



Center for Public  
Representation



November 17, 2023  
By Electronic Mail

Sen. Robyn K. Kennedy, Chair  
Sen. Rebecca L. Rausch, Vice Chair  
Rep. Jay D. Livingstone, Chair  
Rep. Jessica Ann Giannino, Vice Chair  
Joint Committee of Children, Families and Persons with Disabilities  
[JointCommittee.Children&Families@malegislature.gov](mailto:JointCommittee.Children&Families@malegislature.gov)

Re: H.180 An Act regarding the use of aversive therapy and  
H.170 An Act requiring licensure for use of graduated electronic decelerators

Dear Joint Committee Members:

As further background for the public hearing on November 13, 2023, the Center for Public Representation (CPR)<sup>1</sup> and the Disability Law Center (DLC)<sup>2</sup> submit the following written testimony in support of H.180 *An Act regarding the use of aversive therapy*. In recognition of changing professional standards, as well as legal and human rights concerns, the majority of States have severely limited or banned the use of aversive interventions, including through legislative action.

Our organizations oppose H.170 *An Act requiring licensure for use of graduated electronic decelerators* for two reasons: (1) the inability of licensure to resolve the serious health and safety risks attendant to use of the Graduated Electronic Decelerator (GED), and (2) the federal Food &

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<sup>1</sup> Based in Easthampton, Massachusetts, CPR is a national legal advocacy center dedicated to enforcing and expanding the rights of people with disabilities and others who are in segregated settings. CPR uses legal strategies, advocacy, and policy to design and implement systemic reform initiatives that promote integration and full community participation for people with disabilities and others who are devalued by society.

<sup>2</sup> DLC is the designated federal Protection and Advocacy (P&A) system for adults and children in the Commonwealth with intellectual and developmental disabilities, emotional and mental health disabilities, physical disabilities, and traumatic brain injuries. Our work includes monitoring facilities, investigating allegations of abuse and neglect, issuing public reports, providing individual and systemic advocacy, and advising policymakers on issues affecting the disability community.

Drug Administration’s conclusion that a ban of Electrical Stimulation Devices (ESDs) like the GED is necessary to protect individuals with disabilities from a substantial risk or injury and harm.

As discussed in detail below, State and federal agencies, disability professionals, provider associations, family groups, consumer run organizations, and even the United Nations have unequivocally disavowed the use of aversive interventions like the contingent electric shock administered by the GED. These interventions violate legal, ethical, and professional standards for the care and treatment of people with disabilities. Contingent electric shock is not “treatment.” It is not supported by modern treatment theories and, as determined by the FDA, there is no reliable evidence of its long-term efficacy.

Recently, the Supreme Judicial Court has made clear that a legislative ban of aversive interventions like the GED would be a change in law sufficient to prompt modification or termination of the thirty-five-year-old Consent Decree that has continued to allow for the use of aversive therapy like the GED in Massachusetts.<sup>3</sup> People with disabilities in the Commonwealth deserve better, and H180 provides a vehicle for the legislature to act on their behalf.

I. A Legislative Ban of Aversive Therapy, Including the GED, is Warranted Given Significant Changes in the Standard of Care for People with IDD and Serious Health and Safety Risks Associated with Electric Shock Devices

A. *The FDA’s lengthy rule-making process and extensive factual record supporting the ban of Electrical Stimulation Devices warrants a ban of aversive therapy in Massachusetts.*

In March of 2020, the FDA issued its final rule banning the use of Electrical Stimulation Devices (ESDs) on individuals who experience self-injurious or aggressive behaviors.<sup>4</sup> In doing so, the FDA reaffirmed its conclusion in 2016 that ESDs presented an “unreasonable and substantial risk to public health”<sup>5</sup> and should not be used, even in individual cases where other treatments may not completely reduce or eliminate these behaviors.<sup>6</sup>

The supporting FDA record was exhaustively compiled over six years and two administrations, and included individual testimony, research from clinical experts, complaint data from JRC and DDS, professional standards from national disability organizations, and reviews of the professional literature. Extensive evidence underpinning the agency’s decision was collected between 2014 and 2016, cited in the proposed rule, and later incorporated into the final rulemaking.

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<sup>3</sup> *Judge Rotenberg Educational Center, Inc. v. Commissioner of the Department of Developmental Services*, 492 Mass 772, 809-810 (2023).

<sup>4</sup> See 85 Fed. Reg. 13312; <https://www.federalregister.gov/documents/2020/03/06/2020-04328/banned-devices-electrical-stimulation-devices-for-self-injurious-or-aggressive-behavior>.

