistry
American Association of People with Disabilities
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Civil Liberties Union
American Foundation for the Blind
American Network of Community Options and Resources
American Occupational Therapy Association
ao Strategies
The Arc Arapahoe & Douglas
The Arc Michigan
The Arc of Adams County
The Arc of Colorado
The Arc of Hunterdon County
The Arc - Jefferson, Clear Creek & Gilpin Counties

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Chicago
Rochester
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Topeka
Missoula
Salt Lake City
Marshall
Framingham
Denver
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Tempe
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Louisville
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Disability Policy Consortium
Disability Power & Pride
DQIA Disabled Queers in ACTION!
Disability Rights Center
Disability Rights Center of Kansas
Disability Rights Center- NH
Disability Rights DC at University Legal Services
Disability Rights Education & Defense Fund
Disability Rights California
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Disability Rights Maine
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Disability Rights New Jersey
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Disability Rights Pennsylvania
Disability Rights Wisconsin
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Down Syndrome Association of Delaware
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Down Syndrome Association of West Michigan
Down Syndrome Awareness Group of East Tennessee
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HIGH IMPACT Mission-based Consulting & Training
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Hope House Foundation
Human Services Research Institute

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Institute on Disabilities, Temple University
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National Association of State Head Injury Administrators
National Association of the Deaf (NAD)
National Coalition for Mental Health Recovery
National Consumer Voice for Quality Long-Term Care
National Council on Independent Living
National Disability Rights Network

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National Down Syndrome Society
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Tampa FL
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Salem OR
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Bala Cynwyd PA
UMKC Institute for Human Development
Kansas City MO
Unbound Books Autism Acceptance Library
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Cc:

Roger Severino
Director
HHS Office of Civil Rights

Lance Robertson
Administrator
Administration on Community Living

Joseph L. Grogan
Director of Health Programs
White House Office of Management and Budget

Neomi Rao
Administrator
Office of Information and Regulatory Affairs