<sup>5</sup> U.S. Food & Drug Admin., FDA News Release (April 22, 2016); <https://www.fda.gov/news-events/press-announcements/fda-proposes-ban-electrical-stimulation-devices-intended-treat-self-injurious-or-aggressive-behavior>.

<sup>6</sup> Banned Devices; Proposal To Ban Electrical Stimulation Devices, 81 Fed. Reg. 24406 (Apr. 25, 2016); <https://www.federalregister.gov/documents/2016/04/25/2016-09433/banned-devices-proposal-to-ban-electrical-stimulation-devices-used-to-treat-self-injurious-or>.

Although the D.C. Circuit Court of Appeals subsequently held that the FDA’s statutory authority did not extend to banning devices for specific purposes, it did not opine about the merits of the agency’s findings and conclusions.<sup>7</sup> Moreover, the Appeals Court’s statutory interpretation has now been superseded by Congress’s recent amendment to the FDA’s statute, signed into law in late December 2022 as part of the federal spending bill. That legislative change clarifies that the FDA has the authority to ban devices for specific purposes.<sup>8</sup>

The FDA’s administrative record clearly demonstrates that the overwhelming weight of professional research, and virtually all peer-reviewed scientific literature, supports banning aversive interventions like contingent electric shock. First, the FDA determined that ESDs (like the GED) create “unreasonable and substantial risks of illness and injury,” with little or no credible evidence of efficacy or long-term benefit.<sup>9</sup> Risks of harm include pain, skin burns, loss of sensitivity to fatigue or pain, and injuries from falling, as well as psychological harms, including depression, PTSD, anxiety, fearfulness, suicidality, chronic stress, acute stress disorder, neuropathy, withdrawal, nightmares, flashbacks of panic and rage, and hypervigilance.<sup>10</sup> It also found that ESDs may worsen underlying clinical conditions, replacing one negative behavior with another, and result in a loss of agency or “learned helplessness.”<sup>11</sup>

Second, the FDA concluded that there have been virtually no systematic investigations of the effectiveness of ESDs for self-injurious and/or aggressive behavior.<sup>12</sup> Studies that do exist are outdated and methodologically flawed, and many are silent as to any attempts to assess negative side effects.<sup>13</sup> Concerns about the accuracy of adverse event reporting were compounded by the age and scientific rigor of the studies themselves.<sup>14</sup> No randomized controlled trials were

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<sup>7</sup> *Judge Rotenberg Educ. Ctr., Inc. v. United States Food & Drug Admin.*, 3 F.4th 390, 394 (D.C. Cir. 2021) (rehearing en banc denied Nov. 22, 2021) (concluding in a 2:1 panel decision that the FDA does not have the statutory authority to partially ban devices for a particular use).

<sup>8</sup> Consolidated Appropriations Act, 2023, Pub. L. No. 117-328, § 3306, amending 21 USCA §360(f) (banned devices). The FDA is once again considering a new proposed regulation to ban electrical stimulation devices. See <https://www.fda.gov/media/157208/download>, line 93. However, even if such a device issues, it will likely be challenged in the federal courts. However, as noted above, the SJC has clearly acknowledged the right of the General Court to ban the use of this device. *Judge Rotenberg Educational Center, Inc. v. Commissioner of the Department of Developmental Services*, 492 Mass 772, 809-810 (2023).

<sup>9</sup> 85 Fed. Reg. 11315.

<sup>10</sup> 85 Fed. Reg. 13315; *see also*, 81 Fed. Reg. at 24389. The consent form used by the Judge Rotenberg Educational Center identifies many of the same side effects. See Jennifer R. Zarcone et al., *Contingent Electric Shock as a Treatment for Challenging Behavior for People with Intellectual and Developmental Disabilities: Support for the IASSIDD Policy Statement Opposing Its Use*, 17 *Journal of Policy and Practice in Intellectual Disabilities* 291, 295 (May 22, 2020).

<sup>11</sup> 81 Fed. Reg. at 24389.

<sup>12</sup> FDA Executive Summary, Neurological Devices Panel (“Panel Summary”) (April 2014) FDA-2016-N-1111-1748 at 44, 58; Table 4: Articles Reviewed for Adverse Events Associated with ESDs for Aversive Conditioning for Patients with SIB and Assaultive/Destructive Behavior associated with Developmental Disabilities at 59-61; <https://bit.ly/3Z4EbBc>; *see also*, 81 Fed. Reg. 24406.

<sup>13</sup> Panel Summary at 44, 58.

<sup>14</sup> Panel Summary at 58, 64-65. In its Final Rule, the FDA notes that “the only article specifically about JRC’s GED device was published in a peer-reviewed journal over a decade ago, and it studied only nine subjects at JRC (Ref. 7). Studies of ESDs more generally have been published in peer-reviewed journals,

identified by the FDA or its expert panel.<sup>15</sup> Articles identified by or presented to the FDA in support of ESDs did not “adhere to current, more exacting peer-review standards for study conduct and reporting.”<sup>16</sup> The FDA also considered the potential for bias in case studies reporting only ESD benefits and no side effects, including the possibility that some investigators may have been “pre-disposed to see only positive side effects.”<sup>17</sup> This potential for bias in overlooking adverse events included the largest case study -- a retrospective review conducted by JRC.<sup>18</sup>

Third, the FDA found that there are effective, less restrictive alternatives to electric shock resulting in “durable, long-term benefits” including the reduction or elimination of challenging behaviors.<sup>19</sup> The FDA identified a substantial body of peer reviewed literature and empirical research showing that positive behavioral supports, as well as other evidenced-based treatments and therapies, can reduce and eliminate harmful behaviors through environmental modification and the teaching of adaptive, replacement behaviors. As noted in the FDA’s 2016 proposed rule:

scientific advances have yielded new insights into the organic causes and external (environmental or social) triggers of SIB [self-injurious behaviors] and AG [aggressive behaviors], allowing the field to move beyond intrusive punishment techniques such as aversive conditioning with ESDs.<sup>20</sup>

This evolution in treatment is now well-established. “Surveys show the [Applied Behavior Analysis] field as a whole moved away from intrusive physical aversive conditioning techniques such as ESDs 2 decades ago.”<sup>21</sup> One FDA Panel expert described this shift by saying: “the Statements of professional programs and the fact of wholesale abandonment of aversive electrical shock therapy professional programs by the peers in this field show that it is unreasonable to conclude that these devices are part of the standard of care for this class of patients . . . .” *Id.*

Put simply, the FDA concluded in its proposed rule, and confirmed in its final 2020 ban, that the risks associated with contingent electric shock are not worth taking:

Although other treatments may not completely reduce or eliminate SIB or AB in all patients, that does not mean ESDs should be used. In determining whether to ban these

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but many of them are decades old. In the intervening decades, the understanding of pathophysiology has evolved as has the ability to identify and systematically record AEs. [Adverse Events]. These developments are alongside heightened peer-review standards for study and reporting. Accordingly, it is reasonable to assign these studies less weight than more modern studies.” 85 Fed. Reg. 13319.

<sup>15</sup> Panel Summary at 57.

<sup>16</sup> *Id.* at 64-65; 81 Fed. Reg. at 24401 (the majority of articles did not “adhere to current, more exacting peer-review standards for study conduct and reporting.”).

<sup>17</sup> Panel Summary at 65 (citing Carr and Lovaas (1981) (“in light of the intrusive nature of shock treatment, it is puzzling that so few negative side effects have been reported.”).

<sup>18</sup> Panel Summary at 58 (citing Israel et al., 2008).

<sup>19</sup> 81 Fed. Reg. at 24410; 85 Fed. Reg. 13315.

<sup>20</sup> 81 Fed. Reg. at 24387.

<sup>21</sup> 85 Fed. Reg. 13317 (“the professional field, with the sole exception of JRC, has moved beyond the use of ESDs for SIB or AB.”).

devices, FDA balances effectiveness against the risks they pose and assesses the reasonableness of such risks in light of the State of the art. The State of the art is to use positive behavioral interventions, sometimes in conjunction with pharmacotherapy, even for the most challenging SIB and AB; the unsubstantiated claim that ESDs are uniquely effective for refractory individuals does not alter that conclusion.<sup>22</sup>

In sum, the FDA's compilation of evidence provides comprehensive and compelling evidence of a significant change in professional standards of care, justifying the legislature's rejection of aversive interventions in favor of safer, more effective treatments.

*B. The majority of States have limited or prohibited the use of contingent electric shock and other painful aversives, including through legislative action.*

Recognizing clinical advances in the field, the majority of States have severely limited or banned aversive interventions. As one State legislature concluded:

- (1) Research does not support the long-term efficacy of aversive behavioral intervention;
- (2) The use of aversive or abusive treatment raises disturbing legal and ethical issues, and may well deprive the recipient of constitutional or statutory rights and be outside the ethical guidelines imposed upon the treatment professional;
- (3) Any person with a disability has the same right to be treated with dignity and respect as any other citizen; and
- (4) The use of aversive and abusive treatments on any person with a disability diminishes the dignity and humanity of the treatment professional and the person with a disability.

S. D. Codified Laws § 27B-8-50 (2011).

In 2015, the National Association of State Developmental Disability Directors (NASDDDS) surveyed States about their rules, policies, guidelines, contracts, or practices that governed aversive interventions. Of the 45 States responding, 82% reported that aversives are disallowed for use in services for people with I/DD.<sup>23</sup>

A more recent review indicates that at least twenty-eight States have enacted prohibitions against the use of contingent electric shock and other painful aversive procedures.<sup>24</sup> The proliferation of State statutes and regulations severely limiting or banning the use of contingent electric shock

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<sup>22</sup> 81 Fed. Reg. at 24406.

<sup>23</sup> National Association of State Directors of Developmental Disabilities Services, Comment on Proposal to Ban Electrical Stimulation Devices Used to Treat Self-Injurious or Aggressive Behavior, <https://www.nasddds.org/nasddds-offers-comments-to-ban-electrical-stimulation-devices/>.

<sup>24</sup> Jurisdictions banning skin shock or other painful aversive techniques include California, Colorado, Illinois, Indiana, Maine, Maryland, Michigan, Missouri, Montana, Nebraska, Nevada, New Mexico, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Virginia, Washington, West Virginia, and Wisconsin.

and other painful aversive techniques, both prior to and after 2018, clearly demonstrates a significant and widespread change in the standard of care for people with disabilities.

C. *Policy statements issued by leading national organizations support the need for a ban on aversive interventions like the GED.*

For years, professional disability organizations, national associations, and other clinical experts have taken public positions against the use of contingent electric shock and other aversive interventions. On September 30, 2009, a group of pre-eminent professional and consumer associations for persons with I/DD sent a joint letter to the federal Department of Health and Human Services, the Department of Education, the U.S. Attorney General, Congressional Committees, and Human Rights organizations, calling for an end to “inhumane and unnecessary methods of behavior modification,” including the use of “painful electric shock and food deprivation.”<sup>25</sup>

In 2010, The Arc of the United States and The American Association of Intellectual and Developmental Disabilities (AAIDD), the oldest and largest interdisciplinary organization of professionals and citizens concerned about the human rights of persons with intellectual and developmental disabilities, issued a joint policy Statement against the use of painful aversives and in favor of positive behavioral supports. *Joint Position Statement of AAIDD and the Arc on Behavioral Supports*, August 23, 2010, extended 2015. In 2019, AAIDD renewed their long-standing call for the “immediate elimination and permanent discontinuation of electric skin shock as an intervention for the behavior of people with intellectual and developmental disabilities.”<sup>26</sup>

In 2016, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) which represents State I/DD agencies in 50 jurisdictions, Puerto Rico, and the District of Columbia, submitted formal comments to the FDA, rejecting the use of interventions that cause pain and harm for the purpose of modifying behavior and instead promoting the use of Positive Behavioral Support.<sup>27</sup>

More recently, professional associations specializing in Applied Behavior Analysis have followed suit. The Association of Professional Behavior Analysts (APBA) Board of Directors

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<sup>25</sup> *Letter from Disability Advocates: A Call to Action to Eliminate the Use of Aversive Procedures and Other Inhumane Practices*, to the Dept. of Health and Hum. Serv. et al., (Sept. 30, 2009), <https://mn.gov/mnddc/future/pdf/olmstead/09-ASL-NEW.pdf>. National signatories included the American Association on Intellectual and Developmental Disabilities; the Association of University Centers on Disabilities; The Arc of the United States; the Autism National Committee; The Autistic Self Advocacy Network; the Center on Human Policy, Law, and Disability Studies, Syracuse University; the Disability Rights Education and Defense Fund; the National Association of County Behavioral Health and Developmental Disability Directors; the National Association of Councils on Developmental Disabilities; the National Association for the Dually Diagnosed; the National Disability Rights Network; and the National Leadership Consortium on Developmental Disabilities.

<sup>26</sup> See, <https://www.aaidd.org/news-policy/policy/position-Statements/electric-shock>.

<sup>27</sup> See, NASDDDS Comments to Ban Electrical Stimulation Devices, <https://www.nasdddsrg/nasddds-offers-comments-to-ban-electrical-stimulation-devices/>.

issued a statement concluding that contingent electric shock “is generally not the accepted standard of care in the behavior analytic treatment of severe or challenging behavior,” and that its use “goes against the profession’s overarching ethical principles of maximizing benefits for clients, doing no harm, and treating others with compassion, dignity, and respect.”<sup>28</sup>

The Massachusetts Association for Applied Behavior Analysis (MassABA), an organization that represents the interests of behavior analysts in the State, issued a 2021 position paper stating that contingent electric skin shock is “an unnecessary and demonstrably harmful tactic with possible long-term negative physical and emotional effects,” whose use is “immoral, inhumane, and unethical” and “outside the scope of practice of behavior analysis.”<sup>29</sup> Even the Association for Behavior Analysis International (ABAI), which had previously included the Judge Rotenberg Center in its national conferences, recently voted to “strongly oppose the use of contingent electric skin shock (CESS) under any condition.”<sup>30</sup>

Taken together, these statements reflect a well-established, emphatic, and widespread rejection of electric shock as a form of behavior modification and provide compelling evidence of the need to conform Massachusetts law with significant changes in the standard of care for people with disabilities.

*D. Suggested Amendment to H.180*

As H. 180 is currently written, the prohibition on procedures to inflict physical pain, including electric shock, applies to persons with physical, intellectual, or developmental disabilities. There is no logical reason to exclude persons with behavioral or mental health related conditions from these same protections. We suggest revising the bill accordingly, as described below. When adding this language, we would also distinguish between aversive contingent electrical shock and electroconvulsive therapy (ECT), an entirely different procedure.

An Act regarding the use of aversive therapy.

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

SECTION 1. Section 16 of Chapter 6A of the General Laws, as appearing in the 2010 official edition, is hereby amended by inserting the following text:-

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<sup>28</sup> APBA Board of Director Position Statement on the Use of Electric Skin Shock, <https://www.apbahome.net/page/practiceguidelines>.

<sup>29</sup> See, [https://www.massaba.net/wp-content/uploads/Position-Statement\\_Electric-Shock\\_2021.pdf](https://www.massaba.net/wp-content/uploads/Position-Statement_Electric-Shock_2021.pdf).

<sup>30</sup> See, <https://www.abainternational.org/about-us/policies-and-positions/position-Statement-on-the-use-of-cess-2022.aspx>. The ABAI position statement concludes “The published literature based in applied behavioral analysis does not support [contingent electric skin shock] CESS as an evidence-based treatment.”

No program, agency, or facility funded, operated, licensed, or approved by any agency or subdivision of the Commonwealth shall administer or cause to be administered to any person with a physical, intellectual, developmental, behavioral, or psychiatric disability any procedure which causes obvious signs of physical pain, including, but not limited to, hitting, pinching, and electric shock for the purposes of changing the behavior of the person. This section shall not prohibit the use of electroconvulsive therapy (ECT), conducted under anesthesia, where otherwise permitted by law.

No such program may employ any form of physical contact or punishment that is otherwise prohibited by law or would be prohibited if used on a non-disabled person.

No such program may employ any procedure which denies a person with a physical, intellectual, developmental, behavioral, or psychiatric disability reasonable sleep, food, shelter, bedding, bathroom facilities, and any other aspect expected of a humane existence in the Commonwealth.

II. Legislative Proposals to License the GED Would Legitimize an Intervention Which has been Recognized Nationally and Around the World as Inhumane, Ineffective, and Unsafe.

Requiring licensure for the use of graduated electronic decelerators sends precisely the wrong message regarding the continued use of aversive interventions in Massachusetts. A vote in support of H170 is no different than stating that it is acceptable for individuals with disabilities to be subjected to contingent electric shock, provided it is appropriately regulated. This could not be further from the truth.

DDS already licenses the operation of the one program in the United States that uses the GED. However, this licensing authority has not been sufficient to guard against its misuse, or the substantial risk of injury and harm created by the GED. Nor can staff training mitigate these risks, which are tied to the device itself and to the serious risk of physical and psychological harms it has been found to create.

Finally, licensure cannot account for, or adequately respond to, the overwhelming view of disability experts, State agencies, and national professional organizations that the GED is dangerous, ineffective, and inconsistent with professionally accepted standards of care. Only the elimination of contingent electric shock as a “treatment” modality in Massachusetts will adequately protect and ensure the dignity of those who are currently subjected to the GED.



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The Supreme Judicial Court's recent decision demonstrates the need for legislative action to protect persons with disabilities who are or who will be subjected to contingent electric shock. The Department of Developmental Service's regulations (banning any use of aversive electric shock beyond a small legacy group) have been set aside. It is now incumbent upon the legislature to pass this legislation, in order to align our practices with the findings of the FDA, the vast majority of other States, and the professional consensus of leading national disability organizations.

Thank you for the opportunity to comment on these important questions. If you would like to discuss these issues in more depth, please do not hesitate to contact us at [krucker@cpr-ma.org](mailto:krucker@cpr-ma.org) or [rglassman@dlc-ma.org](mailto:rglassman@dlc-ma.org).

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